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# Relationships Between Stress Self-Management, Social Support, and Health in Hispanic Informal Caregiver Burnout Prevention

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Walden University
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Dissertation Submitted in Partial Fulfillment
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Doctor of Philosophy
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# Abstract

Burnout syndrome is a psychological disorder characterized by physical, emotional, and mental distress and exhaustion resulting in feelings of depression, anxiety, irritability, and negative attitudes. If left unattended, burnout syndrome can lead to new or worsening health outcomes. The purpose of this nonexperimental quantitative study was to examine the relationship between stress self-management, perceived social support, health status, and burden among Puerto Rican informal caregivers. The theoretical foundations for this research were the informal caregiving integrative model and the individual and family self-management theory. Survey data were collected from 415 participants. Multiple regression analyses were performed to determine the relationship between the predictor variables (stress self-management and perceived social support) and dependent variables (self-rated health and caregiver burden). Results showed that higher levels of stress self-management and perceived social support were significant predictors of informal caregivers' self-rated health and burden. Results suggested that addressing the stress self-management and social support of informal caregivers may improve their health and reduce their burden. Findings may prompt health education and promotion strategies to raise awareness of the experiences and needs of informal caregivers and to develop initiatives for the prevention of burnout syndrome among this community.

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# Dedication

This dissertation is dedicated to my grandmother, Patria Luz Pérez Serrano. She has been a caregiver most of her life caring for her siblings, children, grandchildren, parents, and finally for her late husband, my grandfather. Her unwavering love and dedication to her family is proof of the invaluable nature of informal caregivers within our society. Her compassion for those in need and her personal sacrifices were the inspiration for this research.

# Acknowledgments

I am so grateful for the support I have received from my family and friends during this dissertation process. In particular, I would like to thank my mother, Norma Román Pérez, for her eternal love and support in all that I do and to my husband, Mario Ortiz Morales, for always believing in me, even when I forget to believe in myself.

I would like to extend my greatest gratitude to my dissertation chair, Dr. David Brown, for his continuous support and patience during this process. His guidance not only helped me improve the quality of my research but also made this dissertation process much more bearable and manageable.

Thank you to all of the informal caregivers who participated in this research and to those who assisted in the dissemination of my survey because without you this achievement would not have been possible. Obtaining a doctoral degree has been a lifelong goal for me, and I am very proud and excited that this day has finally come.

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# Chapter 1: Introduction to the Study

Informal caregivers are individuals who provide care to others without financial compensation and who have not received formal clinical training (Yancura, 2018). These individuals are usually close relatives of the care recipients. The importance of informal caregivers has increased over the past decades as the population of older adults has grown significantly (American Association for Retired Persons [AARP] & National Alliance for Caregiving [NAC], 2020). Informal caregiving services are vital because they serve as a relief for the burden that older adults may place on society and health systems (Pérez & Ailshire, 2017; Rabarison et al., 2018). In Puerto Rico, due to recent climatic and financial catastrophes, there has been a massive migration of young and middle-age adults to the continental United States, causing a dramatic increase in the proportion of older adults remaining on the island. Due to the collectivist Hispanic culture of Puerto Rico, these families bear the burden of caring for their sick, older, or disabled family members because this is expected, and the use of formal care services and nursing homes is looked down upon in the Puerto Rican culture (Lucero et al., 2022).

Providing care for older people can be a burdensome task because informal caregivers must take on the needs of the care recipients, as well as their own personal, financial, and professional responsibilities (Amankwaa, 2017). It is important to study the perceived social support, self-rated health, and stress self-management strategies of informal caregivers because these are influential factors in the development of burnout syndrome, which can adversely affect the well-being of informal caregivers and the care recipient (Hong & Harrington, 2016). The outcomes of the current study may assist in the identification of the social support and stress management needs of Hispanic informal caregivers. These results may influence positive social change through the development of culturally competent health education and promotion initiatives in support of the well-being of Hispanic informal caregivers. In addition, the research tools that may be developed by this study may be applied to other ethnic groups to determine the needs and the development of other culturally competent initiatives of informal caregivers across other cultures. This chapter includes a discussion of the issues of informal caregiver burnout; addresses the significance, purpose, and nature of this study; and provides the pertinent definitions, scope, and limitations of this research.

## Background

Informal caregiving is by no means a new topic; however, the available literature has focused on singular aspects of informal caregiving, such as the social support, stress, mental health, or perceived burden (Ong et al., 2018; Zhang et al, 2020). I sought to combine various factors related to informal caregiving to determine the relationships between them. These factors included stress self-management strategies and the perceived social support used by informal caregivers, and how this may influence their self-rated health and perceived burden, both of which are important factors for the development in burnout syndrome (see Díaz et al., 2019). Social support and stress self-management practices have been found to have a protective role against caregiver burden (Ong et al., 2018).

Research related to Hispanic informal caregivers and Puerto Rican informal caregivers was limited. According to Badger et al. (2019), few evidence-based practices and support interventions tailored to Hispanics are available, but these are needed due to the rapidly growing and aging Hispanic populations in the United States. The population of Puerto Rico is an interesting group because they reside on a Caribbean Island, are Hispanic with European and Afro-Caribbean influences, speak Spanish as their primary language, and are U.S. citizens greatly influenced by the United States. The population of this U.S. territory has a unique culture and multiple societal influences. The current study was designed to address the gaps in informal caregiver literature regarding Puerto Rican informal caregiving and their caregiving support needs. The results of this research may be used to promote health education and promotion initiatives designed to support the needs of Puerto Rican informal caregivers residing on the island.

## Problem Statement

The population of older adults continues to grow due to the baby boomer population, lower mortality rates, and better health practices (U.S. Census Bureau, 2018b). This population is estimated to reach 77 million individuals by the year 2034, and for the first time in U.S. history, older people will outnumber youths (U.S. Census Bureau, 2018b). It is estimated that 1 in every 5 adults in the United States are informal caregivers, meaning they have no formal health care training and provide unpaid regular care for their loved ones with chronic health conditions or disabilities (American Cancer Society, 2016; Centers for Disease Control and Prevention [CDC], 2019).

Hispanics have been found to provide more informal caregiving services in comparison to other ethnic groups (Luchsinger et al., 2018). This population is the largest and fastest growing racial minority group in the United States, accounting for over 18%

of the general population and estimated to comprise 28% of the older adult population by the year 2060 (U.S. Census Bureau, 2018a). According to recent U.S. Census data, Puerto Rico is the fourth U.S. jurisdiction with the highest older adult population (State Data Center of Puerto Rico [SDC-PR], 2019a). The population of Puerto Rico is 98.9% Hispanic, 20.7% of whom are 65 years or older, surpassing the youth population, which comprises 18.6% of the island’s population (U.S. Census Bureau, 2019). As the population ages, more caregivers will be needed, particularly in Puerto Rico, where most of the population resides in rural areas in which formal care services may not be readily available, and many must travel to the metropolitan areas and sometimes to the mainland United States to receive specialized health services (Mellgard et al., 2019).

As mentioned by Maggi (2015), the needs of informal caregivers deserve as much attention by society as those of the care recipient, especially in terms of the physical, emotional, mental, and financial burden. The stressors and burden experienced by informal caregivers, if maintained over long periods of time, can lead to the development of caregiver burnout (Díaz et al., 2019). Burnout syndrome is a multifactorial psychological disorder characterized by physical, emotional, and mental distress and exhaustion, resulting in feelings of depression, anxiety, irritability, negative attitudes toward care provision, and neglect of the care recipient (Krishnan et al., 2017). Burnout syndrome prevention is a significant public health issue because over 40% of informal caregivers have reported feeling burned-out, which may negatively affect the overall health and quality of life of the caregivers and care recipients (AARP, 2015). Informal caregivers experiencing burnout syndrome, particularly symptoms of emotional exhaustion, have been found to experience high levels of depression coupled with worse physical health outcomes (Gérain & Zech, 2022). Burned-out informal caregivers with these types of symptoms were also found to be more likely to be physically violent with the care recipients, further demonstrating the importance of the current study to benefit caregivers and care recipients (see Gérain & Zech, 2022).

Research has shown that social support can have a protective or mediative role in regard to the informal caregiver's burden (Ong et al., 2018). Puerto Ricans are known for their strong national identity, collectivist culture, and emphasis on familism, as well as the value of families caring for their sick, older, or disabled members (Pérez & Ailshire, 2017). The value of social support is embedded in the upbringing of Puerto Ricans, which is thought to be a protective factor among this population as they are provided social support and resources for maintaining their health (Pérez & Ailshire, 2017).

Little research has been performed on stress self-management as a method for burnout syndrome prevention among informal caregivers (Huis et al., 2015), much less among Hispanic caregivers, despite having lower caregiver burden perceptions. This is thought to be due to the concept of familism and reluctance to use formal care services, which may lead to higher burnout levels (Luchsinger et al., 2018). Additionally, 1 in 8 Puerto Rican adults are considered informal caregivers who provide at least 20 hours of care per week, and within 2 years 1 in 10 noncaregiving Puerto Rican adults expect to assume this role (CDC, 2018b).

Recent informal caregiving literature indicated that sacrificing hobbies and other stress-relieving activities as well as avoiding social contacts and activities leads to poorer quality of life, burden, and ultimately burnout (Detaille et al., 2020). Moreover, it was found that women with dual-care duties, such as caring for their children or working full-time, especially as a nurse or related health care professional, experience limited support from others and poor health over time (Detaille et al., 2020). Given the continuous aging of the Puerto Rican population and the lack of data collected on the island, it was imperative to research the self-management practices and social support systems of Puerto Rican caregivers to prevent them from burning out and suffering negative health effects. The findings could assist in the development of health education and promotion efforts in support of these informal caregivers because they are a vital part of society and the maintenance of the health care system.

## Purpose of the Study

The purpose of this quantitative nonexperimental study was to examine the relationship between stress self-management, perceived social support, health status, and burden among Puerto Rican informal caregivers. Research had not addressed these topics for this population. To address the gap in the existing literature, I used a quantitative approach to collect and analyze primary data related to multiple factors of informal caregiving. The predictors in this study were perceived stress self-management and perceived social support, while the outcomes were self-rated health and the burden of informal caregivers. Quantitative regression analyses were performed to determine the relationships between these factors. Findings may be applied to the development of health education and promotion initiatives for the benefit of Puerto Rican informal caregivers and their care recipients.

## Research Questions and Hypotheses

The independent variables for this study were the stress self-management perceptions and perceived social support of Hispanic informal caregivers. The dependent variables were the self-rated health and the informal caregiver burden among Hispanic caregivers. Potential covariates were the age and gender of the informal caregiver because these factors had been found to be influential on informal caregiver burden (AARP, 2020). The length of time the caregiver has been caring for the care recipient can also impact the caregiver's burden (AARP, 2020); therefore, this was also considered as a potential covariate. The research questions and hypotheses for this study were as follows:

RQ1: Is there an association between perceived stress self-management, perceived social support, and Hispanic informal caregiver health?

$H_o1$: There is no association between perceived stress self-management, perceived social support, and Hispanic informal caregiver health.

$H_a1$: A significant and positive association exists between perceived stress self-management, perceived social support, and Hispanic informal caregiver health.

RQ2: Is there an association between perceived stress self-management, perceived social support, and Hispanic informal caregiver burden?

$H_o2$: There is no association between perceived stress self-management, perceived social support, and Hispanic informal caregiver burden.

$H_a2$: A significant and negative association exists between perceived stress self-management, perceived social support, and Hispanic informal caregiver burden.

## Theoretical Framework

The theoretical foundations for this research were the informal caregiving integrative model (ICIM) and the individual and family self-management theory (IFSMT). The ICIM was developed based on the combination of the caregiver stress and burden model and the job demands-resources model but was adapted to address the elements that influence the potential development of informal caregiver burnout (Gérain & Zech, 2019). The ICIM considers three determinants of informal caregiver burnout: the caregiver's characteristics, the caregiving setting, and the caregiver's social environment (Gérain & Zech, 2019). According to Gérain and Zech (2019), caregiver burnout can be mediated by the caregiver's perception of the caregiving experience and the quality of the relationship with the care recipient. This model can be used to determine the risk of informal caregiver burnout and the appropriate coping strategies for reducing the negative physical and emotional outcomes of caregiver burnout.

The IFSMT framework describes self-management as a complex phenomenon. The IFSMT was designed to test the efficacy of self-management interventions and was developed based on behavior change and self-regulation theories (P. Ryan & Sawin, 2009). This framework divides self-management into three dimensions: context, process, and outcomes (P. Ryan & Sawin, 2009). These dimensions can be applied to the stress self-management strategies used by informal caregivers to determine their influence on the risk for burnout syndrome and the overall health of these people.

## Nature of the Study

I adhered to a positivist approach because the study’s purpose was the collection of primary data from a specific population and the quantifiable and objective interpretation of the findings (see Creswell & Creswell, 2018). This was achieved through the use of several reliable and valid data collection instruments, which were used in their entirety, and the statistical analysis of the primary data. This study was nonexperimental because the data were collected through questionnaires, thereby providing cross-sectional data of the caregiving experience including stress management, social support, health, and burden trends of the Puerto Rican informal caregiver population (see Creswell & Creswell, 2018).

The nature of this study was the quantitative analysis of primary data collected from a sample of Hispanic informal caregivers who reside in the island of Puerto Rico. The older adult population comprises an estimated 661,095 people; the minimum sample size for this study was 384 participants, which resulted from a 95% confidence interval power analysis for a homogeneous convenience sampling conducted using the Open Epi program (Dean et al., 2013). The use of quantitative methodology was appropriate for this study because its primary goal was to examine the relationship between stress self-management, perceived social support, and Puerto Rican informal caregiver health and burnout.

The collected data were analyzed using descriptive statistics and multiple regression analyses to determine the associations between the variables under study. Regression analyses were selected because they are appropriate to describe the relationship between multiple variables in a precise and concise manner (Frankfort-Nachmias & Leon-Guerrero, 2015). The key predictors studied were the stress self-management perceptions of informal caregivers and their perceived social support, while the main outcomes under study were informal caregiver health and levels of burden. The quantitative analyses of the data collected were consistent with the constructs of the ICIM and IFSMT frameworks because they facilitated the determination of the sociodemographic, social, and environmental factors that may facilitate or inhibit the self-management process, their impact on the informal caregiver's stress levels, and their influence on the development of burnout syndrome, potentially resulting in the deterioration of the caregiver's physical and emotional health (see Gérain & Zech, 2019, P. Ryan & Sawin, 2009). The cross-sectional nature of this study determined the relationship between the self-management practices of Puerto Rican informal caregivers, their social support networks, and their perceptions of their levels of burden and health.

## Definitions

*Burnout syndrome*: A multifactorial psychological phenomenon that may cause physical and emotional exhaustion leading to negative health outcomes for the informal caregiver and care recipient (Maggi, 2015).

*Caregiver burden*: The negative physical, mental, emotional, financial, or social outcomes associated with providing care (Halpern et al., 2017).

*Caregiver health*: The physical, emotional, and quality-of-life dimensions that can be affected by the caregiving role (Farzi et al., 2019).

*Familism*: A social phenomenon that is very common among Hispanic caregivers and emphasizes the importance of the family unit and familial support over individualism (Rote et al., 2019).

*Informal caregivers*: Individuals who provide assistance to others, usually family members, who have physical, psychological, or developmental needs and who receive no financial compensation (Yancura, 2018).

*Self-management*: The ability and the extent to which individuals are in control of their situations and lifestyles and how they use the resources available to them to manage their situations of conditions (Verkaik et al., 2018).

*Social support*: The existence and availability of human resources on which a person can rely, which shows that they are cared for, loved, and valued (Benson et al., 2020).

## Assumptions

I assumed that the participants understood the contents and inquiries of the survey and that they were informal caregivers who reside on the island of Puerto Rico. I also assumed that participants provided honest responses to the survey questions and that the responses received were accurate and were submitted in an ethical manner. These assumptions were important to this study because the data provided and conclusions reached were expected to be beneficial for the understanding of informal caregiver needs and development of health education and promotion initiatives in support of informal caregivers in Puerto Rico and potentially other cultures as well.

## Scope, Delimitations, and Limitations

The results of this research may enhance the existing informal caregiving literature, particularly for the Puerto Rican population. The focus on island-residing Puerto Rican informal caregivers and the exclusion of other participants was due to the lack of research dedicated to this population, which is an interesting mixture of cultural and social influences due to its U.S. territorial status, its geographic location in the Caribbean, and the traditional Hispanic and Afro-Caribbean culture. The survey developed for this research and the results obtained are expected to be useful and generalizable for the application of similar studies using the ICIM and IFSMT among informal caregivers from other ethnic backgrounds.

Among the delimitations of this research was the exclusion of the identification of the care recipient's health conditions. The burden and stress related to caring for a loved one may vary depending on the health conditions to be managed; however, information related to this was not included in the study's questionnaire. This factor could be studied in future research on informal caregiver burnout and self-management. A limitation of this research could be its focus on Hispanic informal caregivers residing in Puerto Rico. The data collected were specific to this population; however, this was planned due to the limited data and research on Puerto Rican informal caregivers. Another limitation was the exclusion of individuals who did not speak English or Spanish. Although there are small communities in Puerto Rico who speak other languages and immigrated to the island from other countries, these individuals make up less than 1% of the island's population (U.S. Census Bureau, 2019).

Potential bias included my personal experience as an informal caregiver working with older adults. However, this bias was controlled through the use of convenience sampling, online participant recruitment via social media (Amazon Mechanical Turk [MTurk]), and a questionnaire completed online; there was no direct contact between me and the participants, and there was no way of identifying information collected. Another limitation was the cross-sectional nature of this investigation, which addressed the measure of the prevalence of caregiver burnout, social support, and self-management practices rather than a longitudinal study of the potential development or reduction of burnout among the participants.

## Significance

This study was meaningful because it addressed gaps in the literature related to Hispanic informal caregivers, stress self-management, social support, caregiver burden, and burnout syndrome. The uniqueness of this research was achieved through its focus on Puerto Rican informal caregivers residing on the island because this population had been ignored in the existing literature. The results of this research may be applied to the development of stress management, social support, and burnout prevention health education and promotion programs tailored for Puerto Rican informal caregivers who are influenced by various sociocultural factors. These programs may have a positive effect on the health and well-being of informal caregivers and that of the care recipients, thereby improving the quality of life of both parties.

Informal caregivers should be included in health care policy and practice decisions, and funding should be provided for their care and support. The insights provided by this study may contribute to positive social change because they may encourage health care providers and policy developers to recognize the importance of informal caregivers in society as a crucial part of the health care system. Other potential positive social change may include the development of culturally inclusive health education and promotion initiatives focused on the management of informal caregiver stress and perceived social support and their relationships with burden and health status for the improvement of the physical and emotional health and well-being of the caregiver and that of the care recipient. Furthermore, the findings from this research may be useful for legislation and advocacy efforts in favor of informal caregivers, which may initiate improved access to respite and health-related services, leading to the improved health and quality of life of the caregiver and care recipient. These efforts may alleviate the burden of the growing older adult population on the health care system.

## Summary

As populations age, the need for informal caregivers continues to increase, especially in areas with limited health-related resources due to financial, social, and geographical restrictions, as is the case in Puerto Rico. Informal caregivers are often ignored by health care professionals and society because the attention is focused on the care recipients and their needs and ailments. The high stress levels and burden experienced by informal caregivers over time may result in the development of burnout syndrome and poor health outcomes for the caregiver and care recipient. Social support and stress self-management have been found to have a protective role against caregiver burden (Díaz et al., 2019); however, little research had been performed with a focus on island-residing Puerto Ricans. This population is known for its collectivist culture and familism ideals. Social support values are rooted in Puerto Rican culture and upbringing, leading to a reluctance to use formal respite services and lowered burnout perceptions despite reported high levels of burden (Pérez & Ailshire, 2017). The purpose of the current study was to examine the relationship between perceived stress self-management, social support, caregiver health, and burden among island-residing Puerto Ricans through primary data collection and analysis. The findings may be useful for the development of effective health education and promotion initiatives to preserve the well-being of informal caregivers and care recipients because they are essential for the maintenance of the health care system and societal health.

Chapter 2 is dedicated to the review of the current literature related to stress self-management, social support, caregiver health, caregiver burden, and burnout syndrome among informal caregivers and island-residing Puerto Ricans. A profile of informal caregivers in the United States and Puerto Rico is provided along with the unique characteristics and circumstances that define island-residing Puerto Ricans. The effects of familism values, recurrent natural disasters, and economic crises in Puerto Rico are also discussed. The major concepts and key variables of this study are reviewed, including caregiver burden, burnout syndrome, social support, and stress self-management. The theoretical frameworks and data collection tools for this research are presented along with the rationale and applications for this study. The chapter concludes with a summary of the findings of this literature review and the potential implications of this research for the field of health education and promotion.

# Chapter 2: Literature Review

This chapter presents the literature review for the current study. The literature search strategies are presented for the peer-reviewed and non-peer-reviewed resources used. Various terms, phenomena, and factors related to the research questions are presented and explained using the existing literature found. Among these topics are informal caregivers in the United States and Puerto Rico, the factors that influence Puerto Rican caregivers, familism, caregiver burden and burnout, stress self-management, and social support. Furthermore, the literature related to the data collections tools is discussed along with the reasoning behind their selection. This literature review is expected to assist the reader in understanding the background, evolutions, and continued need for research related to informal caregivers.

## Literature Search Strategy

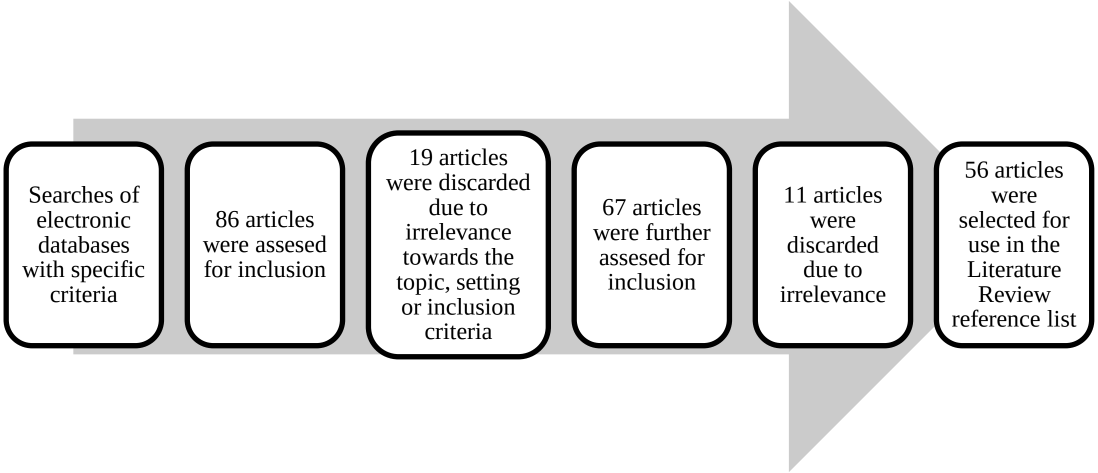
The scope of this literature review included peer-reviewed articles and other academic resources from the past 6 years (2015–2021). Several seminal resources were used due to their value as the original publications of the theoretical frameworks and data collection tools applied in this study. Figure 1 provides a visual illustration of the literature search process for the literature review portion of this study. This figure includes the selection and discarding of articles due to irrelevance to the topic. Among these seminal works are the P. Ryan and Sawin publication from 2009 that discusses the development and potential applications of the IFSMT, which was one of the theoretical frameworks applied in this study. Another seminal article was published in 1988 by Zimet et al. that presents the development and uses of the Multidimensional Scale of

Perceived Social Support (MSPSS) survey, which was one of the data collection tools for this study. Lastly, the 1986 publication by Maslach et al. provided the original and currently valid explanation of burnout syndrome, including its dimensions, symptomology, potential causes, and possible outcomes.

The databases used to search for the peer-reviewed resources were Google Scholar and EBSCOHost. Other non-peer-reviewed resources were included in this research and found through general search engines such as Google, Data.gov, and the websites pertaining to the CDC, the AARP, and the U.S. Census Bureau. The keywords and phrases used were *informal caregivers*, *informal caregiving*, *caregiving in the United States*, *Hispanic caregivers*, *caregiver burnout*, *informal caregiver burnout*, *caregiver burden*, *informal caregiver burden*, *caregiver social support*, *social support* and *caregiving*, *caregiver health*, *burnout syndrome, caregiver stress*, *stress management* and *caregiving*, *self-management*, *self-management* and *caregiving*, *stress self-management, caregiver interventions*, *caregiving health education programs*, *Puerto Rican caregivers, Puerto Rico health system*, *Puerto Rico health status, Puerto Rico health crisis*, *family caregivers, familism*, *familism* and *caregivers, caregiver quality of life*, *compassion fatigue*, *natural disasters*, and *caregiving*.

**Figure 1**

*Literature Search Process for Chapter 2*



## Informal Caregivers in the United States

As reported by the U.S. Census Bureau (2018), the population of older adults is expected to continue to grow to an estimated 77 million individuals by the year 2034. This projected growth is due to the continued aging of the baby boomer population, better health practices, and lowered mortality rates; therefore, this aging populace will require more care as time passes (U.S. Census Bureau, 2018). Current limitations in health care and long-term care systems, along with efforts to facilitate aging in place and home or community-based services, have led to an increase in informal caregiving of older adults (Ong et al., 2018). Informal caregivers are family, friends, or community members who provide unpaid assistance to a care recipient with physical, psychological, or developmental needs (Yancura, 2018). Individuals can become informal caregivers at any point of their lives and usually assume this role at unexpected times, lacking the appropriate support systems and with limited access to affordable health-related and respite services (AARP & NAC, 2020). This can limit the care provided to the patient because the caregivers may not fully understand the care recipient’s health issues or the proper treatment options; potentially leading to poor health outcomes and high levels of caregiver stress and burden (Yuen et al., 2018).

The most common informal caregivers are those who care for older adults, mainly spouses or parents, who tend to experience worse physical and emotional health than their noncaregiving counterparts due to the stress and burden associated with caring for the elderly (Amankwaa, 2017; Yancura, 2018). Informal caregivers provide a wide range of services for the care recipient, including bathing, dressing, meal preparation, financial management, transportation, medical and treatment appointment coordination, administration of medications, and patient advocacy (Amankwaa, 2017; CDC, 2018). According to Rabarison et al. (2018), the services provided by informal care providers complement formal care and traditional medical services because they perform personal and household tasks; thus, are of high economic value to the health care systems, the government, and society. One in 5, or 53 million U.S. adults identify themselves as informal caregivers, with about 24% providing care to multiple individuals, compared to 43.5 million and 18% in 2015 (AARP & NAC, 2020). There has been an increase in the need for these services, and the estimated yearly value of the services provided by these caregivers is over $500 billion (Yancura, 2018).

The average age of an informal caregiver in the United States is 49.4 years, and over 60% are women who provide an average of 24 hours of care per week (AARP & NAC, 2020). There are an additional 3.4 million “hidden” caregivers who are the children of informal caregivers that provide support and assistance to their parents and the care recipient (AARP & NAC, 2020). Most informal caregivers report that caring for their loved ones provides them with a sense of satisfaction and fulfillment, yet a significant number report feeling alone, stressed, physically and emotionally drained, and struggling financially (Ong et al., 2018; Salamizadeh, 2017). One in 4 informal caregivers report difficulties caring for their health, feel the caregiving experience has made their health worse, and report a poor health status (AARP & NAC, 2020). Díaz et al. (2019) found that informal caregiving is a responsibility usually taken on by women with near 30% reporting poor health, the presence of several chronic health issues, feeling undervalued, and hopeless for the future. If the current informal caring trends continue, fewer caregivers will be available due to their own aging, poor health, and unmet needs, and as a result the health care and long-term care system will be increasingly strained, which may lead to negative health consequences for the older and vulnerable populations (Rabarison et al., 2018). The sociodemographic factors of caregiver age, sex, time providing care, relationship with the care recipient, and health conditions of the care recipient are vital for studying informal caregiver burnout because these may influence the stress and burden experienced by informal caregivers (AARP & NAC, 2020).

## Hispanic Caregivers

According to Rote et al. (2019), informal caregiving is more prevalent and intense among ethnic minorities, because over 30% of family caregivers in the United States identify as members of ethnic minority populations. Recent data have shown that over 17% of informal caregivers in the United States are of Hispanic ethnicities and 25% of noncaregiving Hispanics are expected to become informal caregivers by the year 2022 (AARP & NAC, 2020). The U.S. Census Bureau (2018a) identified Hispanics as the largest and fastest growing racial minority population in the United States representing about 18% of the general population, and by the year 2060 older Hispanics will compose about a quarter of the nation's older adults (Diallo et al., 2019).

Research has shown that cultural and societal factors play an important role in the definition and perceptions of caregiver burden (Maggi, 2015). Hispanic informal caregivers may experience higher levels of caregiver burden due to their cultural reluctance of delegating caregiving responsibilities to extrafamilial individuals and the influence of the familism phenomenon (Luchsinger et al., 2018). Familism emphasizes the importance of the family unit and familial support over individualism, causing Hispanic caregivers to underreport physical and emotional distress associated with their responsibilities (Rote et al., 2019). Hispanic caregivers often report high levels of satisfaction with their roles and quality of life; however, over time their physical and emotional health may deteriorate, suggesting high levels of caregiver stress and burden (Rote et al., 2019).

Rote et al. (2019) found that in comparison with non-Hispanic White and African American informal caregivers, Hispanic caregivers reported lower levels of social support, higher levels of distress, poor self-rated health, and caregiving intensity. The intensity of caregiving tends to increase with the dependency of care recipient of the caregiver, the duration of care, and coresidence of the care recipient and provider, both of which are prevalent in Hispanic caregiving situations (Rote et al., 2019). Despite the intensity of care and the long-term care expectations, Hispanic caregivers are more likely to reject the use of formal care and respite services due to cultural preferences of family-provided care within the home (Koerner & Shirai, 2019; Rote et al., 2019).

## Puerto Rican Caregivers

Puerto Ricans compose the third largest Hispanic group in the United States with approximately 4.7 million Puerto Ricans residing in the mainland while about 3.7 million live on the island (Pérez & Ailshire, 2017; U.S. Census Bureau, 2019). Approximately 20.7% of the island's population are adults aged 65 years or older, making it the United States jurisdiction with the fourth largest population of older adults according to the U.S. Census Bureau (2019); furthermore, 15.1% of Puerto Ricans under the age of 65 have at least one disability. Consequently, the strain on the already drained health and economic systems of the island has worsened over the years, which historically has had worse population health and financial stability than the continental United States (Alcorn, 2017; SDC-PR, 2019). Island-residing Puerto Ricans are less likely than their mainland-residing counterparts to suffer from heart and lung diseases, stroke, cancer, and mobility limitations, yet they are more likely to develop diabetes, hypertension, and other metabolic syndromes (Pérez & Ailshire, 2017). The prevalence of chronic health conditions, along with the accelerated aging of the Puerto Rican population, are indicators of the need for long-term care on the island, emphasizing the need for informal caregivers in Puerto Rico (Pérez & Ailshire, 2017).

Puerto Ricans are a collectivist culture with a strong national identity regardless of where they reside, and they emphasize the use of the Spanish language, familism ideals, and traditional practices, which serve as protective factors for the health of Puerto Ricans as they provide their loved ones with emotional support and resources for maintaining good health (Pérez & Ailshire, 2017). About 14% of island-residing Puerto Ricans are informal caregivers, whereas 10% of noncaregiving adults are expected to become caregivers within 2 years (CDC, 2018). Approximately 62% of Puerto Rican caregivers are women who care for their parents or parents-in-law, have provided care for at least 2 years, and offer at least 20 hours of care per week (AARP & NAC, 2020). Informal caregiving is a costly and long-term responsibility, with an estimated value of $8.70 to $10.28 per hour of care in Puerto Rico, totaling about $13,069 annually in indirect costs of caregiving per caregiver (Rabarison et al., 2018). The CDC (2018) found that 21.6% of Puerto Rican informal caregivers reported suffering from frequent mental distress, 40.8% had two or more chronic health conditions, and 18% of these illnesses were heart disease. Therefore, health education and promotion initiatives should be developed to address informal caregiver burden and burnout among Puerto Rican caregivers, because this is an important public health issue that affects those who provide health care services that alleviate strain on the island’s historically weak health system.

## Profile of Island-Residing Puerto Ricans

The island of Puerto Rico has suffered the consequences of an 80-million-dollar budget deficit, prompting an economic crisis that has exacerbated the already weakened and fragmented health system due to the massive emigration of health professionals to the continental United States and the closure of hospitals and other health-related service providers (Mattei et al., 2018; Meléndez & Hinojosa, 2017; Roman, 2018). A study conducted on the health conditions and lifestyles of island-residing Puerto Ricans after Hurricane María demonstrated that many participants had higher education levels (46.3%); however, 59.9% had annual household incomes of less than $10,000, 48.2% were retired, 15.3% were unemployed, and 51% were enrolled in federal nutritional assistance programs, yet 93% had health insurance mainly due to Medicare/Medicaid policies (Mattei et al., 2018). Nighty-two percent of these participants reported their plans to emigrate to the continental United States due to diminished quality of life on the island (82.3%), searching for employment or financial opportunities (72.6%), personal reasons (69.4%), and seeking better health care services (54.8%; Mattei et al., 2018). Poor self-rated health was reported among 40.1% of the island's residents, more than half (53%) of the participants presented symptoms of depression, and 21.7% had symptoms of anxiety that aligned with the prevalence of unhealthy lifestyle habits, including difficulty sleeping, smoking, and sedentarism (Mattei et al., 2018). Family history of cardiometabolic diseases was frequently reported, and women were found to have higher prevalence of obesity, arthritis, osteoporosis, high cholesterol levels, and thyroid diseases than their male counterparts (Mattei et al., 2018). More than 50% of Puerto Ricans depend on Medicare and Medicaid health insurance, yet the island receives much less health-related funding than the continental United States. These coverages are not transferable to the continental United States; however, many Puerto Ricans seek health care services in the mainland because many specialized health services are unavailable on the island (Mellgard et al., 2019; Roman, 2018).

## Effects of Natural Disasters on Informal Caregivers

As mentioned by Mellgard et al. (2018), hurricane and natural disaster damages are inevitable, but healthcare consequences are preventable. Evidence has shown that following a natural disaster there is an increased need for mental health services for caregivers (Fujitani et al., 2016). This study suggested that long-term psychological support and caregiving resources are essential for the sustainability of caregiving services following natural disasters and during the recuperation of the areas most affected by these catastrophes. Research following the 2011 Great East Japan Earthquake and Fukushima Nuclear Disaster found that two years after these incidents, caregivers were still experiencing high levels of burden, mental health distress and burnout syndrome (Fujitani, et al., 2016). This study also found that despite the caregivers' burden and emotional exhaustion, they remained highly invested with their care recipients. It was concluded that their caring attitudes and emotional and personal investments with the care recipient are what encouraged them to continue providing care (Fujitani, et al., 2016).

Fujitani, et al. (2016) suggests that emotional exhaustion after a natural disaster may partially arise from limited access to basic necessities for caregivers and care recipients, including clean water, food, and adequate sleep quality, which are essential for the maintenance of overall caregiver health. Emotional exhaustion and sleep deprivation were found to build up after natural disasters as stress relieving and leisure activities are highly limited following these events (Fujitani, et al., 2016). Female caregivers were found to suffer from higher levels of burnout after climatic events due to worrying more about their family, care recipient health, and food accessibility in comparison to their male counterparts (Fujitani, et al., 2016).

Due to public health crises following natural disasters, best practices have been studied and implemented for preparing vulnerable populations for these events. Disabled and older populations who depend on formal or informal services for their well-being are among the most vulnerable. Informal caregivers also experience increased stress and burden because they must prepare themselves and their family for the natural disaster but must also take into consideration the care and well-being of the care recipient, whose needs may not be met in the absence of health, respite or utility services. Those who reside in vulnerable areas must evacuate or stay in shelters have a significantly difficult time meeting the care recipient's needs, particularly if the latter is cognitively or physically impaired. Gibson, et al. (2018), described these complex circumstances and feelings of uncertainty as "a perfect storm", which can make it very difficult for the informal caregiver to make decisions and prepare for what is to come.

In 2017 more natural disasters were recorded in the United States than in previous years and this is expected to increase over the years as climate change continues to worsen, accompanied by rapidly changing demographics including more cultural diversity and an aging population (Gibson, et al., 2018). Older adults are more vulnerable to natural disasters due to their high prevalence of comorbidity and disabilities, higher rates of disaster-related deaths, and are least likely to be prepared for these events due to their low disaster literacy (Gibson, et al., 2018). Older adults are less likely to evacuate their homes because many are not comfortable making decisions and depend on family members for support and assistance during the disaster recovery. Those with cognitive impairments, like Alzheimer’s disease and related dementias may experience symptom exacerbation when their schedules and routines are disrupted, making it more difficult for their caregivers to manage their care and behaviors during a natural disaster, even more so if the caregiver is an older adult as well. A recent study reported that about 37% of cognitively impaired patients and their caregivers who were forced to evacuate during the 2015 South Carolina flood experienced disaster-related symptom exacerbation including feelings of general discomfort, anxiety, agitation, disorientation, stress, and aggression (Gibson, et al., 2018). Within the local shelters, caregivers reported difficulties with privacy, disclosure of the care recipient’s illness, resources for dealing with the chronically ill, disabled, and cognitively impaired. However, once formal care and community-based services were available, caregivers felt relief because their loved ones could return to their daily routines while the caregiver continued with recovery efforts (Gibson, et al., 2018). Emergency preparedness, educational programs, and trainings are recommended for informal caregivers to reduce the uncertainty during these situations. This will enable them to manage the available resources before and after the event, and make the best decisions for the care recipient and themselves during these already stressful circumstances.

## Consequences of Recent Natural Disasters in Puerto Rico

Natural disasters can exacerbate the existing health and social issues within entire nations or communities and worsen the health outcomes of vulnerable populations. This has been the case for the island of Puerto Rico, which has experienced several catastrophic natural events including major hurricanes and earthquakes, followed by the COVID-19 pandemic, which have left the already delicate health system and other basic services in poor conditions. Hurricanes are climatic events that are expected in Puerto Rico and in the Caribbean, however these events have been occurring more frequently and with greater intensity in recent years due to climate changes, causing greater damages and less time to recover from these events. By September 20, 2017, Puerto Rico and other Caribbean nations had been struck by two consecutive major hurricanes, Irma and Maria, causing island-wide power outages, loss of potable water services, and a lack of communication services (Roman, 2018). Outpatient clinics were closed, and many were eventually shut down due to severe structural damages and lack of utilities, resulting in patients being unable to receive vital medical treatments including dialysis, chemotherapy, transfusions, oxygen concentrators, nebulizers and ventilators. Many emergency rooms were inoperable due to these conditions, while limited communications hindered emergency transportation services and rescue operations (Roman, 2018). Three weeks following Hurricane Maria’s landfall, 89% of the island had no electricity, 47% had no cellular phone service, and the death toll was estimated at about 4,645 individuals (Roman, 2018).

The median income of island residing Puerto Ricans is $20,166 and between the years 2019 and 2020 the proportion of individuals living under the poverty line increased from 11.8% to 45%, about 1.54 million people, due to the compounding effects of the ongoing economic crisis, infrastructural, and socioeconomical damages from the 2017 hurricane season, the 2020 earthquake swarm, and the ongoing COVID-19 pandemic

(Garriga-López, 2020, Pérez-Pedrogo et al., 2020, U.S. Census Bureau, 2019). The seismic activity began in late December 2019 but peaked on January 7, 2020, with a 6.4 earthquake that caused an island-wide power outage and a declaration of a state of emergency in Puerto Rico with aftershocks expected to continue for over 10 years and thousands of earthquakes felt since then (Hennen, 2020). This earthquake swarm has resulted in the displacement of many residents as well as the closing of several health service providers due to the massive loss of homes, workplaces, and historical infrastructures (Garriga-López, 2020). A significant number of Puerto Ricans were forced to leave the island, move in with other families, or stay in temporary housing as they had nowhere to go and were unable to meet their basic needs (States News Service, 2020)

## Exodus of Puerto Ricans to the Mainland United States

The damages caused by these recent natural catastrophes, weakened health system, economic crisis, and mass exodus in Puerto Rico have created new and worsening circumstances for those caring for older adults and the disabled in Puerto Rico because they have experienced personal and financial losses themselves and must continue providing care while managing their loved ones health conditions and quality of life with potentially less family members able to help and limited health resources (Mellgard et al., 2018). Numerous island residents have lost family members, their homes, employment, and have developed new or worsened health conditions following these recent climatic events; causing a physical and mental public health crisis in Puerto Rico. Due to these harsh and uncertain living conditions, many Puerto Ricans have emigrated to the mainland United States, leaving behind their remaining family, friends, and properties behind (Meléndez & Hinojosa, 2017). This can be a very difficult transition for those who remain on the island because they mostly consist of older adults and the disabled and the responsibility for their care inevitably falls upon younger and healthier family members who were able or pressured to stay in Puerto Rico. Many of those who have remained on the island have done so because they feel morally inclined to care for their vulnerable loved ones and may be forced to accept low-paying jobs that they are overqualified for to support themselves, their immediate family, and the care recipient. As the Puerto Rican population continues to age, island residents are entrusted with the care of multiple older or disabled adults, which puts them at a higher risk of burning out.

According to Meléndez & Hinojosa (2017), due to Puerto Rico's economic crisis, about 14% of the population, or 525,769 individuals, left the island between the years 2006 and 2016, a trend that has accelerated since the Hurricane Maria disaster in 2017 and the 2020 earthquake swarm. Demographic studies found that adults between the ages of 25 and 64 accounted for the largest group that moved to the continental United States, resulting in the accelerated aging of the island's population, with adults aged 65 or older accounting for over 20% of the island's population (Meléndez & Hinojosa, 2017, SDC-PR, 2018). After Hurricane Maria, between October 3rd to the 25th 2017, over 73,000 Puerto Ricans emigrated from the island to the state of Florida seeking refuge, many to ensure the continuance of their health care services (dialysis, chemotherapy, radiotherapy, intravenous infusions, non-elective or emergency surgeries, and other outpatient treatments) because delays resulted in preventable hospitalizations and increases in morbidity and mortality (Mellgard et al., 2018). By the end of the year 2018, approximately 133,451 individuals had emigrated to the mainland U.S. from Puerto Rico (SDC-PR, 2019).

## Caregiver Burden and Burnout

Assuming the role of an informal caregiver, for older adults, chronically ill, or cognitively impaired patients can have a negative impact on the overall health, well-being, and quality of life of the caregiver (Farzi et al., 2019). Informal caregivers are the first line of care for patients with chronic, terminal, or developmental illnesses because they maintain patient hygiene, prepare diet-specific meals, provide transportation, are present for hospitalizations, and emotionally support the patient to manage their ailments (Farzi et al., 2019). Providing continuous and long-term care for a loved one can be a tiresome and rigorous task, because informal caregivers aim to provide quality care and a dignified quality of life to the care recipient free of charge, yet have no formal clinical training, limited financial, and social supports (Salamizadeh, 2017). These individuals are constantly exposed to progressive physical and cognitive decline of their loved ones which can lead to physical and emotional vulnerability if they are continuously stressed and burdened by their responsibilities (Salamizadeh, 2017).

Burden is the physiological, emotional, and financial consequence of responses and attitudes of an informal caregiver towards the demands of care provision (Gratão et al., 2019). The physical and emotional strains of caregiver burden can be reflected through symptoms of fatigue, anxiety, depression, irritability, hostility, sleeping disorders, physical pain, impatience, lack of concentration, and stress (Gratão et al., 2019). Many female caregivers feel morally pressured to become informal caregivers, which can exacerbate the negative effects of care work; this burden tends to be greater when caregivers report worse health, especially on the psychological level (Díaz et al. 2019). Sustained levels of high burden can lead to the loss of efficacy in meeting the care recipient's needs and the worsening of the caregiver's personal well-being, resulting in the development of burnout syndrome if the stressful issues remain unmanaged.

Burnout syndrome is a multifactorial psychological phenomenon caused by physical and emotional exhaustion and can lead to negative health outcomes for the informal caregiver and care recipient (Maggi, 2015). Burnout syndrome was described and measured in 1986 by Cristina Maslach and Susan Jackson who determined that it consisted of three dimensions: emotional exhaustion, depersonalization, and diminished personal accomplishment (Maslach et al., 1986). Emotional exhaustion occurs when a person feels he or she can no longer offer any part of themselves because their emotional resources are depleted accomplishment (Maslach et al., 1986). Depersonalization is the development of negative, callous, or cynical feelings towards others, and diminished personal accomplishment is the negative evaluation of one's actions and abilities (Maslach et al., 1986). The development of burnout syndrome can be potentially dangerous for the health and well-being of informal caregivers who can become ill themselves and incapable of caring for their loved ones, or can potentially lead to the neglect and mistreatment of the care recipient (Maggi, 2015).

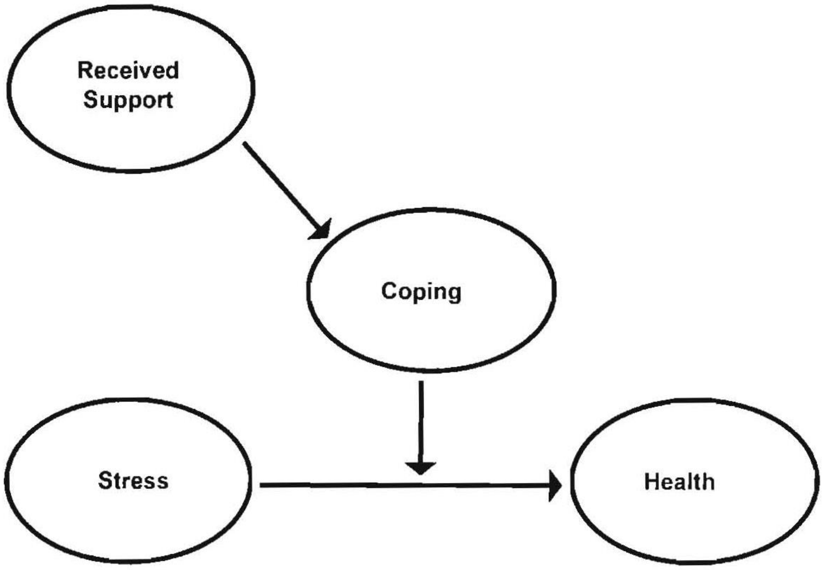
Informal caregivers are seen as a type of "hidden patient" because they do not receive the same amount of attention as the care recipient in the general society nor in clinical settings; yet they merit recognition and equal attention due to the value and physical, emotional, and economical sacrifices associated with their responsibilities (Maggi, 2015, Farzi et al., 2019). Research has shown that informal caregivers with greater feelings of competency and self-efficacy better cope with the stress of caring for their loved ones, thereby reducing their levels of caregiver burden and maintaining their physical and emotional health (Maggi, 2015).

## Social Support

Social support is a complex concept that has been studied over the past decades and multiple theories and perceptions of social support have been developed. In their social support theory development research, Shumaker and Brownell (1984) placed a heavy focus on the chronically ill and informal caregivers, and defined social support as an “exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient” (pp. 11). Social support is very important for the physical and emotional health of individuals and can have health-sustaining and stress-buffering effects on the recipient (Shumaker & Brownell, 1984). Receiving social support is theorized to reduce the harmful physical and emotional health effects caused by stressful events; thus, can be perceived as a stress buffer (see figure 2, Lakey & Cohen, 2000). Perceptions of social support are thought to improve the support recipient’s coping strategies, allowing the recipient to view stressful situations as less intimidating (Lakey & Cohen, 2000; Sarason et al., 1999). Those who receive and perceive more social support are expected to experience less stress and have better health due to the stress-buffering effects of social support (Lakey & Cohen, 2000; Sarason et al., 1990).

**Figure 2**

*Social Support Stress-Buffering Perspective*



*Note*. Adapted from Lakey and Cohen (2020).

It can be difficult for a support provider to determine the needs of the recipient as they may struggle to define their specific needs, especially during a highly stressful situation. The social support exchanges between individuals may lead to assumptions of costs, benefits, and reciprocity of supportive behaviors, in which the recipients of the support may feel they should “return the favor” to the support providers and may develop a feeling of burden if they are unable to reciprocate the behaviors; thus, may be less likely to accept or solicit support in the future (Shumaker & Brownell, 1984). These feelings of burden can be avoided through the use of formal support networks including therapists, religious groups, health professionals, and community support groups, because they do not require or anticipate reciprocity in exchange for their services (Shumaker & Brownell, 1984).

According to Sarason et al. (1990), the perception of social support has been consistently related to stress outcome measures rather than the actual support received. This is due to research showing that if a person does not perceive that social support may be available, then they are likely to solicit support (Sarason et al., 1990). Lakey & Cohen (2000) emphasized the importance of the social support provisions to match the social support needs or demands, because each stressful situation can have a different effect on individuals. Among the most important determinants of social support is the stability of the relationship dyad between the support provider and recipient, the relationship satisfaction, and the harmonization of the support needs and support offered (Lakey & Cohen, 2000; Sarason et al., 1990). The most important factor for social support is the belief that a person has someone who cares about them and is willing to offer their help when assistance is needed or solicited (Sarason et al., 1990).

## Social Support and Caregiver Health

Caring for loved ones, especially to those with terminal or catastrophic illnesses, puts informal caregivers at a higher risk for poor physical and emotional health. Social support is essential for the reduction and management of informal caregiver stress, burden, maintaining their well-being, and is associated with better physical and emotional health (Rote et al., 2019). Benson et al. (2020), defined social support for informal caregivers as the existence and availability of human resources on which a person can rely, shows that they care, value, and love the person in need of assistance. As described by Ong et al. (2018), there are two aspects of social support: perceived social support and received social support. Perceived social support is the personal perception of the quality and quantity of support available to an individual within his or her social network (Ong et al., 2018). Received social support is the actual quantification of the support provided by an individual's social network. Perceived social support was found to be a stronger predictor of greater physical and emotional health, and less stress and burden among informal caregivers (Ong et al., 2018). Poor health was found to be associated with high perceived caregiver burden, especially among those who had lower perceived social support, because this perception of support is a significant mediator of the negative relationship between perceived burden and overall caregiver health (Díaz et al. 2019).

The challenges of providing care can disrupt the caregiver's and household daily routines, causing changes to family roles and responsibilities which can be difficult to accept and may strain intrafamilial relationships (Diallo et al., 2019). Informal caregivers often report an overall poor quality of life, including self-neglect, breakdowns in spousal or partner relationships, loss of work, economic strain, resentment or hostility towards the care recipient, headaches, joint pain, low self-esteem, anxiety, clinical depression, insomnia or other sleep disturbances, and high levels of stress and burden (Benson et al., 2020; Díaz et al. 2019). Social support can significantly improve overall informal caregiver health and well-being, and is associated with greater life satisfaction and a reduction in the negative effects of care provision (Díaz et al. 2019). Informal caregivers tend to lack adequate social support resources and experience social isolation, even more so when the caregiving situation becomes more frequent and intense, usually when the care recipient is close to death or in hospice care (Benson et al., 2020). The presence and level of social support are predictors of informal caregiver burden because there is a significant negative association between social support and caregiver burden, and higher burden is associated with worse caregiver health (Díaz et al. 2019).

## Types of Social Support

Social support can be varied, but usually falls into one of the following categories: emotional, appraisal, companionship, informational, and instrumental. Emotional support is composed of expressions of caring, compassion, concerns, empathy, and sympathy (Benson et al., 2020). Appraisal support includes compliments and validation statements to promote a person’s value and skills. Companionship support is the perception of having a social network, and feelings of solidarity, friendship, inclusion and togetherness (Benson et al., 2020). Informational support consists of sharing knowledge, information, facts, advice, tips, and suggestions. Lastly, instrumental support consists of providing tangible goods or services (Benson et al., 2020).

Caregiver support can be offered formally through community or home care services, and has been found to reduce the stress, intensity, and burden associated with caring for a loved one (Rote et al., 2019). Due to technological advances, social support can be solicited and received in a variety of ways, such as face-to-face or virtual support groups, community social media pages, video messaging and calls, searching and sending health information, among others that can put informal caregivers in contact with their family, friends, healthcare professionals, and other caregivers, no matter where they are physically present (Benson et al., 2020). About 38% informal caregivers recognize the value of formal care and respite services to help their situation, but only 14% of caregivers report using these services (AARP & NAC, 2020). As reported in the Caregiving in the U.S. 2020 survey, 26% of informal caregivers seek informational and training support related to keeping the care recipient safe at home, 26% seek support to manage their stress and 25% seek support related to navigating the healthcare system, available support services and related forms and paperwork (AARP & NAC, 2020).

## Solicitation of Social Support

Social support can occur verbally or non-verbally and can be solicited directly, as in asking for assistance or information on a specific issue, or indirectly through the disclosure of a situation which may reveal unmet needs. Benson et al.'s (2020) study on the use of online social support among informal caregivers, showed that emotional support was the most common type of support provided, followed by companionship support, appraisal support, and informational support. Informational support was the least elicited by the participants because it is readily provided informally by family and friends, or formally by external service providers, hospice or respite staff, healthcare professionals, and local services (Benson et al., 2020). The participants expressed the desire and need for more appraisal and companionship support to reduce the effects of pessimistic and depressive feelings related to their caregiving situations, especially when their loved one is close to death or has passed away.

Emotional self-disclosure was the most common form of support solicitation, which consists of participants expressing their feelings about certain aspects of their caregiving situation, which usually resulted in other participants offering emotional support through expressions of solidarity, compassion and expressions of their own emotions (Benson et al., 2020). Social support can also be elicited through informational self-disclosure, which consists of participants stating information related to their caregiving activities and personal history, such as sociodemographic profile of both the caregiver and care recipient and their health status; however, these statements are rarely unaccompanied by an emotional statement (Benson et al., 2020). The researchers found that while informal caregivers found social media or virtual support interventions to be effective and valuable, they expressed feeling the need to complement the program with face-to-face support interventions to experience human interactions and converse synchronously.

## Social Support Within a Family System

Chronic illnesses and disabilities can affect entire families and social support is crucial for positive health outcomes and possible rehabilitation. Familial dissent negatively affects the rehabilitation and health outcomes of chronically ill and disabled patients, meaning that unhealthy or dysfunctional family systems can be exacerbated when a member becomes ill, leading to stressful and burdensome circumstances (Diallo et al., 2019). Positive family resources can alleviate the demands of caregiving, including problem-solving skills, interconnectedness, effective communication, and mutual respect (Diallo et al., 2019). The presence of external support resources is essential for a family to effectively manage and overcome stressful situations when a member is chronically ill or disabled and can influence familial relationships, behaviors, practices, and beliefs.

Social support resources for informal caregivers tend to decrease significantly after five years of providing care, so as care recipients age and their health worsens, caregivers receive less support from their family and friends (Hong & Harrington, 2016). Research has shown that with longer periods of providing care, caregivers tend to report higher levels of perceived burden and lower self-rated health (Hong & Harrington, 2016). When informal caregivers lose social support resources, they experience higher levels of stress as they try to mitigate the negative effects of these losses, which can result in caregiver burnout (Hong & Harrington, 2016). Social support is an effective buffer against caregiver stress and can protect against worsening health, so it is recommended that health education and promotion programs be designed and implemented to teach informal caregivers various coping mechanisms, develop self-care plans, provide them with support, guidance, and useful information related to their care situation (Díaz et al. 2019).

## Social Support Among Hispanic Informal Caregivers

Hispanics rely heavily on their families for support, bonding, cohesion, and providing care for their loved ones within the home is a cultural practice (Diallo et al., 2019). These caregivers often report low levels of formal care services usage due to familism values, lack of service providers in their community, or economic barriers to access these services (Rote et al., 2019). Hispanic informal caregivers are less likely to seek external support resources than their counterparts from other ethnic backgrounds despite this lack of external support potentially resulting in increased stress and burden (Diallo et al., 2019). They report low levels of satisfaction and availability with the informal caregiving networks formed by family and community members, which if used properly, can mediate or serve as protective factors against poor health and burden among Hispanic caregivers (Rote et al., 2019). The limited social support received by Hispanic informal caregivers from their friends and family can provoke anger, frustration, and resentments which may be further exacerbated by quality of the caregiver and care recipient relationship, familial appreciation for the care provided, and the reason behind the lack of support (Koerner & Shirai, 2019). In some cases, the reasons provided or justifications for not providing support and assistance to the primary caregiver may also mitigate the negative feelings depending on the caregiver's perception of these explanations.

Hispanic families tend to be culturally grounded in familism ideals which promote family caregiving within the home without extrafamilial or formal care services. The responsibility for caring for older adults typically falls upon the wives, daughters, daughters-in-law, or closest female family member, regardless of the family size (Koerner & Shirai, 2019). While these informal caregivers place high value on supportive family members, they often perceive little to no social support from their families and their dissatisfaction with this lack of support has been associated with depressive symptoms and poor overall health (Koerner & Shirai, 2019). In accordance with the familism phenomenon, most caregivers feel a strong feeling of personal and moral satisfaction while providing familial care, despite reporting feeling stressed and sometimes overwhelmed with their responsibilities (Ong et al., 2018). Hispanic caregivers may experience conflicting feelings towards their caregiving responsibilities because they feel a strong familial obligation to provide quality care for the care recipient but may lack the desired support from their loved ones (Koerner & Shirai, 2019).

Limited or non-existent family support may provoke familial disagreements and conflicts in most Hispanic families, particularly among siblings regarding the responsibilities of caring for their parents (Koerner & Shirai, 2019). Diallo et al. (2019) concluded that one of the major barriers for Hispanic informal caregivers to family interconnectedness are the opposing cultural expectations within the family system, such as some family members being more individualistic rather than adhering to collectivism as is expected within this culture.

Recent studies show that positive familial resources, such as family functioning, managing logistics related to patient care, family closeness, support, respect, personal responsibilities, and putting the family’s needs first, are significantly related to a reduction in informal caregiver stress (Diallo et al., 2019). Social interactions and affective social support were found to be the most effective as reducing psychological burden, and informal social support was found to be more effective than formal support resources (Ong et al., 2018). Despite having very strong family ties and familial resources, Hispanic informal caregivers experience the highest levels of stress among other ethnic groups (Diallo et al., 2019).

Prolonged periods of care provision, constant unmet needs, and chronic stress can lead to informal caregiver burnout; however, the perception of social support can serve as a protective factor against poor physical and emotional health (Ong et al., 2018). Strong correlations were found between the use of external support services and caregiver stress, yet the solid familial connections among Hispanics greatly reduce or delay informal caregiver efforts to seek external support and as a result further exacerbate their stress levels (Diallo et al., 2019). Those with highly functional family systems can benefit from their family’s support when caring for a loved one; however, those with dysfunctional families can greatly benefit from seeking external support services in order to preserve and improve theirs and care recipient’s overall health and well-being (Diallo et al., 2019).

## Self-Management

Health issues have shifted over the years from acute problems to chronic ones, leading to the delivery of health services outside of the traditional hospital or clinical settings. Consequently, more individuals must manage their health conditions from home, many times with the assistance of a loved one, particularly among older adults or those with multiple health conditions. Healthcare professionals encourage and expect patients and their caregivers to manage their health conditions, yet provide little guidance on how to self-manage their conditions. Self-management is defined as the ability of an individual to manage the symptoms, treatment, and the physical, psychosocial, and lifestyle changes associated with living with a chronic condition (Huis in het Veld et al., 2020). In other words, self-management is the ability and the extent to which individuals, or their families are in control of their condition and lifestyle and how they use the resources available to them (Verkaik et al., 2018).

### Constructs of Self-Management

The self-management phenomenon is often divided into three constructs: processes, programs, and outcomes (P. Ryan & Sawin, 2009). Self-management processes refer to self-regulation skills for managing the risk factors and health issues associated with health behaviors such as: setting specific goals, decision making, reflective thinking, planning and engaging in specific behaviors, managing physical and emotional responses, and self-evaluation (P. Ryan & Sawin, 2009). Self-management programs are interventions designed and implemented by healthcare professionals for patients to assume the responsibility of managing their health conditions through their engagement in health education and promotion initiatives. Outcomes refer to what is achieved by engaging in self-management practices such as blood pressure stabilization, lowered cholesterol levels, smoking cessation, and reduced stress levels. The goals of self-management practices are the enhancement of health behavior changes, reduction of healthcare costs, and improved quality of life and well-being (P. Ryan & Sawin, 2009). Self-management is the process of learning and engaging in specific behaviors for the enhancement of a person's ability to reduce risk factors, management of a chronic health condition, and is highly associated with the fields of health education and promotion.

## Self-Management and Informal Caregivers

Self-management can occur in various settings or contexts; as an individual, in a family, and within a community, so these behaviors can be applied to different levels of society (P. Ryan & Sawin, 2009). Regarding informal caregivers, self-management practices include the management of the care recipient's illness and symptomologies but also their health conditions and the stress they experience due to their caregiving responsibilities (Verkaik et al., 2018). These practices can be implemented by patients and their family members or caregivers, because they form the caregiver-care recipient dyad, meaning that their health and well-being are interdependent of each other (Zhang et al., 2020). Accordingly, self-management behaviors can be influenced by many risk and protective factors, including health status, individual and family characteristics, sociocultural factors, and environmental factors (P. Ryan & Sawin, 2009).

Evidence has shown that those who engage in self-management behaviors have better health outcomes and significant reduction in stress and burden related to caregiving circumstances (Zhang et al., 2019). Commonly recommended self-management practices by healthcare professionals include symptom management, taking and managing medications, efficient resource utilization, recognizing severe health episodes, stress reduction, following nutritional diets, exercising, communicating with healthcare providers and forming a relationship with them, seeking health-related information, managing emotions and relationships, developing action plans, and adapting health accommodations at work (P. Ryan & Sawin, 2009). The most common self-management strategies used by informal caregivers are getting rest, using respite care, sharing their feelings with their peers or a professional, and looking for distractions (Verkaik et al., 2018). Regardless of the strategies implemented, seeking knowledge and social support were found to be essential for efficient self-management. When patients and their caregivers engage in self-management behaviors, they contribute to society and the health system because they can improve their health status and quality of life, thereby reducing their reliance on clinical and emergency services as well as reducing their medical expenses. Self-management practices can improve health outcomes through the prevention, postponement, and attenuation of chronic health conditions (P. Ryan & Sawin, 2009).

### Self-Management and Hispanic Cultures

Self-management of stress and frustration due to the lack of support received by family, friends, and the community can help the caregiver's feeling towards this to evolve through cognitive reframing, application of self-protecting strategies, and realizing and accepting that negative reactions and feelings are ineffective and may lead to conflict with their loved ones (Koerner & Shirai, 2019). Letting go of expectations from their family members, no longer asking for help or involvement from others to avoid disappointment, disregarding uninformed or unsolicited advice and/or blame have been found effective at reducing Hispanic caregiver distress and negative emotional outcomes, (Koerner & Shirai, 2019). These practices can be challenging for Hispanic caregivers because their collectivist and familism-based culture can contradict these practices due to their high expectations for their family and community's involvement (Koerner & Shirai, 2019). Despite receiving less support and perceiving more intense caregiving situations, Hispanic caregivers often express more positive attitudes towards informal caregiving and better relationship quality with the care recipient than their non-Hispanic White counterparts, both of which are associated with better emotional health and caregiving outcomes (Rote et al., 2019).

Hispanic cultures tend to be highly spiritual and religious, so spiritual counseling and interventions in association with religious congregations and clergy members can be positively received by informal caregivers (Koerner & Shirai, 2019). Spiritual care can improve self-efficacy in caregivers, especially those who care for patients with severe mental health issues and Alzheimer’s and related dementia patients, spirituality-based interventions can empower these caregivers and reduce their risk for caregiver burnout and improve resiliency when faced with difficult situations related to caring and making decisions for their loved one (Salamizadeh, 2017).

According to Salamizadeh (2017), spirituality and religiosity are highly associated with efficient coping with stressful life events, problems associated with family and care recipients, social, personal, and economic deprivations, and death of the care recipient. Spiritual care interventions were also found to improve family interdependence, reduce psychological distress, and improve tolerance to distress associated with informal caregiving (Salamizadeh, 2017). Spiritual care includes simple and cost-effective interventions that can consist of brief sessions including the provision of educational materials and discussions surrounding topics related to God, prayer, seeking help from clergy members, altruism, mantras, generosity, and patience, among other related topics (Salamizadeh, 2017).

Koerner & Shirai (2019), suggested that Hispanic informal caregivers are less likely to seek help in-person, therefore interventions via telephone, social media blogs, foto-novelas (picture books with caregiver stories and Hispanic characters), and community-based interventions guided by former caregivers and/or community health workers, may be beneficial for this populace. Healthcare professionals can play a significant role in promoting informal caregiver well-being and stress self-management since they come in regular contact during the care recipient’s medical appointments or through pre-arranged visits to the home (Salamizadeh, 2017). These interventions can range from the provision of educational materials, promotions of available support and respite services, brief therapy or consultation sessions, spiritual guidance, the development and implementations of health education and promotion initiatives to support informal caregivers or giving advice on how to provide better care and improve their coping strategies (Salamizadeh, 2017). Respite care services can be beneficial to those Hispanic caregivers willing to allow strangers in the home which usually occurs when they can no longer care on their own and are highly burdened (Koerner & Shirai, 2019).

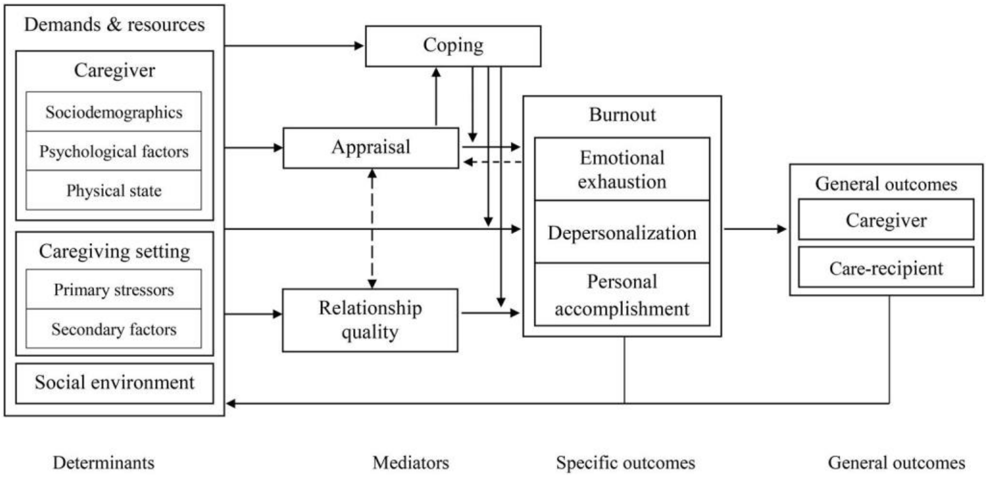
## Theoretical Foundation

### Informal Caregiving Integrative Model (ICIM)

The ICIM is a theoretical framework that was developed using the job-demands and resources model and the model of carer stress and burden because neither considered all the major factors pertaining to informal caregiver burden and burnout syndrome (Gerain & Zech, 2019). The goal of the ICIM is to emphasize the importance of the determinants of informal caregiver burnout: characteristics of the caregiver, the caregiving setting, and the sociocultural context of the caregiving situation (Gerain & Zech, 2019). The relationship between the caregiver and care recipient, and the appreciation the caregiver perceives are categorized as mediators for the development of informal caregiver burnout (Gerain & Zech, 2019). This integration of the caregiver-care recipient dyad is essential for the ICIM because it had not been considered by previous models. Figure 3 illustrates the ICIM and the relationships between the caregiving determinants, mediators, and the outcomes of informal caregiver burnout.

**Figure 3**

*Informal Caregiving Integrative Model*



*Note*. Adapted from Gerain and Zech (2019).

### *Informal Caregiver Burden and Burnout Syndrome*

Gerain and Zech (2019), define burden as the caregivers' assessment of the stress that occurs as a consequence of the assistance situation, as well as the appraisal of their experience and the physical, emotional, social, and financial consequences of caregiving. Caregiver burden is the caregivers' perception of their role and of the resources available to them. Positive and negative impacts of care provision are present in all caregiving situations; therefore, each caregiver will present a unique combination of caregiver strain and fulfillment. Within the ICIM model, burden in a key mediator between the determinants and outcomes. If caregivers are unable to cope with their burden, they are more likely to develop burnout syndrome; resulting in negative health outcomes for both the caregiver and care recipient (Gerain & Zech, 2019).

Informal caregiver burnout was defined by Gerain and Zech (2019) as a tridimensional syndrome in response to unmanaged caregiver stress and burden. The dimensions of informal caregiver burnout include emotional exhaustion, depersonalization, and personal accomplishment. Emotional exhaustion can be experienced at both the physical and emotional levels as a feeling of being overloaded, emotionally drained, and being unable to continue with the caregiving responsibilities (Gerain & Zech, 2019). Depersonalization is the detached response towards the caregiving situation in which the caregivers put distance between themselves and the care recipient as a defense mechanism against high levels of stress and burden. Personal accomplishment is the only positive dimension of burnout syndrome because it represents the caregivers’ sense of fulfillment and finding meaning in their care work. This dimension also includes the caregivers’ personal growth while providing care and the positive impacts on their physical and emotional health, while acting in accordance with their personal values (Gerain & Zech, 2019). Conforming to the ICIM, these dimensions allow for the effective assessment of the impact of care provision on informal caregivers. Burnout is a key element of the ICIM and can be a direct consequence of the caregiving determinants through the potential mediation of the appraisal and relationship quality perceived by the caregiver (Gerain & Zech, 2019).

### *Informal Caregiver Burnout Determinants*

**Caregiver Characteristics**. As mentioned before, the ICIM determinants of informal caregiver burnout are the characteristics of the caregiver, the caregiving setting, and the sociocultural context of the caregiving situation. Caregiver characteristics encompass the caregivers' sociodemographic profile, psychological factors, and the state of their physical health. The sociodemographic profile of the caregiver are those factors that cannot be chosen or modified, yet influence the vulnerability towards developing burnout syndrome (Gerain & Zech, 2019). Among the most common and influential sociodemographic features are gender and employment or professional status. For example, gender disparities dictate that women are more likely than men to become caregivers and be pressured to reduce working hours or quit their jobs due to cultural and social norms; thus, being an employed female has been shown to be associated with higher levels of caregiver burden (Gerain & Zech, 2019). To be employed while providing informal care has been found to be a protective factor against caregiver burnout because it can alleviate financial strain and serve as a distraction from the emotional distress of care provision. Another influential factor is the conglomeration of roles taken on by the caregiver; being a parent or single-parent, spouse, employee, business owner, among other responsibilities can add to the caregiver's burden (Gerain & Zech, 2019).

Psychological factors are those relating to the mental and emotional state of the caregiver in relation to the caregiving situation, including the relationship with the care recipients and the gravity of their health issues, the caregivers' personal problems and their perception of the caregiving circumstances (Gerain & Zech, 2019). Personality traits including optimism and confidence were found to be associated with lower levels of burden, and being emotionally competent has been found to be a protective factor against caregiver burnout as well as actively managing their stress through the implementation of a variety of coping strategies (Gerain & Zech, 2019). Actively coping with the stressors of care work, the constant worrying and need for control of the caregiving situation serve as predictors of caregiver burden and burnout syndrome because they are directly related to the caregiver's need to learn more about their loved one's health conditions and improving their self-efficacy. The motivation for becoming an informal caregiver can greatly influence burden; those with intrinsic motivations for caring for their loved ones are less likely to experience burnout in contrast to those who feel they were pressured into the caring role (Gerain & Zech, 2019).

The physical state of the caregiver can determine their vulnerability to burnout because healthy caregivers can take on more responsibilities, whereas those with pre-existing health issues are susceptible to the worsening of their symptoms and may experience difficulty accomplishing care tasks, causing greater caregiver burden (Gerain & Zech, 2019). While this factor applies to all caregivers, it has a greater effect on older caregivers who are also aging and are more prone to developing new or more complex health issues and diminishing stamina as they age.

**Caregiving Setting**. The caregiving setting includes the primary and secondary stressors experienced due to the caregiving situation. Primary stressors are the demands and resources available that define the caregiving role, including the duration of care, living with the care recipient, caregiving intensity, being a spousal caregiver, and the autonomy and functional impairments of the care recipient, especially among dementia and Alzheimer’s patients (Gerain & Zech, 2019). Secondary stressors are the demands and resources caused by the primary stressors that increase the caregiver’s risk for burning out, which may include daily life disturbances, social limitations, isolation from friends and loved ones, giving up hobbies, and less time free time for caregivers due to their responsibilities (Gerain & Zech, 2019). In situations of unpredictable care-recipient illness, the caregiver may become hypervigilant towards the development of worsening symptoms. These stressors can lead to emotional distress, frustration and resentment towards the care recipient and the care circumstances (Gerain & Zech, 2019).

**Social Environment**. The final determinant of the ICIM is the social environment in which the caregiving situation has developed, such as the professional or informal support received and the sociocultural environment (Gerain & Zech, 2019). Receiving professional support in the forms of counseling or respite care can alleviate the caregiver’s burden. However, most caregivers wait until they are highly stressed or burnt-out to seek these services. Unsatisfying relationships with health professionals or a lack of recognition from them can increase the caregiver’s burden; nevertheless, healthcare professionals can be very helpful for caregivers during specific health-related situations (Gerain & Zech, 2019). Informal support, like that received by family, friends, community members, and caregiving peers can be beneficial if the relationships are positive, and they agree on the care to be provided and support the primary caregiver’s decisions regarding the care recipient (Gerain & Zech, 2019). The sociocultural environment has been found to be influential for informal caregiver burnout research and the consequences of caregiving (Gerain & Zech, 2019). Cultural norms can influence how caregivers assume their role, the fulfillment and appraisal they perceive, and the support received from family and community members under the caring circumstances (Gerain & Zech, 2019).

### ***Application of the ICIM***

For the purposes of the current study, the focus will be on the ICIM determinants of caregiver burnout. The specific ICIM constructs selected were caregiver characteristics and social environment, which align with the current literature and research constructs of caregiver health and perceived social support. The ICIM may be considered a relatively new theoretical framework, however it has been applied to several recent investigations involving informal caregivers.

The ICIM was found to establish the difference between subjecting informal caregiver burden and informal caregiver burnout, two terms which are often used interchangeably (Gerain, 2020). The ICIM established that caregiver burden is a precursor or determinant of caregiver burnout. In Gerain's study, the determination of caregiver burnout consisted of three dimensions, exhaustion, caregiver and care recipient interactions and the caregiver's sense of accomplishment. The ICIM was used to address both the caregiving and professional stressors of informal caregivers who continue to work or who are professional caregivers as well (Gerain, 2020). Gerain found that caregivers with dual roles are at a higher risk of experiencing burnout in different aspects of their lives including professional, parental, and family care burnout.

Maguire and Maguire (2020) used the ICIM to develop a support intervention for informal caregivers of people with multiple sclerosis, because this model acknowledged the importance of the role of the caregivers, the caregiving setting, and the sociocultural context of the caregiving situation as determinants of informal caregiver burnout. These determinants were found to be associated with the risk factors of burden experienced by informal caregivers of people with multiple sclerosis (Maguire & Maguire, 2020). It was concluded that those informal caregivers with less psychological distress experienced less burden and improved coping with the stressors related to caring for a multiple sclerosis patient (Maguire & Maguire, 2020). Results also showed that while informal caregivers of people with multiple sclerosis are exposed or subjected to burdensome situations, this does not necessarily result in negative outcomes like burnout, because, as presented by the ICIM, the psychological appraisal and state of the caregiver-care recipient dyad can dictate how the caregiver responds to these stressful situations (Maguire & Maguire, 2020).

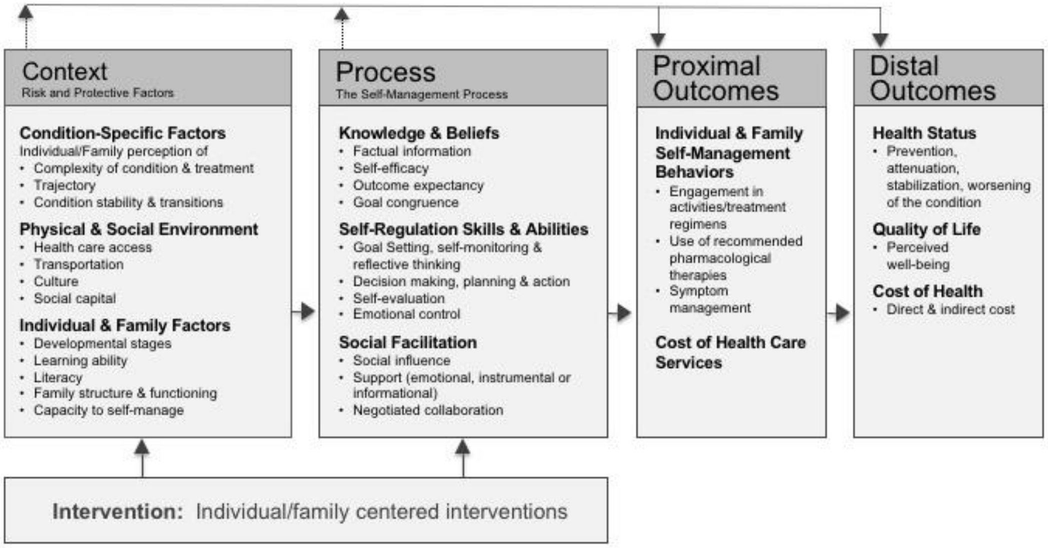
The ICIM constructs have also been applied to the development of gender-responsive approaches to address informal caregiver burnout during the COVID-19 pandemic (N. E. Ryan & Ayadi, 2020). This study found that women were more likely to perform unpaid domestic duties than men while bearing the burden of caring for their elderly parents, children, and other ailing family members (N. E. Ryan & Ayadi, 2020). This persistent and escalating stress, accompanied by the mandates of social distancing, stay-in-place (home) orders, and/or quarantine directives puts women at a greater risk of burnout that their male counterparts. Based on these findings, recommendations were provided for pandemic preparedness, response and recovery for public health, critical healthcare, and policy development (N. E. Ryan & Ayadi, 2020).

## Individual and Family Self-Management Theory

The developers of the IFSMT define self-management as a complex and multidimensional phenomenon that follows a systems theory, in which the family acts as a system and changes within can be led by an individual family member (P. Ryan & Sawin, 2009). The capacity of each member of the family unit to accept their roles and engage in the changes can determine the success or failure of the self-management process; however, members of the family unit need not necessarily be biological family members. The IFSMT defines self-management as a “complex dynamic phenomenon consisting of three dimensions: context, process, and outcomes” (pg. 9, P. Ryan & Sawin, 2009). Figure 4 illustrates the three dimensions of the IFSMT. Contextual factors influence the family system’s engagement in the self-management process and as a result directly influence the immediate and long-term outcomes. The outcomes of self-management behaviors are directly related to the individuals and their families; however, over time these outcomes can also be reflected upon the healthcare professionals and health systems related to the individuals of interest (P. Ryan & Sawin, 2009).

**Figure 4**

*Individual and Family Self-Management Theory*



*Note*. Adapted from P. Ryan and Sawin (2009).

### *Context Dimension*

The context dimension consists of the risk and protective factors that influence the individual’s and family’s engagement in self-management behaviors (P. Ryan & Sawin, 2009). These contextual factors can be specific to a health condition, physical and social environmental factors, and the characteristics unique to the individuals and family members. Health condition specific factors include: the complexity of the health issues and appropriate treatments, stability or trajectory of the health condition, and the specific behaviors for the prevention or management of the health problem (P. Ryan & Sawin, 2009). Physical and social environmental factors are those that can promote or limit the possibility of self-management, including access to health care, health care settings, transportation and transition to health services, community composition (work, school, neighborhoods), and cultural influences (P. Ryan & Sawin, 2009). Individual and family characteristics are those that enhance or diminish the quality of self-management practices including personal abilities, skills, health literacy, personal perspectives, cognitive and developmental stages, familial cooperation, and resourcefulness (P. Ryan & Sawin, 2009).

### *Process Dimension*

The process dimension is the most complex because it depends on the capabilities and willingness of the individuals within the family unit to apply their knowledge and beliefs regarding the health condition of interest, to acquire and apply self-regulation skills, and to encourage social facilitation and collaboration between family members (P. Ryan & Sawin, 2009). The IFSMT states that individuals are more likely to engage in positive health behaviors if they possess the appropriate knowledge and beliefs to engage in the desired behaviors. Health education specialists and health care professionals should strive to increase the individual's and family's self-efficacy, positive outcome expectancy, and goal congruence with regard to the specific health condition and its appropriate management (P. Ryan & Sawin, 2009). Effective self-regulation skills include goal setting, self-monitoring, reflective thinking, action planning, self-evaluation, and response management (P. Ryan & Sawin, 2009). Social facilitation is a phenomenon that occurs when the family unit improves the individual's likelihood for positive health behavior changes and consists of social influences, social support, and family collaboration (P. Ryan & Sawin, 2009).

### ***Outcome Dimension***

This dimension encompasses both short and long-term outcomes. Short-term or proximal outcomes are the active engagement of the individual and family unit in self-management practices, condition-specific treatments, and costs of specific healthcare services (P. Ryan & Sawin, 2009). Conversely, long-term or distal outcomes are determined by the achievement of proximal outcomes and include indirect and direct costs of health care, health status, quality of life, and perceived well-being (P. Ryan & Sawin, 2009).

### ***IFSMT Dimensional Interactions***

The IFSMT dimensions are highly interrelated and can influence familial and individual health outcomes. For example, contextual factors such as socioeconomic status, can determine access to quality healthcare services and educational or professional opportunities, which are associated with the presence and severity of chronic health conditions and disability (P. Ryan & Sawin, 2009). These factors can influence the potential health literacy and cognitive capacities of the persons of interest, which can determine the abilities of an individual to adequately manage their health conditions, and the level of familial or social support required for effective self-management. Self-management interventions for individuals or families can be developed at either the contextual or process dimensions. Interventions directed towards contextual factors can improve the conditions and environments to support effective self-management practices. Those directed at the self-management process serve to emphasize knowledge and beliefs, improve self-regulative behaviors, and increase social support within the family unit or from the community (P. Ryan & Sawin, 2009).

### *Application of the IFSMT*

The IFSMT assumes that social facilitation is highly associated with the encouragement and engagement in self-management behaviors and the achievement of positive health outcomes (P. Ryan & Sawin, 2009). For the purposes of this current study, the constructs of interest are the process and outcomes dimensions. The social facilitation construct of the process dimension aligns with the social support portion of the research questions, while the outcomes dimension corresponds to the self-rated health and self-management strategies portions of the research questions.

The IFSMT has also been applied to other research related to self-management and informal caregiving. Broome et al. (2021) found that there was a lack of caregiver-centered self-management interventions, and developed the food allergy symptom self-management with technology (FASST) mobile health application. The FASST was based on the constructs of the IFSMT and focused on the psychosocial outcomes for informal or parental caregivers of children with food allergies (Broome et al., 2021). The FASST app provides targeted health education and promotion information, including self-monitoring and self-management techniques (Broome et al., 2021). The caregivers of children with food allergies were found to be hypervigilant, exhausted, and overwhelmed, because monitoring children for accidental intake of an allergen is a time-consuming and constant responsibility, which can lead to fear, anxiety and social isolation (Broome et al., 2021). While this research is ongoing, the FASST has been found to be helpful in the self-management and mitigation of the negative psychosocial outcomes of caring for a child with food allergies (Broome et al., 2021).

Still et al. (2021), developed a targeted self-management intervention for reducing stokes in African American men. This intervention aligned with the IFSMT because it combines self-management training, behavior modeling, and support within a family framework (Still et al., 2021). This framework emphasizes the importance of family engagement and involvement, and focuses on the patient and care provider dyad (Still et al., 2021). This intervention also acknowledged the variability of familial support networks, was culturally sensitive to the population of interest, and was found to improve the stroke-related outcomes of African American men (Still et al., 2021).

Houben-Wilke et al. (2021) recently used the IFSMT for the study of care plans for COVID-19 patients or those suspected of having COVID-19. Due to the nature of the COVID-19, patient care is performed in an isolated and socially distanced manner. The patients expressed multiple unmet social and support needs and often searched to meet these needs with online support groups (Houben-Wilke et al., 2021). Using online social media platforms, the authors were able to identify the COVID-19 patients’ perceived health information, and their support and care needs (Houben-Wilke et al., 2021). It was found that most social support came from family members and friends and the presence of this support increased the likelihood of COVID-19 self-management, with more positive health outcomes (Houben-Wilke et al., 2021). The authors of this study called for the development of holistic care plans for self-management of COVID-19 or COVID-like symptoms with the inclusion of the patient’s family in their care and recovery plans, because this increased the odds of having better health consequences (Houben-Wilke et al., 2021).

## Conclusion

This chapter presented a synthesis of the existing literature related to the problem and purpose of the current study to determine the relationships between stress self-management, social support, burden, and health of Hispanic informal caregivers, primarily island residing Puerto Ricans. Informal caregivers are most likely to be middle-aged women who provide extensive hours of care, are the daughters or spouse of the care recipient, and they usually reside together. With greater caregiving intensity and duration, levels of stress and burden tend to increase which can cause adverse physical and emotional health outcomes for both the caregiver and care recipient. Evidence has shown that with improved social support and self-management practices, these negative outcomes can be amended, and burnout syndrome can be prevented.

Profiles of Hispanic informal caregivers in the United States and those residing in Puerto Rico were provided along with circumstances that influence Puerto Rican culture and sociopolitical environments. The social and environmental situations in Puerto Rico are complex and due to recent natural disasters and financial catastrophes, there has been a massive exodus to the United States. This has left the remaining caregivers on the island in highly stressful circumstances with limited health access, financial limitations, and little familial or informal support as a single person may be providing care for multiple care recipients within their families. Furthermore, familism values that are prevalent across Hispanic cultures can lead to a false sense of familial support and control over the caregiving situation, which can keep the caregiver from accepting that they are burdened and seeking external or formal care services, resulting in them being more vulnerable to burning out.

The theoretical frameworks on which this research was founded, and the key constructs and variables were also discussed at length. These theoretical foundations can serve as a map to identify in which of the constructs the caregiver is lacking and what types of interventions should be developed to meet the caregiver’s needs. Lastly, the proposed data collection tools were presented and the justification for their application in this study was also provided. In accordance with the information presented in this literature review and the data to be collected, valuable and effective health education and promotion initiatives should be developed in benefit of Hispanic and Puerto Rican informal care caregivers, as they are vital for the long-term health care system. Furthermore, the findings of the current study may serve as the foundation of future culturally competent health education and promotion proposals.

The CDC (2018a) recommends several health education and promotion strategies for the improvement of the health system in support of caregiver well-being, including increasing health communications for the public and health providers, promoting the importance of the caregiving role, maintaining their physical and emotional health, providing educational and training resources to potential caregivers on what to expect and the resources available locally prior to providing care, encouraging caregivers to self-manage their own chronic health conditions, getting regular check-ups and using preventative services, and increasing health provider awareness and access to services and programs in support of caregivers and the care recipients.

The field of health education and promotion can benefit from the development of culturally competent interventions for Hispanics having difficulties accepting and fulfilling their caregiving roles, through brief family-centered interventions to improve feelings of support, gratitude and appreciation provided by non-caregiving family members to buffer feelings of isolation, anger, and frustration (Koerner & Shirai, 2019). Culturally inclusive research, like the current study, is important for the development of programs, initiatives, and practices to better understand how to effectively encourage positive social change within specific groups and populations. To collect the data necessary for the determination of the social support, stress self-management needs, and perceptions of health and burden of Hispanic informal caregivers the development of an effective methodological design is required, and will be discussed in the following chapter.

# Chapter 3: Research Method

This chapter includes a discussion of the research design for this study and the rationale for the decision to perform quantitative research. The variables under study and the population of interest are presented along with the recruitment methods employed to ensure sufficient participants in this research. The survey design and the rationale for the inclusion of multiple preexisting tools are discussed followed by the scoring instructions. Lastly, the dissemination methods for the survey and the data analysis plan that was applied to interpret the data collected are discussed.

## Research Design

The goal for this research was to examine the relationships between perceived stress self-management, perceived social support, self-rated health, and burden among Hispanic informal caregivers. I followed a positivist approach as primary data were collected from the population of interest and the data were interpreted objectively (see Creswell & Creswell, 2018). A nonexperimental quantitative design was implemented to statistically analyze the relationships, and the data were collected using a questionnaire, which provided cross-sectional data pertaining to the perceived stress management, perceived social support, self-rated health, and burden trends of Hispanic informal caregivers (see Creswell & Creswell, 2018). The survey method was chosen to examine the relationships between the variables under study and to describe the profile of Hispanic informal caregivers residing in Puerto Rico because minimal information about this population was available in recent literature. The questionnaire designed for this study was composed of existing data collection tools that had been used in previous informal caregiving research and were found to be valid and reliable.

A survey or questionnaire data collection method is an inexpensive and easily distributed tool that can be completed in a physical or digital fashion. According to Nayak and Narayan (2019), surveys are among the most popular methods of primary data collection because they serve to extract information from a population of interest and are useful for cross-sectional studies. Digital questionnaires are a cost- and time-efficient method of data collection that can be easily distributed to a large audience (Nayak & Narayan, 2019). Online surveys are particularly useful for facilitating the data collection process, data storage, and data analysis (Nayak & Narayan, 2019). The participants in the current study completed the survey individually, which ensured their privacy and reduced any potential bias or coercion (see Burkholder et al., 2016). Self-administered surveys may reduce participant response rates, which is why it was important to recruit an excess of participants and have an effective distribution plan coupled with the provision of clear and precise instructions and questions (see Burkholder et al., 2016).

## Variables Under Study

The predictors were the perceived stress self-management and perceived social support of caregivers, while the dependent variables were the Hispanic informal caregiver’s health and burden. Table 1 presents the instruments or scales that were used to measure each variable.

**Table 1**

*Instruments and Scales Applied to the Variables Under Study*

| Variable | Instrument | Item/scale |
|---|---|---|
| Perceived stress self-management | Stress Management Self-Efficacy Measure (SMSEM) | Part 1: items 1–10,<br>10-item Likert-type scale |
| Perceived social support | Multidimensional Scale of Perceived Social Support (MSPSS) | Part 2: items 1–12<br>7-item Likert-type scale<br>(overall MSPSS score) |
| Caregiver burden | Zarit Burden Interview (ZBI-12) | Part 3: Items 1–12<br>(overall ZBI-12 score) |
| Caregiver health | Medical Outcomes Study: 20-item Short Form Survey (SF-20) | Part 4: Items 1–20,<br>Likert-type scales ranging from 3 to 6 items, (overall SF-20 score) |
| Participant background information | Sociodemographic section of the survey | Part 5: items 1–4<br>(measures of central tendency) |

## Population of Interest and Study Sample

The population of interest for the study was Hispanic informal caregivers who reside on the island of Puerto Rico. Eligibility criteria for this study consisted of the participants being at least 18 years old, residing in Puerto Rico, and currently providing informal care for individuals age 65 and older. The inclusion criteria for participating in this research and online survey also included literacy in the English and/or Spanish language, having access to the internet, willingness and ability to complete the estimated 10-minute survey, and access to email or social media platforms such as Facebook, Instagram, and WhatsApp where the survey link would be posted and shared with potential participants. Those who did not meet these requirements were excluded from this study because they were not able to access or complete the online survey. Additional participants were recruited from MTurk, an online platform that allowed eligible participants to complete the survey for a small compensation of $1.00.

The estimated population of Puerto Rico is 3,193,694 according to data derived from the SDC-PR (2019c). Approximately 14% of Puerto Rican residents are currently informal caregivers (CDC, 2018b); therefore, the estimated target population was 447,117 individuals. A power analysis was performed using the G-Power software, which resulted in the need for a minimum of 55 participants to achieve a 95% power (see Faul et al., 2009). To calculate the appropriate sample size for this research, I used the Open Epi program. The sample size was calculated to achieve a 95% statistical confidence interval and an effect size of 0.03, resulting in a sample size of 384 participants which was the minimum sample used for the current study (see Dean et al., 2013). The assumptions of this power analysis included a medium effect size of 0.30 and an alpha level of 0.05. Homogeneous convenience sampling was used to select the participants for this research. This type of convenience sampling has been found to be more time- and cost-effective in comparison to probability sampling and has become a standard sampling procedure in modern research (Jager et al., 2017). Although homogeneous convenience sampling reduces the generalizability of the results across a broad population, it can provide a clearer view of the needs of a certain population of interest and can allow for more precise research of this group (Jager et al., 2017).

## Recruitment

Participants were recruited in both the English and Spanish languages through word-of-mouth and social media promotions due to social distancing regulations on the island as well as transportation or mobility limitations of caregivers and their care recipients. Evidence has been found that social media can be a useful and cost-effective recruitment tool for health-related research because it can reach a multitude of potential participants in a short amount of time and can serve to target specific populations (Arigo et al., 2018). According to Boots et al. (2018), many informal caregivers use the internet and social media platforms as a means of communication and to seek support. Existing organizations related to caregiving and support groups were contacted to request permission to share the survey on their social media platforms such as Facebook, Instagram, and WhatsApp or for it to be mentioned during gatherings or activities. Among these organizations dedicated to older adults are the University of Puerto Rico Gerontology program, the Alzheimer's Association of Puerto Rico, Grown Ups Puerto Rico, Caregiver's College of Puerto Rico, and the Susan G. Komen Puerto Rico chapter. This approach did not result in any conflict of interest because I was not affiliated with any of these caregiver support programs.

The questionnaire was made available using the Google Forms digital format, which facilitated the participation and dissemination of this survey. Participant privacy can be an issue when using social media as a recruitment strategy; therefore, those interested accessed the survey link on the social media platform or were instructed to send an email or private message to receive a link to the online questionnaire (see Bender et al., 2017). Prior to answering the survey, the participants consented to completing the survey (Walden University Institutional Review Board [IRB] approval number on the consent form was 12-07-21-0495954), which confirmed that they were an informal caregiver residing in Puerto Rico and were informed that no identifiable personal information was going to be collected. The survey was anonymous. Participants also selected their language of preference because the questionnaire was available in English and Spanish. Most Puerto Ricans on the island identify Spanish as their first language. The link for the digital survey was embedded within posts on social media platforms such as Facebook, Instagram, and WhatsApp to facilitate the participants’ access to the online survey. If the participant did not have access to these social media platforms, a link to the survey was sent via email. This link was also shared through the social media accounts, text messages, and email contact lists of participants who wanted to share the survey with other informal caregivers who were willing to participate.

The initial recruitment efforts resulted in a small group of participants due to the lack of response from leadership of the nonprofit organizations. Therefore, additional recruitment methods were explored, and the survey was published on MTurk, a website that allows workers who are 18 years or older to complete tasks for compensation. MTurk is widely used by academic researchers to enhance their participant pool. This additional method was approved by the Walden IRB, and the link to the English and Spanish versions of the survey were published on the MTurk site with a description of the survey and the requirement for the participant to be an informal caregiver residing in Puerto Rico (see Appendix A). Upon reading the survey description, the participant would click the survey link, complete the consent form and survey, and receive a unique code to be entered into the MTurk platform. All surveys received through MTurk were reviewed for completeness, and the codes were approved for the workers to receive compensation of $1.00 for their time and effort. Because the existence of two participant pools was a potential threat to internal validity, this was mitigated through the use of the same inclusion criteria, use of the same survey for all participants, and the comparison of the characteristics of both groups. A comparison of the sociodemographic profiles of both participant groups was performed, and profiles were found to be similar; therefore, the data from all participants were analyzed as a single sample.

## Ethical Procedures

Several precautions were taken to ensure that participants and all collected data were treated and managed in an ethical manner. First, all data collection tools and recruitment information were submitted and approved by the Walden IRB. A modification for the use of the MTurk platform as an additional recruitment method was submitted and approved by the Walden IRB as well. All data were collected in an anonymous manner because no personally identifiable information was collected from participants. This included the MTurk group who were required to provide only their worker ID to receive their compensation because this is required for approval of the work within the MTurk platform; however, the ID number does not allow requesters to access workers’ personal information or identity. The issue of MTurk compensation may have been an ethical concern because it could have been perceived as coercive for participation in the study; however, this concern was mitigated because the compensation was minimal ($1.00 per completed survey), workers were permitted one-time access to the survey, and the survey had to be approved for completeness and uniqueness prior to approving the compensation. Lastly, the questions included in the survey were designed to cause minimal harm to participants because the questions were from preexisting data collection tools designed for vulnerable populations and had been used extensively in similar research.

## Instrumentation

The questionnaire contained a mixture of open- and closed-ended questions that were designed to collect a variety of information from the participants. According to Burkholder et al. (2016), a well-rounded survey collects descriptive, attitudinal, and behavioral information from the participants because this allows for the provision of valuable and generalizable information. The sociodemographic portion of the survey was included to describe the population under study, while the items regarding caregiver health provided behavioral information. Lastly, attitudinal information was collected through the items related to perceived self-management and perceived social support. The survey contained several Likert-type scales distributed across the five parts of the survey. Part 1 addressed caregiver stress self-management perception, Part 2 addressed caregiver perceived social support, Part 3 addressed caregiver burden, Part 4 addressed caregiver health, and Part 5 addressed sociodemographic Information (see Appendix B).

The questionnaire designed for this study included a section dedicated to collecting sociodemographic information pertaining to the informal caregiver and care recipient. The other sections of this instrument were composed of previously existing and validated data collection tools to gather information related to the informal caregiver’s stress self-management perceptions, perceived social support, self-reported health, and burden. The data collection tools chosen for these purposes were the following: the SMSEM, the MSPSS, the Brief Zarit Burden Interview (ZBI-12), and the Medical

Outcomes Study: 20-Item Short Form Survey (SF-20). The SF-20 and MSPSS data collection tools were free to use as stipulated in their corresponding instructions for use; however, licenses for the SMSEM and the ZBI-12 were requested and obtained (see Appendix C and Appendix D). The publishers of the SMSEM allowed for the use of the English version of the scale and for the translation of the measure to Spanish for the purpose of the current study (see Appendix C). Likewise, permission to use and digital copies of the English and Spanish versions of the ZBI-12 were provided along with a license for use of the survey for the duration of the current study (see Appendix D). Any survey materials that were not readily available in Spanish were translated by me. I am fluent in English and Spanish and used the language that was culturally appropriate to Puerto Rican participants. These translations were compared to the original English version to ensure the same information was being collected. Because this study's questionnaire was designed for a specific population, expert face validation and a small pilot study were conducted to ensure the validity of the scale and the collection of appropriate data measuring of the constructs under study (see Issel, 2014).

### SMSEM

The SMSEM was developed by Jin (2010) and was based on the health belief model and Bandura's theories of self-efficacy. The SMSEM was designed as an assessment of an individual's perception of their abilities to handle or manage their stress and was first used as a method for evaluating the efficacy of computer-based stress self-management interventions (Jin, 2010). According to Jin, stress self-management is essential for improving the quality of life of individuals who are continuously in high-stress environments. In the current study, this measure was chosen to analyze the participants’ perceptions of how they manage their stress while providing care for their loved ones.

The SMSEM is a 10-item Likert scale measure in which participants rate their confidence in regard to the stress management statement presented to them (Jin, 2010). The possible responses consist of a Likert-type scale that ranges in values from 1 to 10 in which 1 = *very strongly disagree*, 2 = *strongly disagree*, 3 = *mostly disagree*, 4 = *moderately disagree*, 5 = *slightly disagree*, 6 = *slightly agree*, 7 = *moderately agree*, 8 = *mostly agree*, 9 = *strongly agree*, and 10 = *very strongly agree* (Jin, 2010). A higher score would indicate that the individual perceives that they handle stress more effectively than those with lower scores (Jin, 2010). The SMSEM was found to be a reliable scale with a Cronbach’s alpha of 0.83, and has been used in previous stress self-management research (Jin, 2010).

## MSPSS

There are a multitude of scales to measure perceived social support because this is a widely studied psychological resource, however the MSPSS was selected for the current study because of its emphasis on support received by family, friends, and significant others. The authors of this instrument claim that it was the first to measure both objective and subjective aspects of social support in a simple and brief questionnaire (Zimet, et al., 1988). The MSPSS is one of the most widely used tools for measuring perceived social support and is divided into three subscales of support, family, friends, and significant others (Zimet, et al., 1988). The developers of this scale also described social support to be helpful in all circumstances; however, in highly stressful situations, social support can be a particularly helpful buffer against the negative effects of stress and burden (Zimet, et al., 1988). The MSPSS authors also tested for correlations between perceived social support and symptoms of depression and anxiety. As they hypothesized, higher perceived social support scores from each subscale were found to be negatively associated with depression and anxiety symptoms among participants (Zimet, et al., 1988).

Each MSPSS subscale and the scale as a whole were tested for reliability and obtained the following alpha coefficients: *family* (.87), *friends* (.85), *significant other* (.91), and the MSPSS as a whole (.88), indicating that this is a psychometrically sound instrument (Zimet, et al., 1988). This 12-item scale includes four items per subscale with each item is scored using a Likert scale ranging from values of 1 to 7: 1 = *very strongly disagree*, 2 = *strongly disagree*, 3 = *mildly disagree*, 4 = *neutral*, 5 = *mildly agree*, 6 = *strongly agree*, and 7 = *very strongly agree*. To calculate the MSPSS score as a whole, each item value selected by the participant was added together, then divided by 12, while subscale scores were obtained by adding each subscale item value and dividing by four, with higher scores indicating greater social support perceptions (Zimet, et al., 1988). For the current study, the global MSPSS score was used to determine the overall perceived social support of informal caregivers (Zimet, et al., 1988).

### Medical Outcomes Survey: SF-20

The SF-20 was developed in 1988 in response to the need for a simplified method of evaluating multiple physical and mental health measures that would be easy for patients to complete (Stewart et al., 1988). The SF-20 was chosen for the current study to assess the health of Hispanic informal caregivers as it is one of the most widely used health-related quality of life assessments (Vilagut, 2005). Twenty questions were selected to represent six health measures: physical functioning (6 items), role functioning (2 items), social functioning (1 item), mental health (5 items), pain (1 item), and health perceptions (5 items) (Stewart et al., 1988). The majority of the SF-20 items consist of a Likert-type scale with possible responses ranging from a minimum score of 1 to a maximum score of 3 to 6 (Stewart et al., 1988). Given the arrangement of some of the items within the health measure subscales, some of the items must be reverse scored, such as self-rated health, pain, and some of the items within the mental health and health perceptions subscales (Stewart et al., 1988). The summation of these scores is assigned a value between 0 to 100, with a higher score indicating better health and quality of life for the participant (Stewart et al., 1988). The SF-20 has been a standard health and quality of life measurement tool and has been found to be a valid and reliable measure with reliability coefficient scores ranging from 0.81 to 0.88 for each health measure (Stewart et al., 1988). The Spanish version of the SF-20 was also found to be a valid and reliable measure with several health measures reaching reliability coefficients of 0.90 (Vilagut, 2005).

### ZBI - 12

The ZBI was originally developed in 1980 by Steven Zarit as a 29-item questionnaire that allows caregivers to self-measure their levels of burden and is often used by agencies around the world related to the research of aging populations (American

Psychological Association [APA], 2020). The ZBI serves as an evaluative tool to collect information on the caregiver’s health, personal life, emotional well-being, social relationships, and financial situation (Gratão et al., 2019). This scale has been revised on several occasions to reduce the number of items included in the questionnaire due to reports of participant difficulty in understanding and completing some items and considering this, the ZBI-12 was developed and is of equal diagnostic utility as the original ZBI (Gratão et al., 2019). This shorter version has been found to be useful for the development of health education and promotion programs aimed at the reduction of caregiver burden and improving their physical and emotional health (Gratão et al., 2019).

The ZBI-12 was selected for this current study because it is considered a gold standard for the self-measurement of informal caregiver burden and its use has been validated across many cultures and languages with obtained alpha coefficient values ranging from 0.81 to 0.89 (Gratão et al., 2019). The ZBI-12 includes 12 items inquiring about the perceived impact of the circumstances of care provision in relation to the caregiver’s physical, emotional, social and financial well-being. Each of the 12 items are recorded using the following Likert scale ranging from 0 to 4: 0 = *never*, 1 = *rarely*, 2 = *sometimes*, 3 = *quite frequently*, and 4 = *nearly always*. The final score of the ZBI-12 is obtained through the summation of the corresponding value of each item with a higher score indicating a greater level of burden (Gratão et al., 2019).

## Data Analysis Plan

Only myself and anyone deemed necessary will have access to the data collected via the survey links. Despite the lack of personally identifiable data, the participant data collected was saved in a password-protected file to ensure participant data confidentiality. The data collected was evaluated using descriptive and inferential statistical analyses using the IBM SPSS version 28 program. The sociodemographic information collected for the participants was analyzed using descriptive statistics, mainly measures of central tendency, in order to create a profile of this study's participants. The independent and dependent variables designated for this research are categorized as scale or continuous variables. Each research question for this study contains two predictors and a single dependent variable; thus, the most appropriate inferential statistical analysis to answer these questions was multiple linear regression (Frankfort-Nachmias & Leon-Guerrero, 2015). To address any missing or inappropriate data, pairwise deletion was applied to retain as much valuable information as possible (Statistics Solutions, n.d.).

Multiple linear regression is a statistical analysis technique that can predict the behavior of interval-ratio level dependent variables using two or more independent variables (Rosner, 2011). The multiple linear regression output can be interpreted through the regression coefficient (B), standard error (SE), confidence interval (CI), R-squared value, Pearson's correlation coefficient, F statistic, and p-value (Frankfort-Nachmias & Leon-Guerrero, 2015). The regression coefficient determines whether there is a positive or negative correlation between the variables (Rosner, 2011). The standard error measures the variability across the sample population, and the confidence interval is a range of values within which the population under study is expected to fall (Frankfort-Nachmias & Leon-Guerrero, 2015). The R-squared value is known as the coefficient of determination which reveals the proportion of the dependent variable's variation as explained by the predictors and can range from 0.0 to 1.0 (Wagner, 2017). The Pearson's correlation coefficient, or r value is the measure of association for interval-ratio level variables and indicates the strength of the linear association between those variables and ranges in values from -1 to 1 (Rosner, 2011). The F statistic represents the variance between groups; therefore, a larger F value signifies there is more between-groups variance than within the group, which increases the likelihood of rejecting the null hypothesis (Frankfort-Nachmias & Leon-Guerrero, 2015). The p-value reflects the statistical significance of the regression results (Frankfort-Nachmias & Leon-Guerrero, 2015).

To ensure the validity of this new data collection instrument, a small pilot study was performed accompanied by face validity measures by the members of the dissertation committee, because they are experts in the field of health education and promotion. The reliability of this questionnaire was also measured using alpha coefficient or Cronbach's alpha statistical measures. To determine the reliability of measuring the stress self-management construct, items 1 to 10 of the questionnaire were analyzed, as were items 11 to 22, to determine the reliability in measuring perceived social support of the informal caregiver. The reliability of the caregiver burden construct was analyzed with items 23 to 35 and caregiver health was analyzed with items 36 to 48.

## Summary

The purpose of this chapter was to describe the methodology and research design for the current study. A questionnaire was developed to collect the necessary data to analyze the proposed relationships between the selected variables and included a section for the collection of sociodemographic information. A survey research design was selected for its cost and time effectiveness. Participant consent and privacy was also taken into account with this research design. The survey was made available in both the English and Spanish languages, as many Puerto Rican residents are fluent on both languages. The questionnaire consisted of a sociodemographic section and several existing and validated scales for the collection participant data that will be useful for the goals of this research. The data collection tools, SMSEM, MSPSS, SF-20, and the ZBI-12, were presented in detail along with their relation to the variables under study. Lastly, the statistical analyses used were presented along with their functions and utility for this study. The following chapter will include the results of the statistical analysis of the current study data.

# Chapter 4: Results

The purpose of this study was to examine the relationships, if any, between stress self-management, social support, and health among Hispanic informal caregivers residing in Puerto Rico, all of which are factors that may lead to burnout syndrome. To determine whether relationships existed, several variables were identified, and two research questions were formulated:

RQ1: Is there an association between perceived stress self-management, perceived social support, and Hispanic informal caregiver health?

$H_o1$: There is no association between perceived stress self-management, perceived social support, and Hispanic informal caregiver health.

$H_a1$: A significant and positive association exists between perceived stress self-management, perceived social support, and Hispanic informal caregiver health.

The independent variables were perceived stress self-management and perceived social support. The dependent variable was caregiver health.

RQ2: Is there an association between perceived stress self-management, perceived social support, and Hispanic informal caregiver burden?

$H_o2$: There is no association between perceived stress self-management, perceived social support, and Hispanic informal caregiver burden.

$H_a2$: A significant and negative association exists between perceived stress self-management, perceived social support, and Hispanic informal caregiver burden.

The independent variables were perceived stress self-management and perceived social support. The dependent variable was caregiver burden.

To test these research hypotheses, I created a survey tool to collect data from Hispanic informal caregivers, which was disseminated online for easy access and completion while maintaining the anonymity of the participants. To test the validity of this survey, I performed a pilot study, and comments by the participants were taken into consideration. After the pilot study, the final survey was published online for data collection. The results of the statistical analyses performed on the data collected for this research are presented in this chapter.

## Pilot Study Data Analysis and Summary

The survey was posted on Google Drive, and the survey link was shared with the pilot study participants. The pilot study data were collected within 2 weeks, and the raw data were coded in Microsoft Excel and imported to Statistical Package for the Social Sciences (SPSS) Version 28. Statistical analyses were performed to determine the sociodemographic profile of the pilot study participants and the relationships between the variables under study. According to the sociodemographic data of the 10 pilot study participants, 60% were women and 40% were men. Sixty percent of the participants completed the survey in Spanish, and 40% completed it in English. The average participant age was 36 years, and they had been caring for their loved one for an average of 7 years. In regard to the relationship between the caregiver and care recipient, 10% cared for their spouse, 30% cared for a parent, 10% cared for their child, 20% cared for an aunt or uncle, 20% cared for a niece or nephew, and 10% cared for a grandparent.

A multiple linear regression analysis was performed to determine the relationships between the survey variables: perceived stress self-management, perceived social support and health. According to the SPSS analysis of variance (ANOVA) output, the *p* value of the overall analysis was 0.124, which was not significant because it was not less than or equal to 0.05. The adjusted *R*-square value was 0.291, meaning that 29.1% of the caregiver health results were influenced by their perceived social support and perceived stress self-management. As presented in Table 2, the relationships between the variables were not significant.

**Table 2**

*Multiple Linear Regression Analysis for RQ1: Pilot Study*

| Predictor | Outcome | B | *SE* | 95% CI | *t* | *p* |
|---|---|---|---|---|---|---|
| Constant | Caregiver health | 49.412 | 3.765 | (40.510, 58.314) | 13.125 | .000 |
| Social support | | .104 | .054 | (-.025, .232) | 1.902 | .099 |
| Stress management | | -.139 | .064 | (-.291, .014) | -2.154 | .068 |
| Adjusted *R* Square | .291 | | | | | |
| *F* | 2.851 | | | | | |
| *SE* | 1.870 | | | | | |
| *p* | .124 | | | | | |

*Note*. SE = standard error, CI = confidence interval, $p < .05$.

A similar multiple regression analysis was performed to determine the relationship between the perceived stress self-management, perceived social support, and burden of Hispanic informal caregivers. As presented in Table 3, the ANOVA output for this analysis produced a *p* value of 0.016, which indicated the relationship was statistically significant. The adjusted *R*-square was 0.604, meaning that 60.4% of the caregiver burden results were influenced by the perceived social support and stress self-management of the participants. The individual regression coefficients showed that the relationship between stress self-management and caregiver burden was statistically significant with a *p* value of 0.005. The corresponding regression coefficient resulted in a value of -0.641, meaning there was a significant and negative relationship between stress self-management and caregiver burden. In other words, with higher levels of self-management, less burden was perceived by the caregiver. On the other hand, the relationship between perceived social support and caregiver burden resulted in a regression coefficient of 0.299, meaning there was a positive association between these variables. With higher levels of social support, more burden was perceived. However, this relationship was not deemed significant because the *p* value was 0.162, which was much higher than the significance threshold of 0.05 or less.

**Table 3**

*Multiple Linear Regression Analysis for RQ2: Pilot Study*

| Predictor | Outcome | B | *SE* | 95% CI | *t* | *p* |
|---|---|---|---|---|---|---|
| Constant | Caregiver burden | 37.599 | 11.202 | (11.112, 64.087) | 3.357 | .012 |
| Social support | | -.641 | .162 | (-1.024, .258) | -3.958 | .005 |
| Stress management | | .299 | .191 | (-.153, .752) | 1.563 | .162 |
| Adjusted *R* Square | .604 | | | | | |
| *F* | 7.874 | | | | | |
| *SE* | 5.56302 | | | | | |
| *p* | .016 | | | | | |

*Note*. SE = standard error, CI = confidence interval, *p* < .05.

The pilot study results demonstrated that the online survey was an easy and efficient data collection method for this population and that the variables could be effectively analyzed using the SPSS Version 28 software. However, these results were not intended to be used to test the research questions and hypotheses; rather, they were used to test the feasibility and validity of the survey tool. Participants found the survey was easily accessible using the links provided and were able to complete it within 10–15 minutes. Feedback was received that the survey questions were easy to answer and that the participants felt comfortable completing the survey on their own. The only question that seemed to cause some confusion was the one regarding the caregiver’s relationship with the care recipient. The original question “What is your relationship with the care recipient?” was changed to read “Who do you provide care for?” to provide more clarity to the participant.

## Final Study

Once the pilot study was completed, the dissemination of the research survey began through word of mouth and social media platforms. The power analysis called for 384 participants to reach a medium effect size of 0.30 and a 95% level of confidence. However, the initial survey dissemination method resulted in only 44 participants after a period of 45 days. Several attempts to contact nonprofit organizations related to caregivers resulted in no responses from these organizations. Therefore, the survey was posted on MTurk to increase the probability of reaching eligible participants. MTurk is a service provided by Amazon Web Services for businesses or individuals to outsource tasks and processes to a human workforce available online. This service is also used to conduct research including the completion of surveys and to receive a monetary compensation for the tasks completed. The participation criteria were highlighted prior to entering the survey to mitigate the risk of ineligible participants completing the survey.

Participants who completed the survey received $1.00 to compensate for their time. This new data collection approach was successful, and over the course of 60 days the survey had been completed by an additional 371 caregivers, resulting in a total of 415 study participants.

A comparison of the sociodemographic profiles of both groups was performed, and no significant differences were found. For example, the median age for the first group of participants was 48 years, while the median age for the MTurk participants was 32 years. The average years providing care was 5 years for both groups, and most individuals provided care for their parents. Due to the similarities of the profiles of both groups, the data were analyzed as a single data set. The population for this study was Hispanic informal caregivers; however, the surveys were published in English and Spanish due to many Puerto Ricans being fully bilingual and some feeling more comfortable responding in English.

The data collected from the survey responses were imported to Microsoft Excel and numerically coded and reviewed for missing or inappropriate data. To address these issues, a pairwise deletion method was applied to retain as much valuable information as possible (Statistics Solutions, n.d.). The coded data were subsequently imported into SPSS Version 28 for analysis. The data were tested to ensure they met the four assumptions of linear regression: linearity, independence, homoscedasticity, and normality (see Statology, 2021). Linearity means that there is a linear relationship between the variables, independence means that the residuals are independent, homoscedasticity means residuals have a constant variance, and normality means that residuals are normally distributed (Statology, 2021). The linearity and homoscedasticity assumptions were tested, which demonstrated the data collected met these parameters. Independence was tested using the Durbin-Watson test for autocorrelation (see Statology, 2021). Durbin-Watson test values of $1.5 < d < 2.5$ showed that there was no autocorrelation in the data; therefore, with a $d$ value of 1.720, the independence assumption was met. Lastly, normality was measured through the Kolmogorov-Smirnov test, which resulted in Asymp. Sig values of < .001, meaning the assumption was met (see Statology, 2021).

## Sociodemographic Profile

Descriptive statistics were performed on the data set. I found 22 missing values within the data set, all of which were due to blank or inappropriate responses to the questions pertaining to the caregiver's age and/or the years spent caring for the care recipient. Pairwise deletion was applied to the missing values to ensure the retention of the remaining data collected; due to the number of participants, the 22 missing values would not have had a significant effect on the statistical analyses for this study. This analysis showed that 54% ($n = 224$) of respondents were women, 44.8% ($n = 186$) were men, and 1.2% ($n = 5$) preferred not to disclose their sex. Most participants responded to the survey in Spanish (54.9%) rather than in English (45.1%). The average age of the participants was 36 years with a range from 20 to 71 years, and participants had been providing care for their loved one for an average of 9 years with a range from 0 to 50 years. Most participants provided care for their spouses (28.2%, $n = 117$) or a parent (27.5%, $n = 114$). This was followed by 16.1% ($n = 67$) of participants caring for their consensual partner (not legally married) and 12% (*n* = 50) caring for their child. The remainder of the participants provided care for a sibling (6.3%), grandparent (3.1%), mother- or father-in-law (2.9%), aunt or uncle (2.2%), or niece or nephew (1.4%).

## Survey Scores

The average caregiver health (SF-20) score was 33.75 with a maximum score of 100, and a higher score indicating better health and quality of life. The average caregiver burden (ZBI-12) score was 25.91 with a higher score indicating greater caregiver burden. According to the ZBI-12 scoring guidelines, a score over 20 indicated a high level of burden; therefore, the average score demonstrated that the participant pool had high levels of caregiver burden. The average perceived stress self-management (SMSEM) score was 54.51 with a range of 90 and a higher score indicating more effective stress management. The average perceived social support (MSPSS) score was 47.58 with a range of 72 and a higher score indicating greater social support perceptions. The MSPSS scoring guidelines indicated that the total score can be divided by 12 to determine the level of perceived social support, which resulted in a score of 3.97 indicating that on average participants perceived a moderate level of social support. However, upon analyzing the MSPSS scores by each subscale, I found that on average participants perceived low levels of support, which are presented in Table 4.

**Table 4**

*MSPSS Subscale Scores*

| MSPSS subscale | Score |
|---|---|
| Family | 1.33 |
| Significant other/special person | 1.32 |
| Friends | 1.31 |
| Overall score | 3.97 |

## Correlations Between Research Variables

To determine the correlations between the predictors, outcomes, and sociodemographic variables of this research, a Pearson Correlation analysis was performed. The table below demonstrates that there are positive and significant correlations between caregiver health, stress self-management, social support, relationship with the care recipient, and burden. On the other hand, caregiver burden was found to have a positive and significant correlation with stress self-management and social support, however, the correlation with caregiver age and the relationship with the care recipient was found to be negatively correlated.

**Table 5**

*Research Variable Correlations*

| | Stress management | Social support | Caregiver burden | Caregiver health | Caregiver age | Years providing care | Caregiver sex | Relationship with care recipient |
|---|---|---|---|---|---|---|---|---|
| Stress management | 1 | .830** | .325** | .356** | .068 | .110* | .146** | .105* |
| Social support | .830** | 1 | .346** | .419** | .066 | .044 | .129** | .137** |
| Caregiver burden | .325** | .346** | 1 | .146** | -.194** | -.015 | .092 | -.098* |
| Caregiver health | .356** | .419** | .146** | 1 | .057 | .024 | .067 | .129** |
| Caregiver age | .068 | .066 | -.194** | .057 | 1 | .363** | -.070 | -.021 |
| Years providing care | .110* | .044 | -.015 | .024 | .363** | 1 | .039 | -.048 |
| Caregiver sex | .146** | .129** | .092 | .067 | -.070 | .039 | 1 | -.036 |
| Relationship with care recipient | .105* | .137** | -.098* | .129** | -.021 | -.048 | -.036 | 1 |

Note. * Correlation is significant p = <0.05
** Correlation is significant p = <0.01

## Research Question 1

RQ1: Is there an association between *perceived stress self-management*, *perceived social support* and Hispanic informal caregiver *health*?

$H_o$1: There is no association between the *perceived stress self-management, perceived social support* and Hispanic informal caregiver *health*.

$H_a$1: A significant and positive association exists between the *perceived stress self-management, perceived social support* and Hispanic informal caregiver *health*.

The independent variables were perceived stress self-management & perceived social support. The dependent variable was caregiver health.

## Multiple Regression Analysis

The regression analysis performed to test research question #1, Is there an association between perceived stress self-management, perceived social support and Hispanic informal caregiver health? Sociodemographic variables such as age, years caring for loved one, and sex were introduced as covariates in the regression analysis to test for adjustments in significance; however, none were identified and the regression analysis applied for this study only included the predictor and outcome variables of research question #1.

The adjusted $R^2$ was 0.172, indicating that 17.2% of the variability of caregiver health within the study sample is influenced by the caregiver's stress self-management perception & perceived social support. There were positive correlations between the predictors and the dependent variables, caregiver health had a correlation of 0.419 with social support and 0.356 with stress self-management. The ANOVA output indicated that the overall regression was statistically significant as the p value was less than 0.001. However, upon analyzing the individual regression coefficients, the social support perception variable had a significant (p-value less than 0.001) relationship with caregiver health, but the relationship between stress self-management perception and caregiver health was not statistically significant with a p-value of 0.766. There was a very strong correlation between the perceived social support and perceived stress self-management scores with a value of .830. Therefore, upon analyzing the data, coupled with the large F statistic of 44.042, the null hypothesis for research question #1 can be rejected; as there is a significant and positive association between the *perceived stress self-management, perceived social support* and Hispanic informal caregiver *health*.

**Table 6**

*Multiple Linear Regression Analysis for RQ1*

| Predictor | Outcome | B | *SE* | 95% CI | *t* | *p* |
|---|---|---|---|---|---|---|
| Constant | Caregiver health | 18.647 | 1.719 | (15.269, 22.025) | 10.850 | < .001 |
| Social support | | .302 | .060 | (.183, .421) | 4.986 | < .001 |
| Stress management | | .013 | .045 | (-.075, .102) | .298 | .766 |
| Adjusted *R* Square | .172 | | | | | |
| *F* | 44.042 | | | | | |
| *SE* | 12.387 | | | | | |
| *p* | <.001 | | | | | |

*Note*. SE = standard error, CI = confidence interval, *p* < .05.

### Research Question 2

RQ2: Is there an association between pe*rceived stress self-management, perceived social support* and Hispanic informal caregiver *burden*?

*H*o2: There is no association between the *perceived stress self-management, perceived social support* and Hispanic informal caregiver *burden*.

*H*a2: A significant and negative association exists between *the perceived stress self-management, perceived social support* and Hispanic informal caregiver *burden*.

The independent variables were perceived stress self-management and perceived social support. The dependent variable was caregiver burden.

### Multiple Regression Analysis

A multiple regression analysis was performed to test research question #2 Is there an association between perceived stress self-management, perceived social support and Hispanic informal caregiver burden? This regression analysis resulted in an adjusted $R^2$ value of 0.120, indicating that 12% of the variability of caregiver burden among the study population was influenced by the caregiver's stress self-management perception & perceived social support. The ANOVA analysis indicated that this relationship overall was statistically significant with a p-value of less than 0.001. Upon analysis of the results of these statistical tests, the null hypothesis cannot be rejected for research question 2 as there is a positive relationship between the perceived stress self-management, perceived social support and Hispanic informal caregiver burden, as this relationship was expected to be negative. This inability to reject the null hypothesis is also supported by the low F statistic value of 7.874, signifying a large within-group variance.

In an effort to determine if sociodemographic covariates would adjust the regression analysis and allow for rejection of the null hypothesis; these variables were included in a follow-up analysis. However, as with the previous regression no adjustments were identified that would allow for $H_0$ rejection for research question #2.

**Table 7**

*Multiple Linear Regression Analysis for RQ2*

| Predictor | Outcome | B | *SE* | 95% CI | *t* | *p* |
|---|---|---|---|---|---|---|
| Constant | Caregiver burden | | 11.202 | (11.112, 64.087) | 3.357 | .012 |
| Social support | | .369 | .162 | (-1.024, .258) | -3.958 | .005 |
| Stress management | | -.934 | .191 | (-.153, .752) | 1.563 | .162 |
| Adjusted *R* Square | .604 | | | | | |
| *F* | 7.874 | | | | | |
| *SE* | 5.56302 | | | | | |
| *p* | .016 | | | | | |

*Note*. SE = standard error, CI = confidence interval, $p < .05$.

## Reliability Analysis

To test the reliability of the Informal Caregiver Stress Self-Management, Social Support, Burden and Health Survey all the items were analyzed in SPSS with a Cronbach's alpha test. The overall survey had a high reliability of 0.955. Because this survey contains pre-existing tools, their reliability was also tested and resulted in high reliability as presented in the following table.

**Table 8**

*Reliability Statistics*

| Data collection tool | Cronbach's alpha | Number of items |
|---|---|---|
| SMSEM | .958 | 10 |
| MSPSS | .963 | 12 |
| ZBI-12 | .921 | 12 |
| SF-20 | .872 | 20 |
| Overall | .955 | 54 |

## Summary

This chapter presented the results of the Informal Caregiver Stress Self-Management, Social Support, Burden and Health Survey. A pilot study was conducted and the feedback reviewed was taken into consideration for the final survey. The final survey was disseminated exclusively online across multiple platforms. Sufficient survey responses were collected to satisfy the power analysis and effect size parameters. The results demonstrated that the majority of respondents were female in their mid-thirties. The participants had been caregivers for an average of 9 years and the care recipients were mainly spouses and parents. In regard to the research questions, the null hypothesis for the first research question was rejected as there is a significant and positive association between the perceived stress self-management, perceived social support and Hispanic informal caregiver health. The null hypothesis for the second research question was not rejected as a positive relationship was found between the perceived stress self-management, perceived social support, and Hispanic informal caregiver burden, rather than the expected negative relationship. The following chapter will discuss the social implications of this research and the recommendations for future informal caregiver burnout research.

# Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this study was to examine the relationship between stress self-management, perceived social support, health status, and burden among Puerto Rican informal caregivers. To determine whether significant relationships existed, I identified several study variables and formulated two research questions and corresponding hypotheses. These hypotheses were tested using the data collected from the participant survey responses, and significant relationships between the variables were found, allowing the null hypotheses to be rejected. In this chapter, the key findings of this study are discussed along with any identified limitations. The implications for positive social change are also discussed as well as recommendations for future research regarding informal caregiver burnout.

## Key Findings

A sociodemographic profile was developed using the descriptive statistics from the participant pool. There were more female (54%) participants than male (44.8%) participants, and most (54.9%) responded to the survey in Spanish, which was expected for Puerto Rico residents. The average participant age was 36 years, and participants had provided care for an average of 9 years. Most participants were caregivers for their spouse (28.2%) or a parent (27.5%). Upon reviewing the survey results, I found that on average the participants reported to have moderate stress self-management (54.51) and moderate social support perceptions (47.58). Participants also reported high levels of burden (25.91) and fair health perceptions (33.73).

The multiple regression results for Research Question 1 demonstrated that positive and significant correlations existed between caregiver health, social support, and stress self-management with an $R^2$ of .172 and a significance of $p < .001$. The large $F$ statistic value of 44.042 further supported the rejection of the null hypothesis for Research Question 1 because there was a significant and positive association between perceived stress self-management, perceived social support, and Hispanic informal caregiver health. Regarding Research Question 2, the overall correlation between caregiver burden, social support, and stress self-management resulted in an $R^2$ value of .604, which was not statistically significant ($p < .016$). The resulting $F$ statistic value of 7.874 was also low; therefore, the null hypothesis for Research Question 2 was not rejected. Furthermore, results indicated a positive relationship rather than the expected negative relationship between perceived stress self-management, perceived social support, and Hispanic informal caregiver burden. Key findings were as follows:

- Most participants were Spanish-speaking middle-age women.
- Most participants had cared for their spouse or parent for an average of 9 years.
- On average, participants reported perceiving moderate self-stress management and social support.
- High burden levels were reported with fair self-reported health.
- Significant and positive relationships were found between stress self-management, social support, burden, and health of Puerto Rican informal caregivers.

## Interpretation of the Findings

The sociodemographic data collected from the participants of this study demonstrated that the average Hispanic informal caregiver was a middle-age adult who began caring for their parent or spouse when they were a young adult. This information aligns with the literature about working-age adults in Puerto Rico taking on caregiving responsibilities due to the lack of formal and informal care options on the island, particularly following the Hurricane Maria disaster in 2017 (see Roman, 2018). In alignment with the informal caregiving literature, there was a strong and significant relationship between informal caregiver health and the levels of social support and stress self-management perceived by the caregiver (see Rote et al., 2019). However, the overall health, social support, and stress self-management perceptions across the participants were moderate; therefore, efforts to provide additional support for informal caregivers in Puerto Rico are essential to increase their stress self-management efficacy and improve their health status (see Rabarison et al., 2018).

The relationships and correlations tested by Research Question 2 between informal caregiver burden, social support, and stress self-management were positive and statistically significant, resulting in rejection of the null hypothesis. This relationship was expected to be negative because informal caregiving literature had demonstrated that with greater social support and stress management, the perceptions of burden are expected to decrease (see Ong et al., 2018). These findings are in alignment with literature regarding Hispanic informal caregivers and the familism phenomenon, which indicates that Hispanics tend to have high familial support (see Luchsinger et al., 2018). However, familial expectations have been found to be so high that with greater social support Hispanic caregivers tend to experience higher burden (Diallo et al., 2019). Previous research also found that familism may lead to higher burnout levels due to a reluctance to use formal care services because the use of these services and placement of the older or disabled in nursing homes is looked down upon (Luchsinger et al., 2018; Pérez & Ailshire, 2017). Therefore, it is important to develop educational campaigns and resources for caregivers in Puerto Rico to learn about formal care options and emphasize their benefits to assist in reducing their burden as well as strategies for them to manage their burden and encourage them to ask for help from their close family and friends when they need respite (Rote et al., 2019).

## Alignment With Theoretical Frameworks

This research was developed using two theoretical frameworks: the IFSMT and the ICIM. The IFSMT is composed of several components including the process dimension, which includes the social facilitation construct, and the outcomes dimension, which was the focus of the current study. The IFSMT assumes that with high social facilitation and encouragement, coupled with efficient self-management, behaviors are more likely to result in better health outcomes (P. Ryan & Sawin, 2009). Previous research has shown that those who engage in self-management behaviors have better health outcomes and significant reduction in stress and burden related to caregiving circumstances (Zhang et al., 2020). Similarly, the ICIM framework assumes that there are various determinants of informal caregiver burnout (characteristics of the caregiver, caregiving setting, and sociocultural context of the caregiving situation) and that caregiver burden is a precursor or determinant of caregiver burnout (Gerain & Zech, 2019). Prior research found that in alignment with the ICIM, the determination of caregiver burnout consisted of three dimensions: exhaustion, caregiver and care recipient interactions, and the caregiver's sense of accomplishment (Gerain, 2020). The ICIM constructs selected for the current study were caregiver characteristics and social environment, which aligned with this study's constructs of caregiver health and perceived social support among Hispanic informal caregivers.

The results of the current study align with the IFSMT and ICIM theoretical frameworks because there was a significant and positive relationship between perceived social support, stress self-management, and health of informal caregivers. The results regarding informal caregiver burden are also in alignment with the ICIM because there was a positive and significant relationship between perceived social support, stress self-management, and informal caregiver burden. Although the ICIM would have predicted that this relationship would have been significant but negative, this theoretical framework acknowledges that there are multiple mediating factors that may lead to an increase in burden, including cultural, environmental, and psychological factors (Gerain & Zech, 2019).

## Alignment With Previous Research

The results of this study align with previous research conducted in the area of informal caregiver burnout. As was found in previous informal caregiver research, this study found that most informal caregivers are women caring for their parents, which is culturally expected among Hispanics (AARP & NAC, 2020). Furthermore, Díaz et al.

(2019) found that female caregivers tend to feel morally burdened to become informal caregivers, leading to increased caregiver burden and poor health, which aligns with the lower self-reported health reported by the current study participants.

The correlation found between social support and health also aligns with research by Koerner and Shirai (2019), who found that informal caregivers place high value on supportive family members; however, they often receive little to no social support from their families, which is associated with depressive symptoms and poor overall health. The results of the current study demonstrated a positive correlation between stress self-management practices and improved caregiver health and burden, which is in alignment with research by Zhang et al. (2020) that demonstrated caregivers who engage in stress self-management behaviors have better health outcomes and less burden.

The participants in the current study reported moderate social support levels and health coupled with high burden levels, meaning they are at a higher risk of developing burnout syndrome should these caregiving conditions continue to progress. Similarly, Rote et al. (2019) found that Hispanic caregivers generally perceive lower levels of social support, higher burden levels, and poor self-rated health, all of which are expected to worsen as the care recipient's health declines. Therefore, it is advised to develop health education and promotion efforts designed to support informal caregivers. Despite the adverse long-term care expectations, Hispanic caregivers are inclined to reject formal care and respite services due to cultural expectations of family-provided care within the home, leading to greater burden on the caregiver, which in turn increases their risk of developing burnout syndrome (Koerner & Shirai, 2019; Rote et al., 2019).

## Limitations of the Study

Among the limitations of this research was the exclusion of the identification of the care recipient’s specific health conditions. The burden and stress related to caring for a loved one may vary depending on the health conditions to be managed; however, information related to specific health conditions was not included in the study’s questionnaire. This could be studied in future research on informal caregiver burnout and self-management. Another limitation of this research was the focus on Hispanic informal caregivers residing in Puerto Rico. The data collected were specific to this population; however, this was planned due to the limited data and research on Puerto Rican informal caregivers. Lastly, the exclusion of individuals who do not speak English of Spanish was another limitation because there are small communities in Puerto Rico who speak other languages. However, these individuals make up less than 1% of the island’s population (U.S. Census Bureau, 2019).

The greatest challenge for this study was the recruitment of informal caregivers willing to complete the questionnaire, which was challenging in regard to the compliance with the necessary statistical power measurements and desired sample size. However, through the use of social media promotion, I reached the desired number of participants. Furthermore, the cross-sectional nature of this investigation only allowed for the measurement of the prevalence of caregiver burnout, social support, and self-management practices, rather than a longitudinal study of the potential development or reduction of burnout among the participants. Lastly, the limited literature related to

Hispanic informal caregivers did not allow for many comparisons with the results and conclusions of other studies.

Another limitation of this study was that it was made available exclusively online. Informal caregivers without internet access or who were not computer/digitally literate were excluded from participation. Also, due to the anonymous and online nature of the survey, the participant identities could not be corroborated. To address this issue, the consent form with the eligibility criteria and acknowledgment of meeting the criteria were required prior to initiating the survey. Furthermore, on the MTurk portal, there were options available to limit the access to the survey, including making it available only to the United States and territories to confirmed adults age 18 years or older. I also provided a detailed introduction to the survey with the inclusion criteria available prior to opening the survey. A unique code was also provided to the participants at the end of the survey to ensure it was completed in its entirety. This code was then confirmed for payment of the MTurk participants.

Lastly, strict COVID-19 policies of many public and private institutions in Puerto Rico constituted an additional research challenge. These policies were put in place to protect the health and safety of individuals receiving services by restricting the number of visitors at enclosed facilities including medical and nonprofit institutions. This greatly limited access to potential participants because meetings could not be arranged to discuss and promote the survey at these sites that provide services to caregivers and care recipients.

## Recommendations

Recommendations for future research include the physical distribution of the survey to capture the caregiving experiences of those without access to the internet or digital literacy because their experiences may differ from participants in the current study. An additional recommendation is to include other ethnic groups in the study population to compare the caregiving experiences across multiple ethnicities to determine the cultural influences. The surveys should be distributed in the appropriate languages that correspond to the ethnicities under study. It would also be interesting to repeat this study once the COVID-19 pandemic subsides and the restrictions are lifted to determine whether the perceptions of the caregivers have changed. Lastly, implications for future research include an in-depth investigation into the types of support wanted or needed by informal caregivers. This may include the types of stress self-management interventions that are most helpful and attractive to caregivers within specific ethnic or cultural groups because this may influence their acceptance of an intervention. Health education and promotion initiatives developed with the informal caregiver’s specific needs in mind and implemented in a culturally competent manner can promote their participation and lead to improved health and burden outcomes (Diallo et al., 2019).

## Implications

The results of this study have implications for positive social change for the prevention of informal caregiver burnout and for the field of health education and promotion because they may encourage health care providers and policy developers to recognize the importance of informal caregivers in society as a crucial part of the health care system. The data collected regarding the experiences and perceptions of Hispanic informal caregivers may be used for the development of advocacy efforts and community-based interventions and assistance programs. For example, findings indicated that the participants perceived a moderate level of social support and experienced high levels of burden; therefore, community-based programs may be developed and implemented by local governments or nonprofit organizations to provide additional support to caregivers in need through respite care, assistance running errands, housekeeping services, support groups, counseling, and family mediation services to facilitate and promote family assistance. These services may alleviate the burden experienced by caregivers and may increase their perception of social support, which in turn may improve their health and stress levels, as noted in previous research (Benson et al., 2020).

At the state and societal levels, advocacy for government funding for the implementation of caregiving resources and further research in this area can be promoted using the data collected from the current study because it demonstrated that Hispanic informal caregivers were experiencing significant health issues, felt highly burdened with their caregiving duties, and are at a greater risk of developing burnout syndrome. High prevalence of burnout syndrome among informal caregivers can put not only the care recipients at risk for experiencing abuse and neglect but can also threaten the stability of the already weakened health systems, particularly in vulnerable areas like Puerto Rico which have experienced long-term aftermath of major natural disasters like Hurricane Maria followed by the ongoing the COVID-19 pandemic. It is essential to develop and implement health education and promotion initiatives, resources, and programs to mitigate and prevent informal caregiver burnout; because these caregivers are essential for the functioning of society (Farzi et al., 2019, Rabarison et al., 2018).

## Conclusion

This research serves to initiate future studies and potential health education and promotion efforts focused on the needs of informal caregivers and that are culturally competent. The survey developed for this current study collected information regarding the experiences and perceptions of Hispanic informal caregivers residing in Puerto Rico, along with valuable information of their stress self-management practices, perceived social support, burden, and health status. The study data is valuable for the promotion of advocacy efforts in support of informal caregivers and the implementation of services to prevent informal caregiver burnout. Results of this research demonstrate that Hispanic informal caregivers in Puerto Rico are experiencing poor health and high burden, which are significant risk factors for burnout syndrome if not properly managed. Informal caregiver burnout has been found to potentially result in the neglect and abuse of care recipients, particularly older adults and may strain local health systems and social services due to limited care options. Future research, advocacy efforts, and the implementation of programs to support and provide resources to informal caregivers are imperative to improve the quality of life of caregivers and their loved ones.

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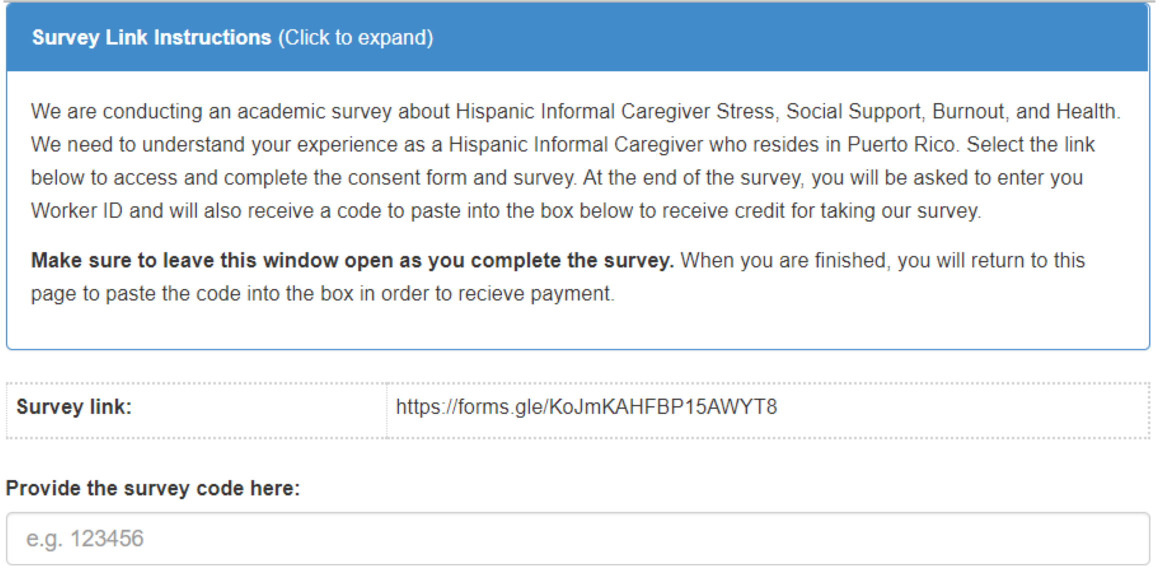
# Appendix A: Amazon MTurk Survey Description

## English Version



**Survey Link Instructions** (Click to expand)

We are conducting an academic survey about Hispanic Informal Caregiver Stress, Social Support, Burnout, and Health. We need to understand your experience as a Hispanic Informal Caregiver who resides in Puerto Rico. Select the link below to access and complete the consent form and survey. At the end of the survey, you will be asked to enter you Worker ID and will also receive a code to paste into the box below to receive credit for taking our survey.

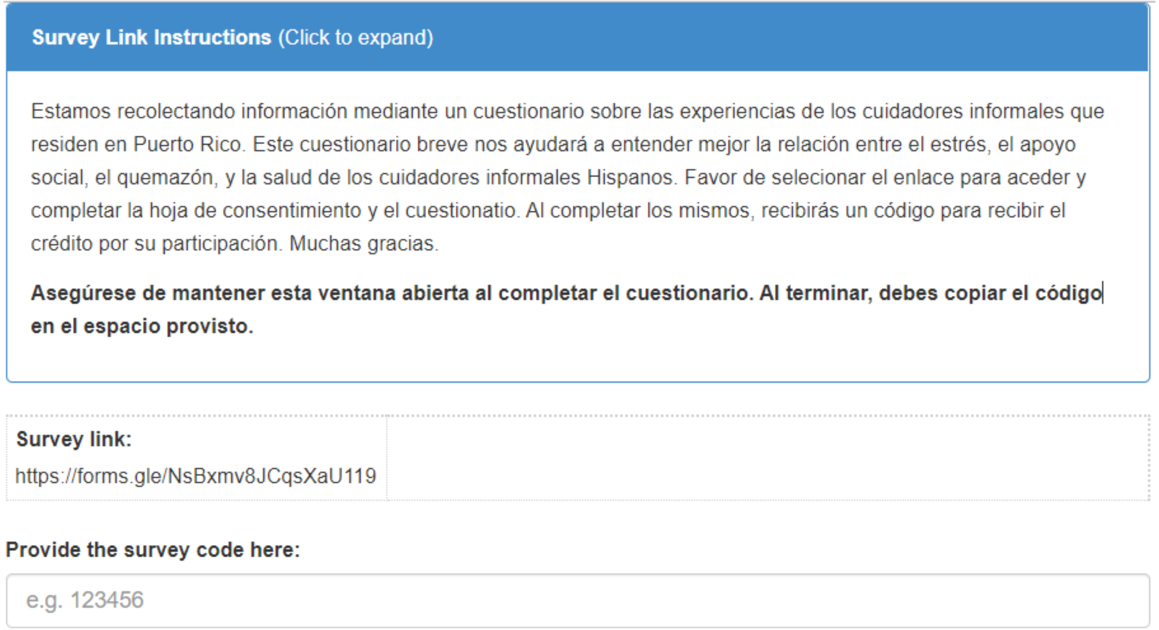
**Make sure to leave this window open as you complete the survey.** When you are finished, you will return to this page to paste the code into the box in order to recieve payment.

**Survey link:** https://forms.gle/KoJmKAHFBP15AWYT8

**Provide the survey code here:**

e.g. 123456

## Spanish Version



**Survey Link Instructions** (Click to expand)

Estamos recolectando información mediante un cuestionario sobre las experiencias de los cuidadores informales que residen en Puerto Rico. Este cuestionario breve nos ayudará a entender mejor la relación entre el estrés, el apoyo social, el quemazón, y la salud de los cuidadores informales Hispanos. Favor de selecionar el enlace para aceder y completar la hoja de consentimiento y el cuestionatio. Al completar los mismos, recibirás un código para recibir el crédito por su participación. Muchas gracias.

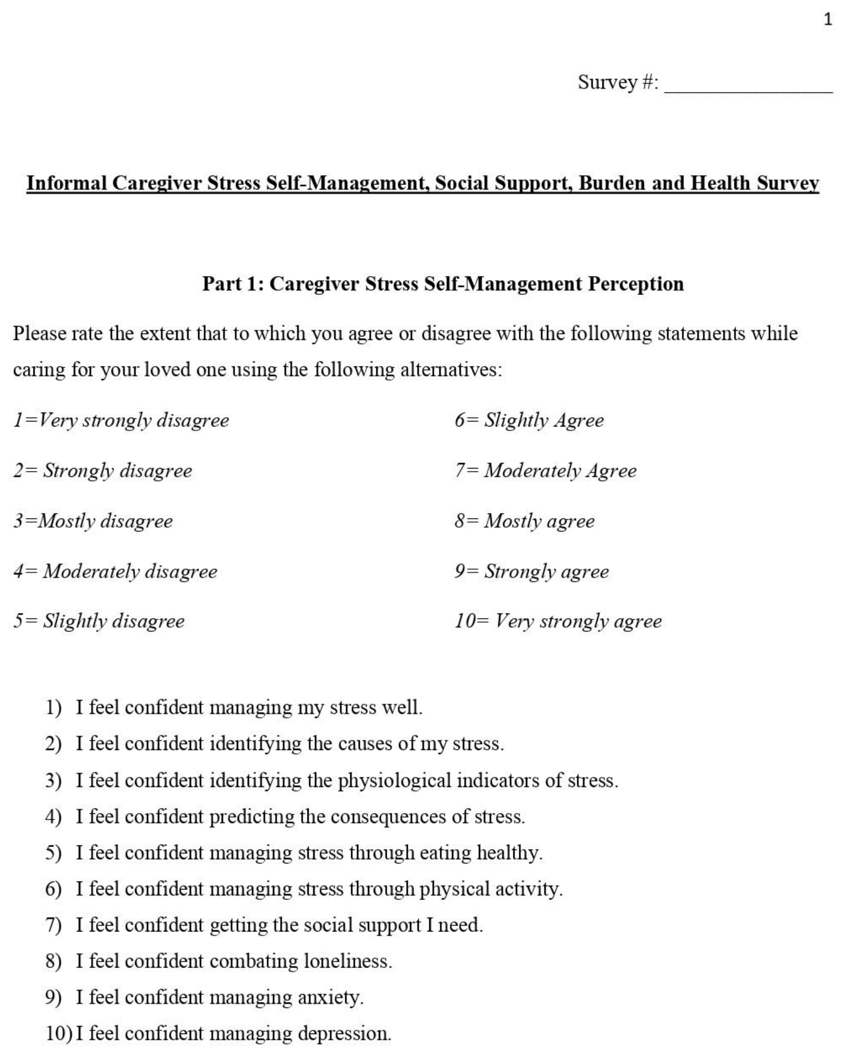
**Asegúrese de mantener esta ventana abierta al completar el cuestionario. Al terminar, debes copiar el código en el espacio provisto.**

**Survey link:**
https://forms.gle/NsBxmv8JCqsXaU119

**Provide the survey code here:**

e.g. 123456

# Appendix B: Informal Caregiver Stress Self-Management, Social Support, Burden and Health Survey



1

Survey #: ________________

**Informal Caregiver Stress Self-Management, Social Support, Burden and Health Survey**

**Part 1: Caregiver Stress Self-Management Perception**

Please rate the extent that to which you agree or disagree with the following statements while caring for your loved one using the following alternatives:

*1=Very strongly disagree*

*2= Strongly disagree*

*3=Mostly disagree*

*4= Moderately disagree*

*5= Slightly disagree*

*6= Slightly Agree*

*7= Moderately Agree*

*8= Mostly agree*

*9= Strongly agree*

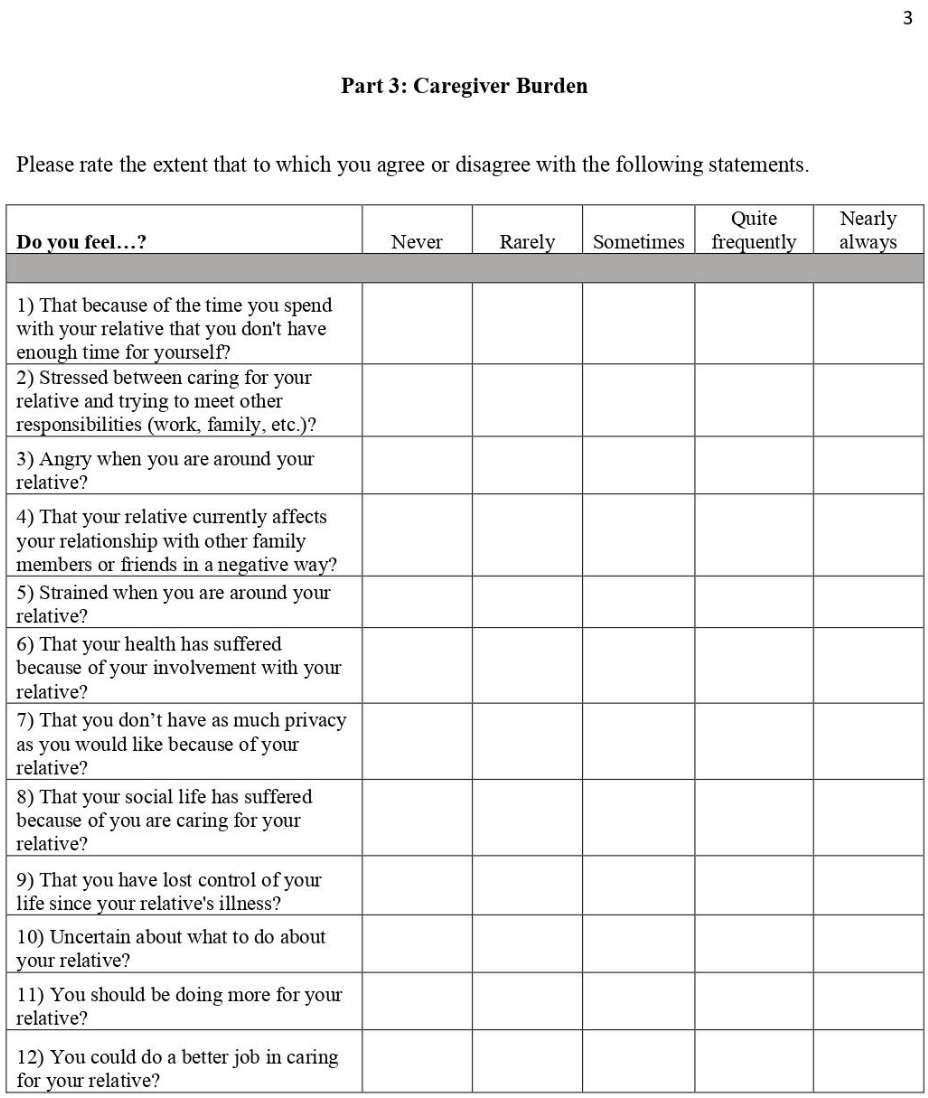
*10= Very strongly agree*

1) I feel confident managing my stress well.
2) I feel confident identifying the causes of my stress.
3) I feel confident identifying the physiological indicators of stress.
4) I feel confident predicting the consequences of stress.
5) I feel confident managing stress through eating healthy.
6) I feel confident managing stress through physical activity.
7) I feel confident getting the social support I need.
8) I feel confident combating loneliness.
9) I feel confident managing anxiety.
10) I feel confident managing depression.

## Part 2: Caregiver Perceived Social Support

Please rate the extent that to which you agree or disagree with the following statements.

| | Very strongly disagree | Strongly disagree | Mildly disagree | Neutral | Mildly agree | Strongly agree | Very strongly agree |
|---|---|---|---|---|---|---|---|
| 1) There is a special person who is around when I am in need. | | | | | | | |
| 2) There is a special person with whom I can share my joys and sorrows. | | | | | | | |
| 3) My family really tries to help me. | | | | | | | |
| 4) I get the emotional help and support I need from my family. | | | | | | | |
| 5) I have a special person who is a real source of comfort to me. | | | | | | | |
| 6) My friends really try to help me. | | | | | | | |
| 7) I can count on my friends when things go wrong. | | | | | | | |
| 8) I can talk about my problems with my family. | | | | | | | |
| 9) I have friends with whom I can share my joys and sorrows. | | | | | | | |
| 10) There is a special person in my life who cares about my feelings. | | | | | | | |
| 11) My family is willing to help me make decisions. | | | | | | | |
| 12) I can talk about my problems with my friends. | | | | | | | |



## Part 3: Caregiver Burden

Please rate the extent that to which you agree or disagree with the following statements.

| **Do you feel…?** | Never | Rarely | Sometimes | Quite frequently | Nearly always |
|---|---|---|---|---|---|
| | | | | | |
| 1) That because of the time you spend with your relative that you don't have enough time for yourself? | | | | | |
| 2) Stressed between caring for your relative and trying to meet other responsibilities (work, family, etc.)? | | | | | |
| 3) Angry when you are around your relative? | | | | | |
| 4) That your relative currently affects your relationship with other family members or friends in a negative way? | | | | | |
| 5) Strained when you are around your relative? | | | | | |
| 6) That your health has suffered because of your involvement with your relative? | | | | | |
| 7) That you don't have as much privacy as you would like because of your relative? | | | | | |
| 8) That your social life has suffered because of you are caring for your relative? | | | | | |
| 9) That you have lost control of your life since your relative's illness? | | | | | |
| 10) Uncertain about what to do about your relative? | | | | | |
| 11) You should be doing more for your relative? | | | | | |
| 12) You could do a better job in caring for your relative? | | | | | |

## Part 4: Caregiver Health

| | Poor | Fair | Good | Very good | Excellent |
|---|---|---|---|---|---|
| 1) In general, how would you say your health is: | | | | | |

| 2) For how long (if at all) has your health limited you in each of the following activities? | | | |
|---|---|---|---|
| | | | |
| | Limited for more than 3 months | Limited for less than 3 months | Not limited at all |
| a) The kinds or amounts of *vigorous* activities you can do, like lifting heavy objects, running, playing sports | | | |
| b) The kinds or amounts of *moderate* activities you can do, like moving a table, carrying groceries, or bowling | | | |
| c) Walking uphill or climbing a few flights of stairs | | | |
| d) Bending, lifting, or stopping | | | |
| e) Walking one block | | | |
| f) Eating, dressing, bathing, or using the toilet | | | |

| | None | Very mild | Mild | Moderate | Severe | Very severe |
|---|---|---|---|---|---|---|
| 3) How much *bodily* pain have you had during the past 4 weeks? | | | | | | |

| | Yes, for more than 3 months | Yes, for 3 months or less | No |
|---|---|---|---|
| 4) Does your health keep you from working a job, doing work around the house or going to school? | | | |
| 5) Have you been unable to do certain kinds or amounts of work, housework or school work because of your health? | | | |

| For each of the following questions, please mark the one answer that comes closest to the way you have been feeling *during the past month.* | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | | |
| **How much of the time, during the past month….?** | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time |
| 6) Has your health *limited your social activities* (like visiting friends or family)? | | | | | | |
| 7) Have you been a *very nervous person*? | | | | | | |
| 8) Have you felt *calm and peaceful*? | | | | | | |
| 9) Have you felt *downhearted and blue*? | | | | | | |
| 10) Have you been a *happy person*? | | | | | | |
| 11) Have you felt so down in the dumps that *nothing could cheer you up*? | | | | | | |

12) Please mark the answer that best describes whether each of the following statements is *true* or *false* to you.

| | Definitely true | Mostly true | Not sure | Mostly false | Definitely false |
|---|---|---|---|---|---|
| a) I am somewhat ill | | | | | |
| b) I am healthy as anybody I know | | | | | |
| c) My health is excellent | | | | | |
| d) I have been feeling bad lately | | | | | |

## Part 5: Sociodemographic Information

1) Caregiver age: ________________

2) Caregiver sex
   a) ____ Male
   b) ____ Female
   c) ____ Prefer not to answer

3) How long have you provided care for your loved one? ____________________

4) What is your relationship with care recipient?
   a) ____ Spouse
   b) ____ Consensual partner (not legally married)
   c) ____ Child
   d) ____ Sibling
   e) ____ Niece or nephew
   f) ____ Son or daughter-in-law
   g) ____ Other (specify) ______________________________

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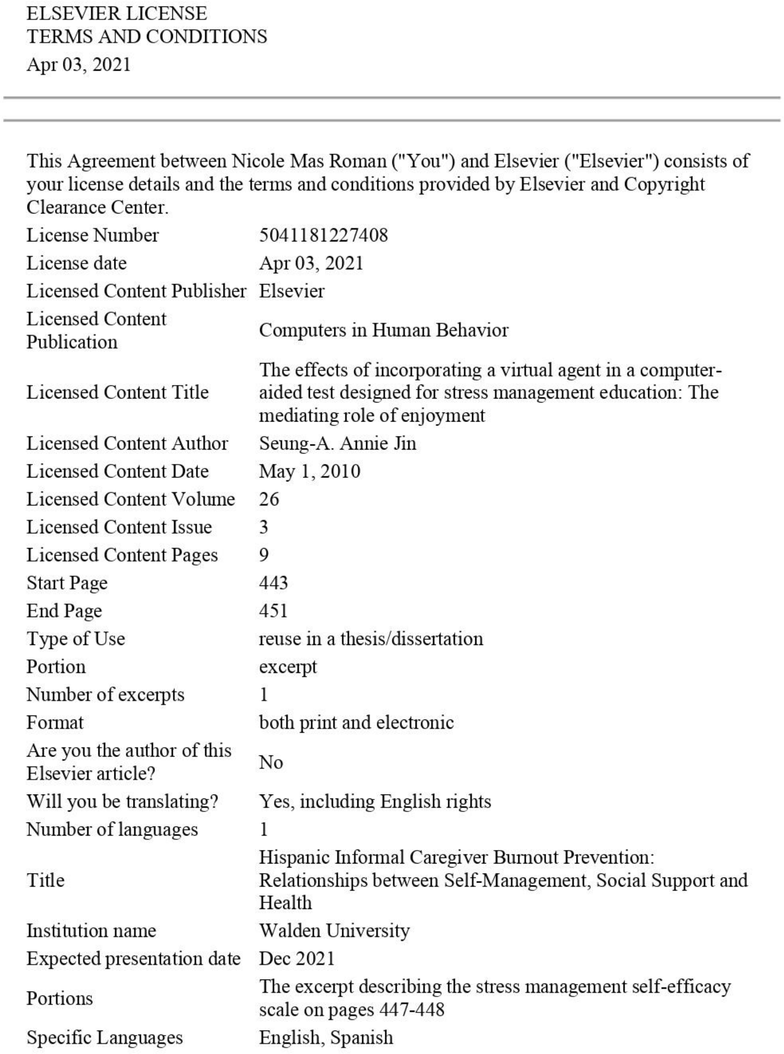

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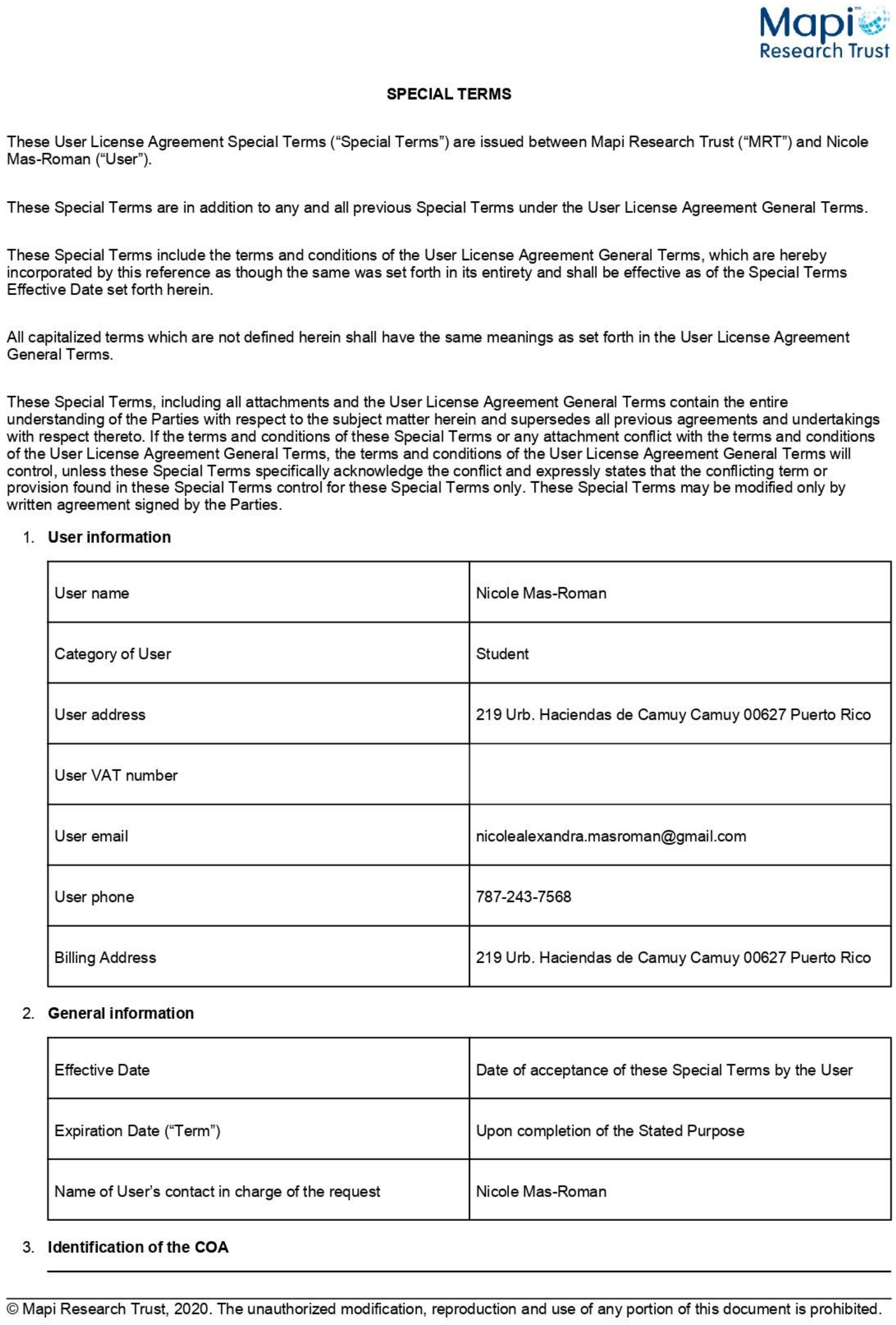
# Appendix D: ZBI-12 User Agreement and Special Terms



Mapi Research Trust

## SPECIAL TERMS

These User License Agreement Special Terms ("Special Terms") are issued between Mapi Research Trust ("MRT") and Nicole Mas-Roman ("User").

These Special Terms are in addition to any and all previous Special Terms under the User License Agreement General Terms.

These Special Terms include the terms and conditions of the User License Agreement General Terms, which are hereby incorporated by this reference as though the same was set forth in its entirety and shall be effective as of the Special Terms Effective Date set forth herein.

All capitalized terms which are not defined herein shall have the same meanings as set forth in the User License Agreement General Terms.

These Special Terms, including all attachments and the User License Agreement General Terms contain the entire understanding of the Parties with respect to the subject matter herein and supersedes all previous agreements and undertakings with respect thereto. If the terms and conditions of these Special Terms or any attachment conflict with the terms and conditions of the User License Agreement General Terms, the terms and conditions of the User License Agreement General Terms will control, unless these Special Terms specifically acknowledge the conflict and expressly states that the conflicting term or provision found in these Special Terms control for these Special Terms only. These Special Terms may be modified only by written agreement signed by the Parties.

1. **User information**

| | |
|---|---|
| User name | Nicole Mas-Roman |
| Category of User | Student |
| User address | 219 Urb. Haciendas de Camuy Camuy 00627 Puerto Rico |
| User VAT number | |
| User email | nicolealexandra.masroman@gmail.com |
| User phone | 787-243-7568 |
| Billing Address | 219 Urb. Haciendas de Camuy Camuy 00627 Puerto Rico |

2. **General information**

| | |
|---|---|
| Effective Date | Date of acceptance of these Special Terms by the User |
| Expiration Date ("Term") | Upon completion of the Stated Purpose |
| Name of User's contact in charge of the request | Nicole Mas-Roman |

3. **Identification of the COA**

| | |
|---|---|
| Name of the COA | ZBI - Zarit Burden Interview |
| Author | Zarit SH |
| Copyright Holder | Zarit Steven H and Zarit Judy M |
| Copyright notice | Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit |
| Bibliographic reference | **ZBI-22**<br>Zarit SH, Reever KE, Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. Gerontologist. 1980;20(6):649-55<br>Zarit SH, Orr NK, Zarit JM. The hidden victims of Alzheimer's disease: Families under stress. New York: New York University Press, 1985<br>Anthony-Bergstone CR, Zarit SH, Gatz M. Symptoms of psychological distress among caregivers of dementia patients. Psychol Aging. 1988 Sep;3(3):245-8 (PubMed abstract)<br>Zarit SH, Zarit JM. The Memory and Behavior Problems Checklist and the Burden Interview. Gerontology Center, Penn State University. 1990<br>**ZBI-12**<br>Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: a new short version and screening version. Gerontologist. 2001 Oct;41(5):652-7 (PubMed Abstract) |
| Modules/versions needed | ZBI-12 |

4. **Context of use of the COA**

The User undertakes to use the COA solely in the context of the Stated Purpose as defined hereafter.

**4.1 Stated Purpose**

Other project

| | |
|---|---|
| Title | Hispanic Informal Caregiver Burnout Prevention: Relationships between Self-Management, Social Support and Health |
| Disease or condition | Burnout syndrome |

|  |  |
|---|---|
| Planned Term* | Start: 03/2021; End: 12/2022 |
| Description (including format or media) | Survey |

**4.2 Country and languages**

MRT grants the License to use the COA on the following countries and in the languages indicated in the table below:

| Version/Module | Language | For use in the following country |
|---|---|---|
| ZBI-12 | English | the USA |
| ZBI-12 | Spanish | the USA |

The User understands that the countries indicated above are provided for information purposes. The User may use the COA in other countries than the ones indicated above.

5. **Specific requirements for the COA**

- The Copyright Holder of the COA has granted ICON LS exclusive rights to translate the COA in the context of commercial studies or any project funded by for-profit entities. ICON LS is the only organization authorized to perform linguistic validation/translation work on the COA.
- In case the User wants to use an e-Version of the COA, the User shall send the Screenshots of the original version of the COA to MRT or ICON LS for review and approval. The Screenshots review may incur additional fees.
- In case the User wants to use an e-Version of the COA, ICON LS shall update (if needed) and populate the COA translations into the User's or IT Company's system and the User shall send the Screenshots of the translations of the COA to ICON LS for approval. The update (if needed), population of translations and the Screenshots review may incur additional fees.

By accepting these Special Terms, the User acknowledges and confirms that it has read and approves the User Agreement General Terms.