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Hispanic Family Caregivers' Experiences With Dementia Patients During the COVID-19 Emergency

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Walden University

College of Social & Behavioral Health

This is to certify that the doctoral study by

Vivian Arroyo

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

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Walden University
2025

Abstract

Hispanic Family Caregivers' Experiences With Dementia Patients During the COVID-19

Emergency

by

Vivian Arroyo

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Social Work

Walden University

February 2025

Abstract

The COVID-19 pandemic significantly impacted caregiving dynamics, particularly for Hispanic family caregivers of dementia patients. This qualitative study explored the experiences, challenges, and coping strategies of these caregivers during the pandemic. The theoretical framework was systems theory. Semistructured interviews were conducted with 12 participants to collect data. Participants were recruited through purposive sampling and responded to open-ended questions regarding their caregiving experiences. The collected data were analyzed using Braun and Clarke's six-step thematic analysis. The findings revealed four themes: (a) caregiving strategies, including time management, collaboration, and reliance on religious faith; (b) self-care experiences, which highlighted the balance between personal well-being and caregiving responsibilities; (c) cultural practices, emphasizing the influence of familial and societal expectations; and (d) challenges, such as limited resources, resistance to care, and heightened stress due to pandemic-related restrictions. Participants employed adaptive strategies to overcome barriers, including leveraging cultural resilience and community support. The study provides critical insights into the experiences of Hispanic caregivers during a global crisis. These findings contribute to positive social change through informing social work practices and policy development, highlighting the importance of culturally sensitive interventions and targeted resources.

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Dedication

This research study is dedicated to the memory of my beloved father, Randolph Aviles, who succumbed to the ravages of dementia on March 20, 2024. His courageous battle against this relentless disease serves as a poignant reminder of the urgent need for advancements in dementia research and care. To my devoted mother, Iris Aviles, whose unwavering dedication and tireless caregiving provided comfort and support to my father until his final moments. Her strength in the face of adversity embodies the resilience of caregivers and underscores the profound impact of familial love in navigating the complexities of dementia. This study is a tribute to both my parents and to the countless families whose lives have been irrevocably altered by the effects of dementia. May your enduring love and the challenges you bravely confronted serve as motivation to continue striving for breakthroughs in understanding, treating, and ultimately preventing this devastating disease.

Acknowledgements

I extend my sincere gratitude to my doctoral project committee, comprising Dr. Rice and Dr. Futrell, who have been steadfast in their support since the inception of my research project. Their guidance, expertise, and unwavering commitment have been instrumental in shaping the trajectory of this study. Without their invaluable contributions, reaching this milestone would not have been possible. Special thanks are owed to Alex Casiano, whose generosity in sharing knowledge and dedication to mentorship have been invaluable throughout this journey. His willingness to lend an ear and provide insightful guidance, even amidst busy schedules, has been immensely appreciated. I am profoundly grateful for his mentorship, which has played an integral role in the progression of this research endeavor. To all those who have played a part in this endeavor, your encouragement and assistance have been invaluable. Your collective support has propelled this project forward, and I am deeply indebted to each and every one of you for your contributions.

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Section 1: Foundation of the Study and Literature Review

Introduction

One area that has been profoundly affected by the COVID-19 pandemic and its related restrictions is caregiving (Messina et al., 2022). The pandemic's disruptions have resulted in caregivers assuming increased responsibilities and dedicating more time to adhering to the Centers for Disease Control and Prevention (CDC) safety guidelines to ensure the safety and well-being of their loved ones with dementia (Kostyál et al., 2022). Simultaneously, they have encountered limited support due to the isolation measures imposed by the pandemic.

This study aims to contribute to the field of social work by enhancing social workers' awareness of the distinct struggles Hispanic family caregivers faced during COVID-19, which could lead to the development of targeted interventions and support systems to improve their well-being and caregiving outcomes. By conducting a comprehensive examination of Hispanic family caregivers' challenges, coping mechanisms, and needs within the context of the pandemic, this study seeks to contribute to the growing body of knowledge in the field of social work and further enhance the understanding of the impact of COVID-19 on this population. Understanding Hispanic family caregivers' unique experiences during the pandemic can help inform and develop targeted interventions, policies, and support systems to address their specific needs effectively (Iribarren et al., 2019).

Using thematic qualitative analysis, this study explored the experiences of Hispanic family caregivers of loved ones with dementia. Section 1 of this research project

includes the following: problem statement, purpose statement, research questions, nature of the doctoral project, significance of the study, theoretical framework, values and ethics, and a review of the professional and academic literature. Section 2 covers the research design and the methodology elements, including the prospective data, participants, data analysis plan, and measures used to establish the trustworthiness and ethical procedures guiding the study. Section 3 includes the data analysis techniques, findings, and summary. Section 4 is organized to include the following: introduction, application to professional ethics in social work practice, recommendations for social work practice, implications for social change, and summary.

Problem Statement

The COVID-19 pandemic and its associated restrictions significantly transformed the caregiving experience, placing immense burdens on caregivers (Bruno et al., 2022), especially those of Hispanic descent (Johnson et al., 2023; Sadler et al., 2021). With the implementation of pandemic-related measures, caregivers shouldered increased responsibilities, devoting more time to adhering to CDC safety guidelines for the protection of dementia patients (Angel et al., 2022). The resulting disruption of normal routines led to exhaustion among caregivers, while society has largely failed to acknowledge the specific challenges faced by those caring for dementia patients during the pandemic. The problem being explored in this study is the restrictions resulting from COVID-19 and how they changed the caregiving experience among caregivers who are of Hispanic descent. Isolation has been identified as a concern but without

acknowledgment of the challenges among caretakers caring for a dementia patient during COVID-19 and the pandemic's restrictions (Cohen et al., 2021).

Insufficient knowledge exists regarding the effects of the COVID-19 emergency on Hispanic family caregivers (Angel et al., 2022). Although some research has focused on caregivers' experiences with dementia patients, there remains a significant gap in understanding the unique challenges faced by Hispanic family caregivers during the pandemic given sociodemographic disparities in healthcare access as well as differences in attitude across cultures surrounding vaccination and other safety measures (Bruno et al., 2022). The associated challenges of coping mechanisms and support needs are of interest to the field of social work (Angel et al., 2022). Additionally, there is a need to enhance awareness of the distinct struggles faced by Hispanic family caregivers. According to Angel et al. (2022), it is also important to inform Hispanic family caregivers of the development of targeted interventions and support systems to improve well-being and caregiving outcomes during the pandemic.

Existing research has shed light on caregivers' experiences when providing care to individuals with dementia (Iribarren et al., 2019). However, there is a notable gap in knowledge regarding how the COVID-19 emergency impacted Hispanic family caregivers who play a significant role in caring for their loved ones with dementia (Angel et al., 2022). This study aims to contribute to the field of social work by enhancing social workers' awareness of the distinct struggles Hispanic family caregivers faced during COVID-19, which could lead to the development of targeted interventions and support systems to improve their well-being and caregiving outcomes.

Purpose Statement

The purpose of this generic qualitative study was to explore the experiences of Hispanic family caregivers providing care to dementia patients during the COVID-19 emergency. This study is necessary because it contributes vital information to supporting Hispanic caregivers during times of upheaval like those experienced during the COVID-19 pandemic. Understanding their unique experiences during the pandemic can help inform and develop targeted interventions, policies, and support systems to address their specific needs effectively (Iribarren et al., 2019).

Research Question

The following research question guided the study:

RQ1: How do Hispanic family caregivers describe their experiences providing care to dementia patients during the COVID-19 pandemic?

RQ2: How do Hispanic family caregivers describe any barriers or challenges they faced due to the restrictions of the COVID-19 pandemic at the family, culture, and societal levels?

RQ3: What coping strategies did Hispanic family caregivers employ to overcome challenges and restrictions due to the COVID-19 pandemic at the family, culture, and societal levels?

Nature of the Doctoral Project

This generic qualitative case study was aimed at exploring the experiences of Hispanic family caregivers providing care to family members with dementia during the COVID-19 emergency. Data were collected from participants using semistructured

interview questions as the main instrument guiding the study. Qualitative research methods are used to analyze open-ended data using experiences and natural language (Levitt et al., 2018). Qualitative researchers tend to focus on human experiences, behaviors, and social processes, which change through time, place, and culture. Rather than looking for universal natural principles, qualitative researchers try to provide findings specific to the situations in which the research methods are used (Levitt et al., 2018).

Data collection involved obtaining information from Hispanic family caretakers who have firsthand experience caring for dementia patients during the COVID-19 emergency. A purposive sampling scheme was utilized to solicit participants who reside in the United States, where the Hispanic family caregivers who are participating must speak English or Spanish proficiently. The interviews were conducted virtually using the Zoom platform for online meetings. A semistructured interview was most appropriate for this study because the open-ended questions allow participants to share additional information and to elaborate and clarify their responses.

The research design for this qualitative study was based on the tenets of the generic qualitative research design. Data were collected using semistructured interviews with the participants in this study. A total of 15 semistructured interview questions were developed for the participants to answer. The questions were developed to reflect the purpose of the study. The responses, open-ended questionnaire, and observation notes completed during the follow-up phase after the interviews were used to answer the research question.

Significance of the Study

This study is significant due to the potential practical applications of the findings in the field of clinical social work. Using this information, researchers in various fields including social work, medicine, nursing, public health, and psychology can design more effective interventions aimed at improving patients' quality of life. According to prior research, investigating the impact of different forms of support on caregivers' experiences and outcomes can guide the development of effective support interventions (Yoon et al., 2022). Gaining further insight into the social problem relating to the care of dementia patients can contribute to improving the quality of life both for individuals with dementia and their caregivers by improving the resources available to support individuals in caregiving roles. When caretakers receive improved support, they are better able to care for loved ones and experience quality-of-life improvements (Yoon et al., 2022).

Theoretical Framework

Systems theory, which grounds this study, was developed in 1937 by Bertalanffy (Van Assche et al., 2019). In the field of social work, systems theory is utilized as a practical model that directs practice and education to analyze the individual across several systems levels while paying attention to the myriads of components that comprise an individual's experience (Cox et al., 2022). Bertalanffy's systems theory provided the theoretical framework needed to explain the underlying mechanism by which the environmental factors associated with providing caregiving services for families with dementia during the COVID-19 pandemic impacted the Hispanic caregiver experience (Van Assche et al., 2019).

Bertalanffy was a biologist and systems theorist known for his work on general systems theory (Van Assche et al., 2019). While his theories were primarily focused on biology and the natural sciences, they have also been applied to other fields, including social work. Bertalanffy's general systems theory proposes that complex systems, whether biological or social, can be understood as a collection of interconnected and interdependent parts that work together to form a whole. According to this theory, the behavior and characteristics of the system cannot be fully understood by analyzing its parts in isolation, but rather by examining the relationships and interactions between the parts.

Social workers who adopt Bertalanffy's systems perspective recognize that individuals are not isolated entities but are embedded within larger social systems such as families, communities, and societies (Van Assche et al., 2019). The well-being of individuals is influenced by surrounding systems and changes in one part of the system have ripple effects throughout. Social workers can assess the individual within their social context by applying the principles of general systems theory to social work practice. Social workers consider the broader social systems that individuals are a part of when conducting assessments including family dynamics, community resources, cultural factors, and societal structures that impact the individual's well-being.

Social workers recognize that changes in one system can affect other systems. For example, addressing an individual's mental health issues may require working with their family or advocating for changes in the healthcare system. Promote holistic interventions, instead of focusing solely on individual-level interventions, social workers using a

systems perspective aim to develop interventions that consider the multiple levels of influence on an individual's life. They may work with families, communities, and organizations to create supportive environments and address systemic barriers to well-being. Social workers can collaborate with diverse stakeholders. Systems thinking encourages social workers to collaborate with various stakeholders, including clients, families, community members, and policymakers. By engaging multiple perspectives and expertise, social workers can develop more comprehensive and effective interventions.

While Bertalanffy's general systems theory has influenced social work practice, social work also draws on a wide range of other theories and perspectives to address the complex needs of individuals, families, and communities. The main concept guiding the systems theory in this study focuses on how Hispanic caregivers can relate to their work environment involving the family system and how the system influences their expectations as caregivers. The theory guided the focus on how COVID-19 affected Hispanic caregivers by examining the families' experiences during COVID-19 and how changes affected caregivers.

Additionally, this study was influenced by the stress process model (SPM), developed by Pearlin et al. (1981). SPM is particularly pertinent for understanding the nature of stress experienced by caregivers, especially in the challenging context of chronic illness management and a global health crisis. At the core of the SPM are primary stressors, which in this context include the direct challenges of caregiving for dementia patients compounded by the COVID-19 pandemic, such as managing daily care needs and dementia symptoms, heightened health risks, and potential isolation. Secondary

stressors arise because of these primary stressors, impacting various life domains like family dynamics, employment, and financial stability. Crucial to this model are the mediators of stress, which encompass the caregivers' coping mechanisms, social support systems, and resource accessibility (Pearlin et al., 1981). These mediators can significantly influence how primary and secondary stressors impact the caregiver, either exacerbating or alleviating their effects (Pearlin et al., 1981).

The SPM, rooted in sociological and psychological stress and coping theories, delineates caregiving as an ongoing career characterized by phases in the lives of family caregivers (Pearlin et al., 1990). These phases include role acquisition, role enactment during home care, potential relocation of the care recipient to a residential setting, and bereavement. Caregivers face stressors linked to their phase in the caregiving career, which can be categorized as primary (related to the care receiver's illness) and secondary (spillover effects on other aspects of life). The cumulative impact of primary and secondary stressors can lead to negative outcomes like depression and compromised health for caregivers (Aneshensel et al., 1995). Resources, such as support from family or services, can mitigate these effects. However, family dynamics may also introduce conflicts, such as disagreements over diagnosis, care, and financial matters. The model serves as a framework for designing interventions to manage stressors and prevent negative mental health consequences.

Recent research integrates a biological component into the SPM, connecting daily stressors to affect measures and biological responses like hormone fluctuations. Chronic stressors contribute to wear and tear on the body, increasing caregivers' risk of mental

and physical illnesses like depression, cardiovascular disease, diabetes, and immune-related disorders. Recognizing these health effects emphasizes the need for effective support services and interventions to reduce stress and promote caregivers' mental and physical well-being (Liu, 2021).

The outcomes of this stress process, which can be psychological (e.g., anxiety, depression) or physical (e.g., changes in health status), are central to understanding the overall impact of caregiving (Pearlin et al., 1981). In applying this model to Hispanic family caregivers, the study considers cultural and societal influences, such as the strong familial responsibility in Hispanic culture and systemic inequalities in healthcare access, which might shape the experience of stressors. The COVID-19 pandemic introduces unique primary stressors, like fear of virus transmission and restricted access to healthcare services, while exacerbating secondary stressors, including social isolation and economic challenges. The resilience factors and coping strategies peculiar to Hispanic caregivers, such as reliance on extended family and community support, are also crucial. These can act as mediators within the stress process, potentially buffering against negative outcomes.

By utilizing the SPM, this study aims to contribute to the field of social work by enhancing social workers' awareness of the distinct struggles Hispanic family caregivers faced during COVID-19 which could lead to the development of targeted interventions and support systems to improve their well-being and caregiving outcomes. It offers a structured approach to understanding how various stressors interact and influence the well-being of Hispanic family caregivers. This framework is pivotal in identifying

targeted interventions and informing policy development to support Hispanic caregivers during times of upheaval.

As the present study considers the experience of Hispanic family caregivers after a pandemic, the study was also influenced by crisis theory. Crisis theory was developed by Caplan in 1989. Crisis theory considers how individuals respond during emergencies or crises. Crisis theory primarily states that, while emergencies present serious challenges to individuals, they also create times of both growth and change. Crises present significant stressors for individuals and can lead to coping mechanisms that are adaptive, allowing individuals to manage stressful situations. This theory works well with systems theory because, combining the two, they provide information about how systems may react and change during emergencies and events.

Values and Ethics

According to Barsky (2021), the National Association of Social Workers recommends the following guidance for social workers in the areas of career values and ethical considerations: (a) self-care, (b) cultural competence, and (c) cultural humility. These three areas demonstrate the social workers' mission of greater awareness of their surroundings, continued learning, and maintaining integrity while on the job (Barsky, 2021). By collecting and examining caregiver accounts detailing their professional experiences, caretakers can cultivate proficiency in assisting diverse populations and ethnic groups, such as Hispanic caregivers who provide care for family members with dementia. Social workers may have to provide clinical or case management services to

these populations and this study has the potential to increase their competence and confidence in working with them.

Review of the Professional and Academic Literature

Articles relevant to the topic were sourced through online databases such as Google Scholar and JSTOR. All articles considered for inclusion were published within the last 5 years. A small number of older articles may have been included as critical seminal sources. The following search terms were used to query relevant articles:

caregiver, Hispanic, COVID-19, family, dementia, and systems theory.

The COVID-19 pandemic, with its profound impact on communities worldwide, has shed light on the unique challenges faced by family caregivers providing care for individuals with dementia (Aledeh & Adam, 2020). Understanding the specific experiences of Hispanic caregivers specifically during the COVID-19 pandemic, as well as in other times of upheaval, is crucial for developing targeted interventions and support systems that address their distinct needs and promote their well-being (Bruno et al., 2022). While the experiences of family caregivers during the COVID-19 pandemic have garnered some attention, the specific experiences, challenges, and coping strategies of Hispanic caregivers remain insufficiently understood (Aledeh & Adam, 2020). Existing literature primarily focuses on the general caregiver experience or specific populations, often neglecting the distinct circumstances faced by Hispanic family caregivers (Kostyál et al., 2022).

This literature review is aimed at synthesizing existing research on the experiences of Hispanic family caregivers, particularly those caring for individuals with

dementia, during the COVID-19 pandemic and other times of upheaval. By examining the literature, this review explored the impact of the COVID-19 pandemic on Hispanic caregivers. In doing so, the specific challenges they face were further investigated along with their coping strategies and sense of resilience (Alonso-Cortes et al., 2021) to extend the existing findings to caring for families living with dementia patients in their household.

Challenges of Family Caregivers

The literature on the experiences of family caregivers during the COVID-19 pandemic has identified several critical variables that should be explored in future studies. Various articles on caregiving focused on various aspects of burden (Aledeh & Adam, 2020; Canevelli et al., 2020; Häikiö et al., 2020). Some studies focused on the physical quantity of work expected of caregivers (Häikiö et al., 2020). For example, Häikiö et al. (2020) discussed how health literacy can reduce the overall workload of caregiving by giving individuals the information they need to effectively streamline care. Others included the mental burden of caregivers as a variable (Cohen et al., 2021). Cohen et al. (2021) found that the COVID-19 pandemic left a massive mental burden on caregivers, as they were more isolated and had less access to support services like in-home care relief. Understanding the caregiver burden is crucial, encompassing the physical, emotional, and financial strains associated with caregiving responsibilities. This connects back to the first stage of SPM, which addresses demand, which in this case is psychological and cognitive (Pearlin et al., 1981).

Caregiver psychological well-being is a significant concern (Ainamani et al., 2020; Chen et al., 2020; Messina et al., 2022). Investigating variables such as stress, anxiety, depression, and caregiver resilience is essential (Van Assche et al., 2019; Wei et al., 2022). Exploring the factors contributing to psychological distress and identifying protective factors that enhance resilience can inform interventions aimed at improving caregivers' mental health outcomes (Chen et al., 2020). As discussed by crisis theory, disasters or crises can create opportunities for adaptation in individuals, including those who are responsible for caregiving.

Pearlin et al. (1981) explained how life events, stress, and social supports form a stress process in which people operate. Life events and external stressors can have serious impacts on how individuals process and manage stress, which can make things that were once manageable more difficult to process. For example, a global pandemic could add a level of stress to a caregiver which changes their ability to handle the act of caregiving. While caregiving may have been stressful, but manageable, Pearlin et al.'s (1981) findings suggest that the pandemic and stress related to it may make caregivers unable to cope with their established role.

The availability and adequacy of social support for caregivers have played a vital role during the pandemic (Perales-Puchalt et al., 2022). Future studies should examine the types of social support caregivers receive, including formal support services, informal support from family and friends, and virtual support networks (Ibanez et al., 2021). Investigating the various adaptive strategies caregivers use to manage stress, uncertainty, and disruptions in caregiving routines can shed light on effective coping mechanisms

(Balbim et al., 2019; Dessy et al., 2022; Lucero et al., 20219). Exploring the effectiveness of different coping strategies and their association with caregiver well-being and patient outcomes can inform the development of targeted interventions that promote effective coping skills (Sehar et al., 2022). By addressing these critical variables in future studies, researchers can advance our understanding of the experiences of family caregivers during the COVID-19 pandemic and develop evidence-based interventions that better support their well-being and caregiving outcomes (Balbim et al., 2019).

A variety of studies explored the experiences of caregivers during the COVID-19 pandemic, each with its strengths and weaknesses. Qualitative studies have been valuable in providing in-depth insights into the subjective experiences, perspectives, and emotions of caregivers (Hazzan et al., 2022). Through interviews, focus groups, or open-ended surveys, qualitative research allows caregivers to share their narratives and provides a rich understanding of the complexities and nuances of their caregiving experiences during the pandemic (Daley et al., 2022). These studies offer a deep exploration of the context, challenges, coping mechanisms, and emotional impact of caregiving, allowing researchers to capture the unique voices and diverse experiences of caregivers (Lillekroken et al., 2023). For this reason, my study included interview questions that explore the issue of Hispanic family caregivers during the time of the pandemic. These findings are important to my study as they reinforce the need to explore the experiences of individuals from varied backgrounds, such as Hispanic caregivers specifically. The findings were reflected in my research question by asking participants to discuss their context, challenges, and coping mechanisms.

Factors such as the duration and severity of dementia, the availability of social support networks, and a caregiver's own physical and mental health can also influence caregiver burden (Gilsenan et al., 2022). Caregiver burden is a complex and multifaceted phenomenon influenced by various individual, interpersonal, and environmental factors. Understanding and addressing caregiver burden is crucial for supporting caregivers in their role (Cohen et al., 2021). Recognizing the unique challenges faced by caregivers and tailoring interventions to their specific needs can help alleviate the burden and promote their well-being. Providing access to respite care, support groups, counseling services, and educational resources can offer caregivers the support they need to navigate their caregiving journey (Aledeh & Adam, 2020).

Additionally, external factors, such as the COVID-19 pandemic, have an effect on caregiver burden (Aledeh & Adam, 2020). Aledeh and Adam (2020) found that dementia caregivers can become extremely isolated from society, which has an impact on their quality of life and quality of care. The pandemic brought additional challenges, including restricted access to healthcare services, social isolation, and increased caregiving responsibilities due to lockdown measures. These factors further intensified caregiver burden and underscore the need for targeted support during times of crisis.

Psychological Well-Being of the Caregiver

Caregiver burden plays a significant role in psychological well-being. The caregiver burden encompasses physical, emotional, and financial strain often experienced associated with caregiving responsibilities (Häikiö et al., 2020). Elevated levels of burden have been linked to increased psychological distress. This relates to systems theory

because elevating or changing burden levels can influence the system in which caregivers operate, requiring adaptation. Meanwhile, crisis theory suggests that crises like a global pandemic might require adaptation in a caregiver and create growth opportunities. Studies examining the experiences of caregivers of individuals with dementia have highlighted the significant burdens they face (Aledoh & Adam, 2020). The demands of caregiving, such as managing daily tasks, addressing behavioral changes, and coordinating healthcare, can contribute to caregiver burden. Addressing caregiver burden through tailored interventions and support services can positively impact caregivers' psychological well-being (Alonso-Cortes et al., 2021).

Academic literature underscores the psychological challenges faced by individuals caring for family members with dementia (Wiegelmann et al., 2021). Wiegelmann et al. (2021) found that mental health support is a critical success factor for family caregivers. Caregivers, particularly Hispanic caregivers, are at a heightened risk of experiencing psychological distress, and the COVID-19 pandemic further intensified these challenges (Alonso-Cortes et al., 2021). Providing social support, addressing caregiver burdens, and considering cultural factors are essential to promoting the psychological well-being of caregivers. Future research should continue to explore effective interventions that support caregivers' mental health and resilience, considering the unique needs of diverse populations, including Hispanic caregivers (Messina et al., 2022).

Caregiver burden is a significant concern for individuals caring for family members with dementia. The burden is influenced by numerous factors, including the

nature of caregiving tasks, a caregiver's well-being, and the availability of support systems (Canevelli et al., 2020). By understanding these factors and implementing appropriate support interventions, caregiver burden can be alleviated and the well-being of caregivers can be enhanced across diverse populations (Häikiö et al., 2020). Numerous academic studies have been conducted to explore caregiver burden among individuals caring for family members with dementia (Gilsenan et al., 2022). For example, Gilsenan et al. (2022) found that situational factors influence caregiving experiences, like type of residency and family support. Additionally, anticipatory grief plays a significant role in the mental health of caregivers. This research has provided valuable insights into the challenges faced by caregivers and the factors that contribute to caregiver burden. While there is a growing focus on the experiences of Hispanic caregivers, the literature is still limited (Rodríguez-González et al., 2021).

Psychological well-being is another topic frequently discussed in academic literature related to caregiver burden (Alonso-Cortes et al., 2021). Academic literature on the psychological well-being of individuals caring for family members with dementia highlights the significant impact of caregiving on caregivers' mental health (Ainamani et al., 2020; Chen et al., 2020). Caregivers often experience elevated levels of psychological distress, including symptoms of stress, anxiety, and depression. The demands of caregiving, such as witnessing the decline of a loved one's cognitive abilities and managing challenging behaviors, can contribute to a caregiver's psychological distress.

Unique Psychological Challenges of Hispanic Caregivers

Caregivers of individuals with dementia are at an increased risk of developing mental health issues compared to the general population (Alonso-Cortes et al., 2021). This risk is further amplified among Hispanic caregivers who face unique challenges related to cultural norms, language barriers, and limited access to resources (Chen et al., 2020). The COVID-19 pandemic exacerbated these challenges for Hispanic caregivers, with restricted access to formal support services and increased isolation due to social distancing measures (Wei et al., 2022). Consequently, the psychological well-being of Hispanic caregivers during the pandemic has been significantly impacted. The literature highlights the importance of considering cultural factors when addressing the psychological well-being of caregivers (Wei et al., 2022). Cultural values, beliefs, and norms shape how caregivers perceive and cope with their caregiving role. Culturally sensitive interventions that acknowledge the unique experiences of Hispanic caregivers can help promote their psychological well-being and resilience (Chen et al., 2020).

Social Support for Hispanic Caregivers

Numerous factors contribute to the caregiver's psychological well-being. Social support has been identified as a crucial protective factor, providing emotional and practical assistance to caregivers (Messina et al., 2022). Engaging in self-care activities and seeking respite from caregiving responsibilities are also important for maintaining caregivers' psychological health (Wei et al., 2022). Access to professional support, such as counseling or therapy, can offer caregivers a safe space to address their emotional needs and develop coping strategies (Alonso-Cortes et al., 2021).

To a certain degree, other variables like social support, can mitigate the life-impacts of psychological challenges (Perales-Puchalt et al., 2022). Academic literature emphasizes the crucial role of social support in the lives of individuals caring for family members with dementia (Ibanez et al., 2021). Ibanez et al. (2021) found that differing geographic locations had various approaches to family caregiving and that not all caregivers take similar approaches or have the same societal expectations about caregiving. Overall, caregiving can be an isolating experience, and social support plays a vital role in alleviating the psychological burden caregivers may face. By providing emotional, informational, and instrumental support, social networks can contribute to the well-being and resilience of caregivers (Yoon et al., 2022).

Research indicates that caregivers who have access to strong social support systems report lower levels of psychological distress (Cartwright et al., 2022). Cartwright et al. (2022) found that emotional support, such as understanding, empathy, and validation from family, friends, and support groups, can help caregivers navigate the challenges and emotional toll of caregiving. Informational support, including access to educational resources and guidance on caregiving strategies, equips caregivers with the knowledge and skills needed to provide effective care. Instrumental support, such as practical assistance with daily tasks or respite care, helps alleviate the physical and time demands of caregiving (Perales-Puchalt et al., 2022).

Social support is particularly critical for Hispanic caregivers who may face unique cultural and linguistic challenges (Yoon et al., 2022). Yoon et al. (2022) discussed engaging with support networks that understand and respect their cultural values and

beliefs can enhance the effectiveness of social support interventions. However, it is essential to recognize that Hispanic caregivers may encounter barriers in accessing culturally appropriate support services due to limited resources and language barriers (Ibanez et al., 2021). Tailored interventions that consider these cultural factors and address the specific needs of Hispanic caregivers can improve social support outcomes.

During the COVID-19 pandemic, social support has become even more vital for caregivers (Angel et al., 2022). The pandemic has posed significant challenges, including limited in-person interactions and restricted access to formal support services. However, innovative strategies, such as virtual support groups and telehealth services, have emerged to ensure continued social support for caregivers, including Hispanic caregivers, during these challenging times (Bruno et al., 2022).

Social support plays a critical role in supporting individuals caring for family members with dementia. By providing emotional, informational, and instrumental support, social networks can help alleviate the psychological burden experienced by caregivers (Iribarren et al., 2019). For Hispanic caregivers, the cultural dimension adds further complexity to the provision of effective social support (Perales-Puchalt et al., 2022). Additionally, the COVID-19 pandemic has emphasized the importance of adapting support services to address the unique challenges faced by caregivers during times of crisis. Continued research and the development of culturally sensitive interventions are necessary to ensure that social support remains accessible and beneficial for caregivers, promoting their well-being and resilience throughout the caregiving journey (Bruno et al., 2022).

Like social support, coping strategies can have a mitigating impact on psychological stressors and harm associated with caregiving for family members (Hu et al., 2021). Coping strategies play a crucial role in supporting individuals caring for family members with dementia (Fink et al., 2023). Academic literature highlights the significance of effective coping mechanisms in managing the various challenges and stressors associated with caregiving. By adopting adaptive coping strategies, caregivers can enhance their psychological well-being and overall quality of life (Fink et al., 2023; Hu et al., 2021). Seeking social support is an essential coping strategy for caregivers. Connecting with others who can provide understanding, empathy, and practical assistance can help caregivers feel validated and less alone in their experiences (Cartwright et al., 2022). Support groups, both in-person and virtual, offer opportunities for caregivers to share their experiences, exchange information, and gain support from individuals who can relate to their challenges (Yoon et al., 2022).

Problem-Focused Coping Strategies

Research suggests that problem-focused coping strategies are beneficial for caregivers (Hu et al., 2021). These strategies involve actively seeking solutions to challenges and addressing the practical aspects of caregiving (Alam et al., 2020; Balbim et al., 2019). For example, caregivers may engage in problem-solving activities, such as seeking information about dementia, attending support groups, or implementing strategies to manage challenging behaviors. Problem-focused coping strategies empower caregivers by providing a sense of control and enabling them to navigate complex caregiving responsibilities more effectively (Balbim et al., 2019).

Emotion-Focused Coping Strategies

Emotion-focused coping strategies also play a vital role in supporting caregivers' psychological well-being (AboJabel & Werner, 2022). These strategies involve regulating emotions, seeking emotional support, and engaging in self-care activities. Caregivers may practice relaxation techniques, engage in hobbies, or seek comfort from family and friends. Emotion-focused coping strategies help caregivers manage their emotional reactions, reduce distress, and foster emotional resilience in the face of caregiving challenges (Kaewwilai et al., 2022).

Coping strategies may vary among caregivers, and cultural factors can influence the selection of coping mechanisms. Hispanic caregivers may rely on culturally informed coping strategies such as seeking support from their extended family, drawing on religious or spiritual beliefs, or using traditional healing practices (Balbim et al., 2019). Culturally sensitive interventions should consider and validate these coping strategies, acknowledging their significance in the caregiving context (Hu et al., 2021).

Virtual Support as a Coping Strategy

During the COVID-19 pandemic, caregivers have faced additional stressors and limitations on their usual coping mechanisms (Etxeberria et al., 2021). Adaptation and innovation have been crucial in developing new coping strategies in response to the unique challenges posed by the pandemic. Utilizing technology for virtual support, engaging in online self-care activities, and finding creative ways to maintain connections with others have become important coping mechanisms for caregivers, including Hispanic caregivers (Ferretti et al., 2021).

Effective coping strategies are essential for supporting individuals caring for family members with dementia (Hu et al., 2021). Problem-focused coping strategies empower caregivers to address practical aspects of caregiving, while emotion-focused coping strategies help manage emotional distress (Sehar et al., 2022). Seeking social support and incorporating culturally informed coping strategies further enhance caregivers' well-being. The COVID-19 pandemic has underscored the need for flexible and adaptive coping strategies that can be tailored to the challenges faced by caregivers during times of crisis (Savla et al., 2021). Continued research and the development of culturally sensitive interventions are required to promote effective coping strategies and support the well-being of caregivers throughout their caregiving journey (Balbim et al., 2019).

Empirical Landscape of Current Studies

While quantitative studies played a crucial role in examining the experiences of caregivers during the pandemic, they failed to capture the multi-faceted human experience (Gaugler et al., 2021). Surveys or structured questionnaires are commonly used to collect standardized data from a larger sample of caregivers, enabling statistical analysis and generalizability of findings. Quantitative research allows for the examination of prevalence rates, the identification of associations between variables, and the exploration of predictive factors (Lorca-Cabrera et al., 2021). These studies have provided valuable insights into the prevalence of caregiver burden, levels of psychological distress, and factors that influence caregivers' well-being (Lepper et al., 2020). However, quantitative studies may overlook the nuances and contextual details of

caregivers' experiences. They often rely on pre-determined measures, limiting the exploration of unique aspects of caregiving that may emerge during times of upheaval. Additionally, self-report biases and recall inaccuracies can impact the reliability of data.

Researchers have employed mixed-methods studies, potentially to overcome the limitations of single-method approaches (Gonella et al., 2022). These studies integrate qualitative and quantitative data collection and analysis techniques to gain a more comprehensive understanding of caregivers' experiences during the COVID-19 pandemic (Bressan et al., 2020). By combining both approaches, researchers capture the richness of qualitative data along with the statistical analysis of quantitative data. This method allows for the triangulation of findings, enhancing the validity and depth of understanding. However, conducting mixed-methods studies can be time-consuming and resource-intensive, requiring careful planning and integration of data from various sources.

Another consideration is the distinction between longitudinal and cross-sectional studies. Cross-sectional studies provide a snapshot of caregiver experiences during a specific period (Wang et al., 2020). They efficiently collect data at a single point in time, allowing for comparisons across diverse groups or conditions. These studies have been valuable in capturing the immediate impact of the pandemic on caregivers' well-being, levels of stress, and utilization of support services (Wang et al., 2019). However, cross-sectional studies are limited in their ability to establish causality and examine changes over time. They may be influenced by recall bias and fail to capture the dynamic nature of caregiving experiences during the pandemic.

On the other hand, longitudinal studies follow caregivers over an extended period, allowing for the examination of changes in their experiences and well-being over time (Morimoto & Takebayashi, 2021). By collecting data at multiple time points, these studies can uncover long-term effects and trajectories of caregiving. Longitudinal studies have the advantage of capturing the evolving impact of the pandemic on caregivers, identifying trends, and understanding how caregivers' experiences may change (Morimoto & Takebayashi, 2021). However, they require substantial time and resources, and attrition and loss to follow-up may limit the sample size and introduce biases.

Employing a combination of study designs and methodologies provides a more comprehensive understanding of the experiences of caregivers during the COVID-19 pandemic. Qualitative studies offer rich and detailed insights into the subjective experiences of caregivers, while quantitative studies provide statistical analysis and generalizability. Mixed-methods studies integrate the strengths of both approaches, and longitudinal studies capture changes over time. Understanding the methodological strengths and limitations of different study types is essential for appropriately interpreting findings and informing future research and practice in supporting caregivers during times of upheaval.

Recent journal articles on the experiences of caregivers during the COVID-19 pandemic possess several notable strengths. One such strength lies in the fresh empirical evidence these articles provide (AboJabel & Werner, 2022). Overall, the literature on this topic is current and relies on recently gathered evidence (Lucero et al., 2019). The topic under consideration is the experiences of caregivers during the COVID-19 pandemic.

Therefore, all the sources closely tied to this topic are recent and use data that was recently collected. They utilize a range of research methods such as surveys, interviews, or observational studies, supplying both qualitative and quantitative data about the experiences of caregivers in this unprecedented time (Bruno et al., 2022; Cartwright et al., 2022). This firsthand information can significantly enhance our understanding of the practical realities and the wide array of challenges caregivers face.

The pandemic thrust caregivers into an extraordinary situation, marked by isolation, increased workload, and a need to adapt swiftly to novel methods of care delivery (Yoon et al., 2022). By bringing these experiences to the fore, such articles can offer a deep, empathetic insight into the trials caregivers have endured. These articles often present valuable policy recommendations aimed at supporting caregivers. These suggestions could be pivotal in informing the decisions of health professionals and policymakers and can directly assist caregivers. By providing actionable advice grounded in rigorous research, these articles serve as a meaningful guide during the crisis and beyond (Ibanez et al., 2021). Given the multidimensional impacts of the COVID-19 pandemic that span across the fields of public health, psychology, and sociology, these articles could offer crucial interdisciplinary insights into caregivers' experiences. This wide lens allows for a comprehensive, well-rounded analysis of the situation, making the research more robust and nuanced.

Several weaknesses might be present in these articles. Potential sampling bias is a problem for articles focused on specific communities or populations, particularly if they do not include a large dataset. If the studies focus primarily on caregivers in specific

locations, belonging to certain age groups, or having specific socioeconomic statuses, it could limit the generalizability of the findings. The experiences of caregivers are diverse and deeply personal, and failing to capture this variety can limit the utility of the research. For example, while the Balbim et al. (2019) article is strong overall, it focuses on a specific population, namely middle-aged or older Latino caregivers to family members with Alzheimers disease. While these results may provide compelling evidence regarding that population, generalizing beyond the group may be problematic (Balbim et al., 2019).

The rapidly evolving nature of the pandemic was another hurdle (Canevelli et al., 2020). Since the pandemic's circumstances change quickly, the findings and recommendations of these articles might become outdated soon after their publication. This is especially true for articles published in the initial stages of the pandemic (Cohen et al., 2021). The pandemic was unique in recent history and took a significant toll on the population. Future experiences with caregiving during times of upheaval may be different than the pandemic response. Therefore, findings related specifically to the COVID-19 pandemic may or may not apply to caregivers in the future (Savla et al., 2021).

There could also be an overemphasis on negative experiences. While it is indeed vital to discuss and address the challenges and struggles, constantly focusing on the negatives might overshadow the positive adaptations or resilience strategies employed by caregivers. Few studies focused on the experiences of caregivers compared with people who were unable to give care to family members. Though these experiences are likely

very different, most articles failed to acknowledge the experiences of caregivers compared to possible alternatives.

Remaining Gaps

The literature on the experiences of family caregivers during the COVID-19 pandemic has provided valuable insights, but there are notable gaps that warrant further investigation. First, there is a need for research that explores the intersectionality of caregiving experiences, considering how multiple dimensions of identity intersect to shape the challenges and strengths faced by caregivers (Alam et al., 2020).

Understanding the unique experiences of caregivers who work with various sociodemographic groups of patients and their families can provide the context and information necessary to design and implement more targeted and culturally sensitive support strategies (Kaewwilai et al., 2022).

Most existing studies have focused on the immediate impact of the pandemic on caregivers, leaving a gap in our understanding of the long-term consequences and trajectories of caregiving experiences (Savla et al., 2021). Longitudinal research is needed to examine the enduring effects of the pandemic on caregivers' well-being, quality of life, and caregiving dynamics, both during and after the crisis (Morimoto & Takebayashi, 2021). Additionally, comparative analyses that compare the experiences of caregivers during the COVID-19 pandemic to those in previous crises or periods of upheaval are lacking (Kostyál et al., 2022). Such analyses can provide insights into the unique challenges posed by the pandemic and shed light on lessons learned from past events.

While some studies have explored the experiences of these populations, there remains a significant gap in understanding how the prolonged impacts of COVID-19 have been impacting the Hispanic caregiver experience when working in the specific cultural and linguistic setting of Hispanic families living with dementia patients. Culturally sensitive approaches that consider diverse caregiving practices, beliefs, and norms can enhance support systems for these caregivers (Lucero et al., 2019). Cultural and ethnic considerations are crucial in understanding the experiences of family caregivers. Exploring how cultural values, beliefs, and norms influence caregivers' experiences during the pandemic is necessary. Examining the unique challenges faced by caregivers from diverse cultural backgrounds can help identify culturally sensitive interventions that address their specific needs (Iribarren et al., 2019).

Future research should assess the impact of specific interventions on caregiver well-being, access to resources, and patient outcomes (Cartwright et al., 2022). Identifying best practices and evidence-based interventions tailored to the Hispanic caregivers dealing with patients who have dementia contributed to the development of comprehensive support programs for this specific population. The pandemic has significantly impacted access to healthcare services for caregivers and care recipients alike. Future studies should examine the barriers and facilitators caregivers face in accessing healthcare services, including telehealth and virtual care options. Investigating the impact of disrupted healthcare services on caregiver burden, patient outcomes, and overall caregiving experiences can inform strategies to improve access and support (Perales-Puchalt et al., 2022).

The literature indicates a need to explore the accessibility and usability of technology for caregivers, particularly considering the digital divide (Lucero et al., 2019). Research is needed to understand the challenges faced by caregivers in accessing and effectively utilizing digital resources, ensuring equitable access to support services for diverse populations. The increased reliance on technology and digital solutions during the pandemic has impacted caregivers' experiences. Future studies should investigate the use and effectiveness of technological tools, such as remote monitoring devices, telehealth platforms, and online support groups. Understanding the benefits, challenges, and limitations of these technologies can inform the integration of digital solutions in caregiving support services (Yoon et al., 2022).

Addressing these gaps in the literature led to a more comprehensive understanding of the experiences of family caregivers during the COVID-19 pandemic. By conducting research that explores intersectionality, examines long-term impacts, includes comparative analyses, embraces cultural diversity, evaluates interventions, and considers the digital divide, we can enhance our knowledge base and develop targeted interventions and policies that better support caregivers during times of upheaval.

Summary

While the literature on the experiences of family caregivers during the COVID-19 pandemic is expanding, there is still a need for further research, especially regarding the specific experiences of esoteric populations such as Hispanic family caregivers treating dementia (Chen et al., 2020). This gap in knowledge underscores the importance of investigating the unique challenges and coping strategies of Hispanic family caregivers

during times of crisis and upheaval, such as the COVID-19 pandemic (Chen et al., 2020; Savla et al., 2021). Understanding their experiences contributed to developing targeted interventions and support structures to address their specific needs and promote their well-being. What follows in Section 2 is the research design and data collection guiding this capstone project.

Section 2: Research Design and Data Collection

Introduction

The COVID-19 pandemic and its associated restrictions have significantly transformed the caregiving experience, placing immense burdens on caregivers (Bruno et al., 2022). With the implementation of pandemic-related measures, caregivers have shouldered increased responsibilities, devoting more time to adhering to CDC safety guidelines for the protection of dementia patients (Angel et al., 2022). The resulting disruption of normal routines has led to exhaustion among caregivers, while society has largely failed to acknowledge the specific challenges faced by those caring for dementia patients during the pandemic. The problem under exploration in this study is COVID-19 and its associated restrictions and how they changed the caregiving experience. During COVID-19, restrictions resulted in caretakers taking on more responsibilities. Caregivers spent more time following CDC safety guidelines to ensure the safety of dementia patients with limited support due to pandemic isolation. COVID-19 and the restrictions have stagnated normal routines leading to exhaustion. Society has identified isolation as a concern but has not acknowledged the challenges among caretakers caring for a dementia patient during COVID-19 and the restrictions (Cohen et al., 2021).

Insufficient knowledge exists regarding the effect of the COVID-19 pandemic on Hispanic family caregivers (Angel et al., 2022). Although some research has been focused on the caregiver's experience with dementia patients, there remains a significant gap in understanding the challenges faced by Hispanic family caregivers during the COVID-19 pandemic (Bruno et al., 2022). This study aims to contribute to the field of

social work by enhancing social workers' awareness of the distinct struggles Hispanic family caregivers faced during COVID-19, which could lead to the development of targeted interventions and support systems to improve their well-being and caregiving outcomes.

In this section, I discuss the description and rationale of the qualitative generic research design. This section then proceeds with a description of the participants, including the planned sampling method and recruitment procedure. Also included is a description of the instrumentation, which is a researcher-developed semistructured interview guide along with an open-ended questionnaire and observation notes, followed by a description of the inductive, thematic analysis method that was applied to the data. The section concludes with a discussion of the ethical considerations, before closing with a summary transitioning to Section 3.

Research Design

A qualitative generic research design was employed to address the research question involving how Hispanic caregivers describe their experiences providing care to dementia patients during the COVID-19 emergency, focusing on their strategies to address any barriers or challenges emergent because of this global pandemic. In this research context, qualitative research offers a distinct advantage over quantitative methods as it provides contextual data rooted in participants' specific experiences related to the phenomenon of interest (Creswell, 2021). The utilization of qualitative research is particularly well-suited for this study, as it aligns with the need to investigate the naturalistic and contextualized settings surrounding the experiences of Hispanic family

caregivers during the COVID-19 pandemic. The highly individual and socially influenced nature of these experiences makes qualitative research an appropriate and valuable approach in this study. The chosen qualitative approach for this study is well-suited due to its open-ended data collection, making it optimal for investigating phenomena not fully characterized in existing literature (Vindrola-Padros et al., 2020). Given the literature gap regarding the impact of the COVID-19 emergency on Hispanic family caregivers (Angel et al., 2022), it is crucial to employ a method that allows for the emergence of unanticipated findings, ensuring a comprehensive understanding of the phenomenon. A quantitative approach, which is confirmatory and requires anticipating all possible outcomes during hypothesis formulation, would not have been suitable (see Creswell, 2021). In contrast, qualitative research, with its open-ended data collection, allows for the discovery of unforeseen themes and insights, potentially expanding the understanding of a phenomenon beyond what was previously known (Vindrola-Padros et al., 2020). Consequently, the selection of a qualitative approach is justified.

The qualitative design used was generic. Generic qualitative research typically involves a researcher conducting semistructured interviews with a purposeful sample of participants familiar with the phenomenon of interest (Doyle et al., 2020; Kostere & Kostere, 2021). This procedure was used in this study and is discussed in more detail in the appropriate sections of this study. The advantage that a generic design offers over other qualitative designs is that it does not impose a theoretical lens on the data collection and analysis processes that could distort the findings (Doyle et al., 2020; Kostere & Kostere, 2021).

For example, a phenomenological design is appropriate when a researcher wishes to describe the internal, subjective component of a lived experience, or what it is like to have the experience, and the external, real-world aspects of the experience are deemphasized accordingly (Neubauer et al., 2019). A phenomenological design was not appropriate for this study because family caregiving is a real-world phenomenon with important real-world components, so a balanced focus was needed on the internal, subjective experiences of family caregivers and the real-world aspects of their experiences. A phenomenological design cannot provide this balanced focus, but a generic design can, so a generic design was more appropriate.

In a case study design, the emphasis is on using multiple sources of evidence to describe a bounded system, or case, in which a process or condition is occurring (Yin, 2018). In this study, the emphasis was not on describing a bounded system, or case, but rather on describing experiences of caregiving from an interconnected, interdependent systems perspective. A grounded theory design is appropriate when the goal of a study is to generate a theory of a phenomenon for which existing theories do not account (Charmaz & Thornberg, 2021). In this study, theory generation is not objective; grounded theory gave an inappropriate emphasis to the study. For these reasons, a generic design was selected.

Methodology

Prospective Data

Semistructured interviews conducted with each participant were used to collect data for this study. The interviews were conducted face-to-face using the Zoom

videoconference application. A semistructured interview is guided by open-ended and scripted questions that cannot be answered with yes or no answers or by selecting a preformulated answer. Participants are encouraged to answer at length using their words so that unforeseen themes and insights can emerge (Vindrola-Padros et al., 2020). The method also gives a researcher the freedom to formulate and ask probing follow-up questions whenever further detail or clarification is needed to ensure that rich, relevant data are collected (Adeoye-Olatunde & Olenik, 2021). Semistructured interviews are the most common and appropriate data collection method for qualitative research in general (Vindrola-Padros et al., 2020), and for general qualitative design specifically (Doyle et al., 2020), because they allow a researcher to focus on the topic of interest while inviting the participant to answer the questions using their own words (Roberts, 2020). An open-ended questionnaire and observation notes support the semistructured interviews.

Participants

The inclusion criteria for this study included Hispanic family caregivers of a family member living with dementia during the COVID-19 pandemic, who resided in the United States and could participate in an interview in English or Spanish. After approval was received from Walden University's Institutional Review Board (IRB; 6-25-24-0385352), a purposeful sampling technique was employed to identify participants. Participants were recruited using digital flyers on open, unregulated Facebook groups for Hispanic family caregivers of dementia patients. Purposeful sampling is a nonrandom method in which recruitment efforts are focused on individuals who are most likely to be familiar with the phenomenon of interest and therefore able to provide relevant data

(Campbell et al., 2020). The specific form of purposeful sampling used was criterion sampling; individuals provide relevant data that are defined by the inclusion criteria (Campbell et al., 2020). Purposeful sampling was used because it maximizes the amount of relevant data that can be collected using limited time and resources and because it is the most common and appropriate sampling method in qualitative research (Vindrola-Padros et al., 2020) and in generic qualitative research (Doyle et al., 2020).

A minimum of 12 participants was the goal for the study. The conclusive sample size would be decided once data saturation was achieved. Data saturation occurs when the continued gathering and analysis of additional data stops offering new insights, only revealing redundant themes and codes already identified from earlier participants (Guest et al., 2020). The preliminary minimum sample size of 12 was determined because Braun and Clarke (2022) have demonstrated that in studies where thematic analysis is utilized, as in this study, data saturation is reached with as few as 12 participants. Once data from at least 12 participants were gathered and analyzed, and data saturation was attained, the recruitment of participants and the collection of data ceased. Upon obtaining approval from the IRB, the process of participant recruitment commenced by placing digital flyers on open, unregulated Facebook groups for Hispanic family caregivers of dementia patients in the United States. Site permissions were not required. The digital recruitment flyer outlined the study's purpose and nature, the inclusion criteria, and invited potential participants to express their interest privately through Facebook's secure messaging service.

When interested participants reached out to me, a preliminary telephonic conversation was arranged via a return message. This initial phone discussion was expected to take around 10 minutes. During this call, I enumerated the selection criteria for the study to the potential participants, asking them to confirm or deny their eligibility based on each criterion. Should a potential participant fail to meet every criterion, they were thanked for their willingness to participate in the study but notified of their ineligibility. However, if they qualified based on all criteria, they received an email with the informed consent form attached as a Word document, which they signed digitally and returned by replying to the email.

A semistructured interview protocol was developed based on earlier instruments published in scholarly peer-reviewed journals relating to the phenomenon and aligned with the social systems theory exploring the cultural and linguistic elements of caregiving among Hispanic caregivers. The protocol included opening comments, approximately 15 open-ended questions, and a list of potential follow-up questions based on responses. Interviews were anticipated to take approximately 1 hour to conduct. I took observation notes during the interview to supplement the interview data. The protocol was field tested with two caregivers who met the inclusion criteria before data collection to receive feedback on whether the interview questions aligned with the research question and the objectives of the study.

Data Analysis

Interviews were audio recorded using Zoom for later transcription. The interviews were transcribed by me using the automated transcription feature provided by Zoom.

Transcriptions were verified by reviewing transcriptions while listening to audio recordings. The verified transcripts, along with the follow-up questionnaire and observation notes, were imported as source files into NVivo 14 computer-assisted qualitative data analysis software (CAQDAS). CAQDAS such as NVivo automates the coding process and increases reliability by maintaining a detailed record of a researcher's decisions (Vindrola-Padros et al., 2020).

The data were analyzed using Braun and Clarke's (2022) six-step thematic analysis protocol. First, data were read and reread to gain familiarity. Second, the data were coded by clustering and labeling excerpts from participants' responses that express similar ideas. Third, the data were themed by clustering similar codes using an inductive open coding procedure carried out using the NVivo software. Fourth, the themes were compared to the original data to ensure accuracy. Fifth, the themes were named to simplify their significance as answers addressing the research questions. Sixth and last, a report of the results was produced (see Braun & Clarke, 2022) including a coding table summarizing the coding and grouping process included in the third section of this study.

Trustworthiness

Credibility refers to the degree to which study findings reflect participants' actual experiences of the phenomenon (Denzin et al., 2023). In this study, credibility was enhanced through a member-checking procedure (Stahl & King, 2020; Vindrola-Padros et al., 2020). Member checking requires asking participants to verify or correct the researcher's interpretations of the data. Credibility was enhanced through data source triangulation (Alston & Bowles, 2019). Data source triangulation involves comparing

data from diverse sources to identify common findings and discrepancies, to gain a more robust understanding of a phenomenon than would be obtained from a single data source, and it can be accomplished by collecting data from multiple sources using a single data collection method (Alston & Bowles, 2019; Fusch et al., 2018). In this study, data source triangulation was conducted by using multiple sources of qualitative data including semi-structured interviews, an open-ended questionnaire, and observation notes (Lemon & Hayes, 2020).

Transferability is the degree to which study findings may apply to other populations, cultures, or settings, and is comparable to external validity (Denzin et al., 2023). To assist readers of this study in assessing transferability, clear inclusion criteria were adhered to in recruiting the sample, as recommended by Stahl and King (2020). The sample was described when the results were reported to the extent consistent with maintaining confidentiality to assist the reader in comparing it to other samples to which the results might be transferred (Vindrola-Padros et al., 2020). This study is expected to demonstrate transferability given the similar nature of healthcare disparities experienced by other underserved populations.

Dependability refers to the extent to which the study findings may be replicated by a different researcher using the same procedures that would validate the integrity of study procedures as reliable (Denzin et al., 2023). In this study, dependability was enhanced through the description of the study procedures provided in this section, which enabled the reader to replicate the study if desired (Stahl & King, 2020). Dependability was further enhanced by using an interview guide that could be used by other researchers

wishing to conduct studies using similar research designs, which contributed to the greater replicability of the data collection procedures (Vindrola-Padros et al., 2020).

Confirmability refers to the extent to which findings may arise from the opinions and perceptions of the study participants, rather than from researcher bias, making it analogous to quantitative objectivity (Denzin et al., 2023). In this study, confirmability was enhanced by using member-checking where the participants reviewed and verified the intended meaning of their responses after the interview, before the data analysis (Vindrola-Padros et al., 2020). Confirmability was enhanced when the results were reported in Section 3 of this study, through the inclusion of direct quotes from the data as evidence for all findings, so the reader could compare the researcher's interpretations of the data to samples of the data on which they were based and verify confirmability independently (Stahl & King, 2020).

Ethical Procedures

Ethical considerations are paramount in any research endeavor. According to Parasidis et al. (2019), the Belmont Report provides robust safeguards for human participants in both behavioral and biomedical research endeavors. Many in the research community, including Jefferson et al. (2021), refer to the Belmont Report's principles to ensure the ethical integrity of their work. This report emphasizes the core values of respect, justice, and beneficence throughout the research process, including project design, sampling methods, and when addressing theoretical frameworks, practical or patient-related issues, and clinical queries. Efforts were made promptly to handle ethical concerns, ensuring participants' safety while upholding their dignity. As outlined in the

Belmont Report, there was strict adherence to the principles of respect, justice, and beneficence during all stages of the research. Before the project started, participants were briefed on aspects such as confidentiality, the assurance of anonymity, non-coercion, privacy considerations, and potential conflicts of interest. Additionally, ethical concerns about the institution, the target sample population, and the methodology of data collection were managed with informed consent, transparent communication, and due respect for privacy rights.

An informed consent form was provided to prospective participants during the preliminary phone call as a Microsoft Word attachment. Prospective participants were invited to review the informed consent form. The terms were discussed with them. Participants could ask questions and express concerns, and these were addressed to their satisfaction. The prospective participant was invited to sign and return the form to the researcher (e.g., by printing it, signing it, photographing it with their phone, and emailing the picture).

During the informed consent process, the prospective participant was informed that participation is completely voluntary, and there were no consequences for declining to participate. Those who do participate could withdraw at any time or could decline to answer any interview question. No direct benefits were received by participants for their service. Minimal risk was involved, meaning risks to participants did not exceed those associated with their everyday activities.

The identity of participants was kept confidential using codenames (P1, P2, etc.) assigned to each participant to be used in all study materials in place of their real names.

Personally identifiable information and interviews were stored on an encrypted, password-protected flash drive accessible only to the researcher. The participants' codenames are associated with personally identifiable information only in the filenames of the audio recordings on that flash drive, which are in the form of P1_interview, etc. After five years the flash drive will be physically destroyed.

Summary

The purpose of this generic qualitative study was to explore the experience of Hispanic family caregivers providing care to dementia patients during the COVID-19 emergency. This study used a generic qualitative design. After IRB approval, a purposeful sample of 12 participants were recruited through digital flyers posted on public Facebook forums serving the target population. After data saturation was achieved, the final sample size was determined. Data collection was achieved using semistructured interviews conducted via Zoom after a signed informed consent was received. Participation was completely voluntary, and the identities of the participants were kept confidential. An interview guide developed by the researcher guided the semistructured interviews. Interviews were audio-recorded and lasted approximately one hour, after which the participants responded to the open-ended questionnaire and the observation notes were prepared. Data analysis is inductive and thematic and conducted in NVivo 14 software. The results of the thematic analysis are reported in Section 3, consisting of themes emergent from interviewing the Hispanic family caregivers.

Section 3: Presentation of the Findings

Introduction

The purpose of this generic qualitative study was to explore the experience of Hispanic family caregivers providing care to dementia patients during the COVID-19 emergency. The following research question guided this study: How do Hispanic family caregivers describe their experiences providing care to dementia patients during the COVID-19 emergency? This section is a presentation of the study findings that emerged from conducting the data collection and data analysis procedures described in Section 2. The following section is a description of the data analysis technique that was applied to the interview data. This section then includes a presentation of the findings, which are organized by theme. A summary of the findings concludes this section.

Data Analysis

The transcripts from the 12 interviews were imported into NVivo 14 CAQDAS. The inductive thematic analysis procedure recommended by Braun and Clarke (2022) was applied to the data. The procedure has six steps. The following subsections indicate how each step applied to the data.

Step 1: Gaining Familiarity With the Data

To gain familiarity, data were read and reread in full. The purpose of this step was to gain a holistic understanding of the data that could be used to identify patterns of meaning that would serve as the basis for code generation in the following step of the analysis (Braun & Clarke, 2022). Handwritten notes were made regarding repeated words, phrases, and ideas in the data.

Step 2: Initial Coding

The interview data were broken down into text segments that each consisted of a phrase or group of phrases that expressed a single idea relevant to addressing the research question in this study. P10 provided an example of a relevant text segment in the following response excerpt: “I called on other family members when I needed that ultimate break, where I couldn’t be present.” A total of 77 relevant text segments were identified across the 12 transcripts. The text segments were then assigned to initial codes by labeling each of them with a descriptive phrase that summarized its meaning. For example, the text segment just quoted from P10 was assigned to an initial code labeled *asking for support*. When different text segments had similar meanings, they were assigned to the same initial code. For example, P8 said, “Just try your best to speak with other family members and try to take turns even though it [caregiving] is a high demand.” This text segment also expressed the idea of asking for support, so it was assigned to the same initial code as the text segment from P10. The 77 relevant text segments were grouped into a total of 17 initial codes. Table 1 indicates the initial codes and the number of text segments assigned to each of them.

Table 1*Data Analysis Initial Codes*

Initial code (alphabetized)	Text segments assigned (<i>n</i>)
Asking for support	5
Balancing self-care and caregiving	2
Careful time management	3
Caring for family is a cultural practice	9
Collaboration and communication	5
Elder behaviors	5
Elder's decline developed caregiver strength	4
Insufficient resources	2
Lack of education on dementia	3
Lack of social support	4
Learning to be more patient	6
Music and food	5
Obligation to care for elders	4
Relying on religious faith	2
Resistance to care	4
Self-care	9
Struggling to balance self-care and caregiving	5

Step 3: Searching for Themes

Themes were developed by clustering related initial codes into a smaller number of broader categories that represented the overarching patterns of meaning in the data and the major findings in the study (Braun & Clarke, 2022). Table 2 indicates how the related codes were clustered to form the themes.

Table 2*Clustering of Related Initial Codes to Form Themes*

Theme and initial codes grouped to form theme	Text segments assigned (<i>n</i>)
Theme 1: Caregiving strategies	20
Careful time management	
Collaboration and communication	
Elder's decline developed caregiver strength	
Learning to be more patient	
Relying on religious faith	
Theme 2: Caregiver self-care experiences	21
Asking for support	
Balancing self-care and caregiving	
Self-care	
Struggling to balance self-care and caregiving	
Theme 3: Caregiver cultural practices	14
Caring for family is a cultural practice	
Music and food	
Theme 4: Caregiver challenges	22
Elder behaviors	
Insufficient resources	
Lack of education on dementia	
Lack of social support	
Obligation to care for elders	
Resistance to care	

Step 4: Reviewing the Themes

The themes were compared to the data in the transcripts to ensure they accurately reflected patterns of meaning in the participants' original responses (Braun & Clarke, 2022). The themes were then compared to one another to ensure they were distinct and did not overlap or express redundant ideas. Lastly, each theme was reviewed individually to ensure it expressed a single, cohesive idea rather than a composite idea that would be more appropriately represented by two or more smaller themes.

Step 5: Naming the Themes

The data assigned to each theme were reviewed concerning the research question to assess its meaning as an answer to the research question. Each theme was then named to indicate the meaning of the data assigned to it as an answer addressing the research question that was used to guide this study.

Findings

The specific research questions used to guide this study were:

RQ1: How do Hispanic family caregivers describe their experiences providing care to dementia patients during the COVID-19 pandemic?

RQ2: How do Hispanic family caregivers describe any barriers or challenges they faced due to the restrictions of the COVID-19 pandemic at the family, culture, and societal levels?

RQ3: What coping strategies did Hispanic family caregivers employ to overcome challenges and restrictions due to the COVID-19 pandemic at the family, culture, and societal levels?

Four themes emerged during data analysis to indicate how the participants described their relevant experiences. Caregiving strategies relate to both how caregivers described their experiences during the pandemic (Theme 1, RQ1) and the strategies they use to cope with challenges (RQ3). Caregiver self-care experiences focus on the strategies employed to manage their well-being, addressing RQ3 (Theme 2). Caregiver cultural practices connect to the caregiving experiences shaped by cultural factors (Theme 3, RQ1) and the barriers encountered at family, cultural, and societal levels

(RQ2). Lastly, caregiver challenges directly address the barriers and challenges faced due to the pandemic's restrictions, aligning with RQ2 (Theme 4).

Theme 1: Caregiving Strategies

The 12 participants described their experiences providing care to dementia patients during the COVID-19 emergency as involving five caregiving strategies: (a) careful time management, (b) collaboration and communication, (c) elder's decline developed caregiver strength, (d) learning to be more patient, and (e) relying on religious faith. Three participants cited careful time management as a caregiving strategy they employed. P10 described time management practices in the following response:

I also have this responsibility of making sure that my loved one is taken care of, and it's difficult to navigate it because I'm not used to having all these schedules and all these doctors' appointments and medication that needs to be taken at certain hours, unless somebody's severely sick. So, it's difficult. It's very, very hard to remember some of those things, I think, in the beginning. That's what it was. I was forgetting some things. And I just bought a planner, and I carry that planner everywhere.

P10 reported buying a planner that they used to keep track of their caregiving schedule, including doctors' appointments and a medication regimen for their elder. P5 also described careful time management as important:

The most I was able to do is just watch how I timed everything. You know, I had to be really careful how I navigated my timing for everything, with work and taking care of her. It was difficult, because a lot of times, I had to do things late at

night, always late. It was hard, but I did it. I navigated. I did what I had to do, taking her to doctors and everything. I had to be really careful with that, and then I had to rush her.

By watching how they timed everything, P5 was able to ensure they conducted adequate caregiving while also discharging other obligations, such as work. Part of P5's time management practices involved fulfilling caregiving duties at night after work obligations were completed.

Five participants described collaboration and communication as a caregiving strategy they use. P12 reported collaborating with the community and with family to care for their elder:

I was blessed to have help from the community, which we were able to apply for resources within the community to get my grandfather connected to an apartment for the elderly and the disabled. So, with that resource, he was able to maintain his independence, but also it was so close to us that we didn't really need him to live in the household. So, he had his own little one-bedroom where we're able to just supply the needs and have his comfort there. And then we had the family all take turns regarding his healthcare. So, family and definitely community support, resources from the community.

With support from a community resource, P12 was able to install her father in a one-bedroom apartment for elderly and disabled people. The remaining caregiving duties were apportioned among family members so that the burden did not fall too heavily on

any one person. P6 described communication and collaboration as a caregiving strategy that emerged from a family-oriented Hispanic culture:

If one person is just solely responsible for the person with dementia, it's not gonna work. So being with the Hispanics is a little more family oriented. You know, I gotta go grocery shopping now. I got to go pick up this stuff. I gotta go repair the car, or something like that. And a family member will come and take my spot and watch my father at that time, because at some point, I have to take care of these errands, and if I don't take care of them, no one else is able to do so. That's why I said it's more of a culture-based thing, where family is more like multiple people involved with taking care of someone who's sick.

P6 indicated that when she needed to run errands, she could find a family member who would take responsibility for her elder. P6 perceived this family collaboration as a feature and a strength of Hispanic culture. P2 corroborated P6's perception of family collaboration as a strength of Hispanic culture:

Caring for an elderly person in our family as Hispanics, it's sort of like a group effort. You know, everybody is given a task. The scary part about it is you're dealing with multiple people that all have to be on the same page. You know what you're doing; I know what I'm doing when I go there. I know that I'm taking every precaution possible to make sure that I'm not sick, I'm not feeling some kind of way, and I'm protecting my family member. And that's something that is always discussed in rotation with people who are going to be visiting and helping out with the care of our elderly.

P2 added that part of caregiving during COVID-19 involved “making sure I’m not sick,” and making sure that other family members who would be caring for the elder were not infected.

Four participants indicated that as their elders’ capacities declined, they became stronger by increasingly supplementing their elders’ self-care and compensating for their elders’ deficits. P3, for example, said:

I think that’s what’s impactful, like to see her decline, to see her loss of everything. And then my loss because you lose them twice, right? You lose them mentally and then physically... It has to make me stronger.

P3 reported that observing her elder’s decline made her stronger because as her elder declined, the caregiving she provided had to increase. P7 agreed, saying,

I feel like what he went through, you shouldn’t take life for granted. I think you should live at that moment. And it made me feel closer to the family. He made me strong ... I felt like he made me stronger.

Instead of feeling weakened and exhausted by caring for her elder during his decline, P7 felt strengthened and rejuvenated by a renewed sense of the value of life and family.

Six participants reported that a caregiving strategy they used was learning to be more patient. P11 said that she had to be patient with her elder’s verbal abuse:

He just became very rude as he got older. It’s one thing to just go off on someone when you’re mad, but he would say very hurtful things, you know, that it’s like you know you can’t take that back now. It’s embedded in there already. It’s one

of those things where I have to remind myself, well, he was sick. Maybe he was just saying something, and he doesn't really know who he's talking to.

P11 facilitated her patience by telling herself that her elder had dementia ("he was sick") and did not know who he was insulting. P6's patience was facilitated by her elder's occasional moments of clarity:

There's moments where he would come up to me and he would cry. And if you were present to see what he would say, it was like he was back, his brain was functioning 100%, and it was like he was watching himself the entire time, act the way he did. And he came to me and says, "I see what I'm doing, and I'm sad because I can't stop. I don't want no one to be sad." And then it was like moments later he would revert right back. So it was almost like he came back just for that moment, just to let me know that, like, "I'm seeing what I'm doing. I see that you're trying. I just need you to know, I can't stop it, no matter how hard I'm trying, I can't stop it."

Those moments of human connection with her elder during his lucid moments helped P6 to be more patient with his behavior when he was not lucid because she felt that his negative behaviors were against his will and that he was a fellow victim of his behaviors rather than a willing perpetrator. P8 also described patience as a necessary caregiving strategy, saying, "I guess the best way to explain my point of view [about caregiving] is, it's a little bit of patience, and a little bit of understanding." For P8, then, patience was facilitated by empathy, which she referred to as "understanding." P2 also achieved patience through empathy and understanding: "I definitely learned how to be more

patient, more understanding with people who have dementia, because it's truly not their fault." By conceiving of dementia as "not their fault," P8 became a more patient, empathetic caregiver.

Two participants reported that relying on their religious faith was one of their caregiving strategies. P12 associated Hispanic culture with the Catholic faith:

In our culture, Puerto Ricans are predominantly [from a] Catholic background.

So, during that time of COVID—which was challenging for all of us, seeing the challenge of fear and the unknown—my grandfather's prayers was a big part of our help and our support during COVID.

P12 described her grandfather's prayers as a source of emotional support during the COVID-19 pandemic. P4 described her prayers as instrumental: "My prayer has helped me so much to just sit back and just say it's going to be okay and take it one day at a time. And I think that's how I coped." Through her practice of prayer, P4 believed that she gained acceptance, resignation, and an ability to navigate adversity by having faith that it would soon be resolved.

Theme 2: Caregiver Self-Care Experiences

The 12 participants described their experiences providing care to dementia patients during the COVID-19 emergency as involving four self-care experiences, as follows: (a) asking for support, (b) balancing self-care and caregiving, (c) timeouts, or breaks for low-stimulus activity, and (d) struggling to balance self-care and caregiving. Five participants reported that asking for support in taking care of their elders was a way

that they also took care of themselves. P10 called the hours when family members took over caring for the elder with dementia respites:

I called on other family members when I needed that ultimate break, where I couldn't be present. I called on other family members, you know, my siblings, cousins. Just other family members that offered, even if it was an hour, right, just offered some respite for that time period.

Asking for support from siblings and cousins enabled P10 to take care of herself. P8 also reported that she asked for support when she needed a break:

Try to see if someone could fill in for you for a little bit, taking the day, relax, detach from the technology and media and all that and just try your best to not overwhelm yourself. Just kind of pull away mentally for a little bit. Just let everything go. Try to see if anybody's willing to cover for you for a little bit.

By getting someone else to "fill in," P8 was able to "pull away mentally" to avoid becoming overwhelmed by caregiving responsibilities.

Two participants reported that they engaged in balancing self-care with caregiving. P5 reported that she balanced self-care with caring for her elder through time management: "I balanced it [self-care and elder care] really well ... I managed pretty well. As far as balancing everything for my own personal doctors and stuff, you know? Yeah, I had to just work with my schedule." P5 indicated that she managed her time to balance self-care with caregiving by keeping a rigorous schedule. P2 also spoke about the need not just to perform self-care, but to balance self-care with elder-care obligations:

I was definitely diligent about making sure that I took that time for myself and also took the time for my family and making sure that we were all on the same page and how we care for one another and especially our elderly.

P2 indicated that her balancing of self-care, family care, and elder care involved diligence to ensure that all obligations were balanced and met.

Nine participants reported that their experiences of caring for their elder with dementia involved timeouts or breaks for low-stimulus activity. P1 referred to experiences of taking time away from the elder: “I think that’s what helps me, is maybe distance, sometimes, like taking time for me, either before I was going to the gym, then how much I think more involved in my music. Maybe watching the show.” P1 described taking time away from the elder to exercise at the gym, listen to music, or watch shows as helping her to cope. P10 reported going out for quiet walks:

Time to just be calm, right? And because it can be so chaotic, yoga helped me a lot because I felt like I was not able to manage a lot of what was happening at the time. But going for walks, it was quiet outside. There wasn’t anybody outside. So, I would put on my mask and just go for a walk.

P10 described her alone time as “time to just be calm” when caregiving became too “chaotic.” When caregiving became overwhelming, going for a solitary walk was a low-stimulus activity that helped P10 restore her calm and regain her ability to cope. P4 also reported occasionally feeling the need to take a break from caregiving:

I sometimes feel also that I need to take a break. So, you know, I talk to my husband, mother, go somewhere, and there’s something like, I need to step out. I

need to also take a break, step away for a moment. So, that also has been helping me lately.

Talking to her husband or her mother or simply stepping out provided P4 with the timeout for low-stimulus activity that she needed to maintain her resilience as a caregiver.

P7 discussed taking a timeout when her elder failed to recognize her:

The time when he looked at me and he didn't know who I was. You know, I was staying strong, but then I had to get up, go to a room, and cry, because I didn't know what to say or what to do at that moment when he was feeling that way, that he didn't know who I was. So, it was hard seeing him that way, so I had to just leave and go to the room and just have time for myself and just let it go. I had to cry.

When P7 felt emotionally overwhelmed by her elder's failure to recognize her, she went to a different room to cry, reset, and regain her composure. P2 also described taking timeouts for low-stimulus activity: "I had to take time, go outside, smoke a cigar, take a walk, get some air, take a hot shower. I mean, it was little things like that to just keep myself sane in some way." P2 described the timeouts as necessary to "keep sane," indicating that they had a high level of perceived importance in facilitating caregiver coping.

Five participants reported that they struggled to maintain a balance between their caregiving responsibilities and their self-care at least some of the time. P11 indicated that she struggled most during the COVID-19 pandemic when she was working from home,

caring for her mother at home, and schooling her children at home, and there was no way to maintain a separation between those different activities:

There was no separation between work and home and school. It all just became one, all at the same time. I'm in the middle of talking to a client. And then she [my mother] would get mad because I'm on the phone and I'm like, I'm working. You know, or the kids were just randomly talking sometimes. That was frustrating, you know.

P11 reported her frustration at feeling unable to maintain clear boundaries in space or time between her home, work, and school spheres of obligation when she was also caring for her mother. P12 reported a similar experience, saying:

Self-care was really out the door. I think my self-care may have looked like drinking water and eating and sleeping, if possible, but it was very challenging. It was very challenging. Maybe a movie with my children and husband. But yeah, majority of the time was balancing the two lives of being the caretaker of my grandfather and the caretaker of my intimate family, which is my children and my husband.

P12 described her caretaking of her grandfather and her caretaking of her immediate family as "two lives" which she needed to balance. Balancing those two lives left her little time for self-care, to the extent that her self-care was often limited to eating, sleeping, and other necessary functions. P6 also described the sense of feeling that she rarely had adequate time for self-care:

If I wasn't at work, I was taking care of what he [my elder] needed. So it was like now and then, I would have a breathing room there, here and there. But for the most part, that breathing room wouldn't last long because I would still be needed. P6 had little time for self-care because of "being needed," she said, either at work or to take care of her elder. P6 rarely had "breathing room" for self-care, and when she did, those gaps in her work and caretaking schedule were often too brief to refresh her completely.

Theme 3: Caregiver Cultural Practices

The 12 participants described their experiences providing care to dementia patients during the COVID-19 emergency as involving two cultural practices, as follows: (a) caring for the family as a cultural practice, and (b) music and food. Nine participants described caring for the family as, itself, a Hispanic cultural practice. P10 described caring for family elders as a cultural practice by saying, "I would say that my cultural background influences the fact that, growing up in a household where you have grandparents and parents all together, right, you learn to take care of each other." P10 suggested that caring for family elders was a cultural practice that emerged from the tradition of housing multiple generations under the same roof. P12 spoke of Puerto Rican culture as involving "family unity":

We had to maintain some of the cultural unification, as far as just family constantly supporting in the Puerto Rican culture. We believe in a lot of just not really outside medical care, like home health aides, but really us helping each other out, so we just took turns as family to provide the care that my grandfather

had needed, me predominantly being the caretaker. But that family unity that comes with our culture remains in place for him.

P12 described Puerto Rican culture as preferring for family to care for their elders, rather than involving hired health aides to provide care. P6 associated the importance of caring for elders with the unifying role the elders played in the family:

Our culture is more of a family-oriented type of culture. So if, for example, the children get older, they tend to take care of their parents, it's not like just, oh, get up and leave and then forget your parents. We don't actually live like that. Like usually as the parents age, they become the grandparents. They literally are the ones that keep the family together.

P6 described elders as keeping the family together, and she associated younger family members' care for elders with this unifying function. P8 described the family closeness that she regarded as characteristic of Hispanic culture as making elder care easier:

Family always stick with each other, no matter what. With that background, it kind of made things easier. Even when somebody is not themselves anymore, because of our background, we're always together. Family gatherings, always doing Christmas stuff, and it's just a whole bond the family has formed. It definitely made it kind of easy to care for another person, even though they were going through something like dementia. But I think the cultural aspect did make it easier, since we were always close.

P8 indicated that because families were close in Hispanic culture, caring for an elder was easier than it might otherwise be because intimacy and unity were already present. P2

described younger members of Hispanic families as being “groomed” to care for their elders:

It’s in our culture to help our families, even without it being a pandemic going on at the moment. You know, we’ve always taken care of the elderly in our families, our grandmothers, our grandfathers, even some great-grandmothers and great-grandfathers. So, growing up, we’ve all been kind of groomed, in a way, to just take care of our grandparents. You know, it’s just something in us.

The participants perceived caring for elders as a Hispanic cultural practice with which younger family members were reared. Caring for elders was also easier to do when multiple generations all lived under one roof, and when younger family members felt close to elders before the onset of dementia.

Five participants reported that their cultural caregiving practices involved food and music. P11 said of bonding with her elder over music:

I don’t know if this is basic or stereotypical, but just listening to music. You know, especially like stuff that was big in the 80s and 90s, you know, like Cruz, Marc Anthony’s still good. But like in the 90s, he was hot. And it was just one of those things where the music was the, I guess, common factor where we could be like, oh, that song is good, and then we would go into conversation about musicians. But it’s good music, and we’re like years apart, obviously, but we could still enjoy it.

Although P11 and the elder for whom she cared were years apart in age, they had a similar nostalgia about the music of the 1980s and 1990s, and they were able to share that

music as a way of maintaining an emotional connection and a shared frame of reference.

P8 discussed family gatherings with their characteristic foods and music as another means of maintaining social bonds, even during the COVID-19 lockdowns:

The Hispanics, we were supposed to social distance and all that. You know, we still managed to have little parties, and have our little flavors of foods, the [inaudible], the coquitos and all that, and with just the music, the salsa, merengue. Even though a lot of things were locked down, the culture still thrived.

P8's "little parties" with family helped to maintain a family cohesion that contributed to collaborative caretaking of the elder with dementia and also helped to relieve stress. P9 said, "I would say music. Music definitely helps out a lot, especially in different stress levels," describing music as a cultural practice for relieving stress.

Theme 4: Caregiver Challenges

The 12 participants described their experiences providing care to dementia patients during the COVID-19 emergency as involving six caregiving challenges, as follows: (a) elder behaviors, (b) insufficient resources, (c) lack of education on dementia, (d) lack of social supports, (e) obligation to care for elders, and (f) resistance to care. Five participants reported that elder behaviors were sometimes a caregiving challenge. P11 said of an elder behavior that had embarrassed her,

He got hospitalized a couple of times before the last time he got COVID. And I realize that people can be rude at any age, you know, in the hospital, to the nurses. But in particular, older Hispanic men are cursing in Spanish. It is just so hurtful.

And he would curse at the nurses. And I had to go out and, you know, apologize to them.

P11 was so embarrassed by her elder's behavior of verbally abusing the nurses in the hospital that she would buy coffee and donuts for them as a way of apologizing. P9 reported caring for an elder who would not stop drinking:

One of the hardest times is, there was a person that I take [of] care at the time [who] used to drink a lot, and it was really hard, especially telling the person, hey, you're not supposed to drink, especially at this age, and it could be really challenging. At the time, I tell the person to stop drinking, stop drinking, it's going to get worse. You're going to end up in a real medical emergency. The person didn't even care and kept going with the drinking. And it's been stressful to the point where moments later, he actually fell, passed out, and that's where I had to take an immediate response and call 911.

When elders with dementia were not cooperative, and when they engaged in behaviors that could harm themselves or others, participants found it challenging to provide adequate care.

Two participants reported that they struggled with the challenge of having insufficient resources to care for their elders. P3 said of her elder:

She doesn't get Medicaid or Medicare. So she doesn't get it. So now it comes to like, they're going to take all of her resources, all of it is going to be taken, like even we try to put her in adult daycare, and paying out of pocket, they're like, no, we want everything. We want your bank information, we want anything. So the

moment you don't pay, she just doesn't go. I think that is a struggle, but she's like, oh, they can take all my money.

P3's elder did not have Medicare and keeping her in adult daycare without state assistance was exhausting the family's resources. P4 said:

Right now, I have a big struggle, and the struggle is that Medicare doesn't cover for someone to come and help. I have to go through Medicaid, and Medicaid is a big problem, because if you are not qualified, you're just not qualified. And I can't, like, afford, really, to pay someone from my pocket, to pay someone to come and take care of him, because that is a struggle. So, I would love for there to be more resources.

P4 spoke of her own and her father's embarrassment when she had to perform intimate tasks such as helping him shower, but she could not afford to have a professional come into their home and care for him without state assistance.

Three participants described their lack of education on dementia as a challenge that made caregiving more difficult. P10 described the confusion and distress of being with an elder who was having a tantrum in public when P10 did not know what was wrong:

I wasn't really informed about what was happening. I did not know that my family member was having these symptoms, and I was also struggling with him. Embarrassment, right, my family member's screaming in the aisle. I don't know what to do and I'm trying to calm them down and they're just screaming and crying, and the only person that they recognized was me. So it was really hard.

And I didn't know why they were confused. I didn't know where this was coming from.

Understanding the nature of dementia helped participants to empathize with their elders and provide better care, as discussed under Theme 2. The corollary of that finding was that not understanding the nature of dementia, and without being informed that dementia was the cause of their elder's negative behaviors, the behaviors could be far more distressing to the caregiver. P4 discussed the challenge of trying to explain dementia to other family members who were uninformed about the condition:

I think that what has affected me in the culture is trying to explain, it's my dad with dementia, trying to explain to his spouse, my mom, what it is, what are the expectations, and still not be able to really explain to her or to any other loved one what we are facing in reference of this disease, because, again, we're not educated with this. We're not. We don't know where to find this information.

P4 perceived a lack of awareness about dementia as a cultural factor that made coordinating care across Hispanic families more challenging. P4's response suggested a need for culturally sensitive information sources to assist Hispanic families in understanding and adapting to the needs of elders with dementia.

Four participants described a lack of adequate social supports as a challenge that made caregiving for an elder with dementia more difficult. P1, for example, said, "We're not as supportive, understanding, or we don't work well, in my family. We don't work well to help each other out." P3 contrasted the lack of family support she experienced with the cultural expectations for Hispanic families:

Whereas a Hispanic, you would think you have family and people come together and you come up with it together and help each other. And I don't have that at all. I have two aunts that live right down the street, and they haven't been a part of anything. And they're her sisters. And they're able-bodied. They drive. But like they'll pick her up once a month.

Thus, while most participants indicated that their families were valuable sources of help in caring for their elders and in allowing primary caregivers to take time for self-care, some participants provided discrepant data indicating that their families were not helpful.

Four participants described the cultural expectation that family care for family as a challenge because it made them feel obligated to provide care that they were not always prepared or qualified to give. P10 said:

I think one of the challenges is just having or feeling obligated to make sure that I am the one who is present. I am the one who is caring for my mother. Other cultures that I've seen, or read, or heard [about], you know, they are not quick to do it. They often put family members in homes or have nurses and stuff like that. And while I understand the need for it sometimes, I feel that for me and for my family, it's best that I be the one involved.

P10 expressed her ambivalence in feeling that the obligation to care for an elder with dementia was burdensome, while at the same time having internalized that expectation sufficiently that she believed she ought to be the one providing care. P6 also appeared to express ambivalence:

Caucasians, they just throw their parents to a home immediately, like they just don't want to be bothered with it. Whereas Hispanics, we tend to be a little more like taking turns and try to care for the parent, because let's be real, nobody can just do that for 24 hours, 7 days a week, especially with this economy, it's impossible. So, we tend to be a little more forward with taking care of our own, because the fact is, we don't trust anyone else taking care of them the way we take care of them.

P6 indicated that the burden of caring for an elder with dementia was too much for any one person to handle alone ("let's be real, nobody can just do that"), but she also expressed distrust of nursing homes. The obligation to care for an elder with dementia was difficult to avoid, then, even for participants such as P1 and P3, who lacked family support.

Summary

Four themes emerged during data analysis to address the research questions. The first theme was: caregiving strategies. The 12 participants described their experiences providing care to dementia patients during the COVID-19 emergency as involving five caregiving strategies, as follows: (a) careful time management, (b) collaboration and communication, (c) elder's decline developed caregiver strength, (d) learning to be more patient, and (e) relying on religious faith. The second theme was: caregiver self-care experiences. The 12 participants described four self-care experiences, including: (a) asking for support, (b) balancing self-care and caregiving, (c) timeouts, or breaks for low-stimulus activity, and (d) struggling to balance self-care and caregiving. The third theme

was: caregiver cultural practices. The 12 participants described two cultural practices, as follows: (a) caring for family as a cultural practice, and (b) music and food. The fourth theme was: caregiver challenges. The participants reported six challenges: (a) elder behaviors, (b) insufficient resources, (c) lack of education on dementia, (d) lack of social supports, (e) obligation to care for elders, and (f) resistance to care. Section 4 includes discussion, interpretations, and recommendations based on these findings.

Section 4: Application to Professional Practice and Implications for Social Change

Introduction

The problem explored in this study was the restrictions resulting from COVID-19 and how they changed the caregiving experience among caregivers of Hispanic descent. The associated challenges of coping mechanisms and support needs are of interest to the field of social work (Angel et al., 2022). The purpose of this generic qualitative study was to explore the experiences of Hispanic family caregivers providing care to dementia patients during the COVID-19 emergency. This study provides vital information on the challenges and support Hispanic caregivers experienced during the COVID-19 pandemic.

A qualitative generic research design was used in this study. Data were collected using semistructured interviews and analyzed using the thematic data analysis method. Section 4 presents a summary of key findings and how they inform social work practice. Further, the section presents the application of these findings to professional ethics and social work practice, recommendations for social work practice, and implications for social change. The section concludes with a summary of the study.

Summary of Key Findings and Contribution to Knowledge

Thematic analysis revealed the strategies the Hispanic caregivers used to provide care to dementia patients during the COVID-19 emergency. One of the strategies was careful time management as participants reported the need to have a planner to keep track of the caregiving schedule, including doctors' appointments and a medication regimen for their elder to ensure effective care. This finding contributes to the field of social work by demonstrating the importance of effective time management among caregivers. The

finding aligns with crisis theory, which considers how individuals respond during emergencies or crises. Crisis theory primarily states that, while emergencies present serious challenges to individuals, they also create times of both growth and change through effective management of schedules (Caplan, 1989). In this regard, time management is an important factor in improving caregiving among social workers.

Effective collaboration and communication with the community and family was another important strategy Hispanic caregivers used to provide care to dementia patients during the COVID-19 emergency. The support from community resources and family members made it easy for caregivers to provide quality care during the pandemic. Providing access to respite care, support groups, counseling services, and educational resources offers caregivers the support needed to navigate their caregiving journey (Aledoh & Adam, 2020). The study's findings contribute to the body of knowledge in the social work field by highlighting the need for effective communication, collaboration, and support from community resources and family members.

The results also demonstrated that Hispanic caregivers learned to be more patient with challenges related to caring for elderly patients with dementia including patients' verbal abuse. Based on the data analyzed, participants reported relying more on religious faith such as depending on prayers as a source of emotional support during the COVID-19 pandemic to help them cope with related challenges. Emotional support, such as understanding, empathy, and validation from family, friends, and support groups, can help caregivers navigate the challenges and emotional toll of caregiving (Cartwright et al., 2022). As a result, despite the challenges experienced when providing care to

dementia patients, Hispanic caregivers have adequate patience and depend on spiritual support as coping strategies.

Self-care practices were used in providing care to dementia patients during the COVID-19 emergency. The results of this study showed that Hispanic caregivers requested support during their caregiving duties, helping them balance between self-care and caregiving roles. Breaks for low-stimulus activity were employed by the participants when providing care to dementia patients during the COVID-19 emergency. In addition, the findings provided significant insights into the cultural practices experienced by Hispanic caregiving while providing care to dementia patients during the COVID-19 emergency. Similarly, Balbim et al. (2019) noted that Hispanic caregivers rely on culturally informed coping strategies such as seeking support from extended family, drawing on religious or spiritual beliefs, or using traditional healing practices.

As indicated in the data analysis, two cultural practices including caring for family, and music and food were experienced among Hispanic caregivers. Despite the strategies and cultural practices that enhanced caregiving among Hispanic caregivers, participants reported various challenges related to providing caregiving services to dementia patients. Participants cited patients' behaviors such as verbal abuse and resistance to care as the challenges faced during care provision. Insufficient resources and the lack of education on dementia and social support were reported as the main challenges during caregiving. When caregivers lack skills, resources, and support, it is challenging to offer quality services coupled with the burden of obligation to care for elders regardless of their resistance to care.

Application to Professional Ethics in Social Work Practice

The current study findings may promote professional ethics in social work practice by encouraging effective time management among social workers such as the Hispanic caregiver. Time management may be enhanced by keeping track of the caregiving schedule, doctor appointments, and patients' medication regimens. Such positive engagement in time management and relationships with doctors may help address barriers encountered by Hispanic caregivers in accessing appropriate support services and tailor interventions that consider Hispanic caregivers improved social support outcomes (Ibanez et al., 2021).

The current study offers guidance for social workers on career values and ethical considerations by indicating that self-care practices help provide care to dementia patients, including breaks for low-stimulus activity and balancing self-care and caregiving. Social workers may understand the importance of cultural competence and cultural humility as the current study has demonstrated that Hispanic caregivers retained their cultural practices including food and music to help cope with challenges faced while providing care to dementia patients during the COVID-19 emergency. The study highlights the social workers' mission of continued learning and maintaining integrity in their jobs (Barsky, 2021). Using the strategies demonstrated in the current study, social workers can cultivate proficiency in assisting diverse populations and ethnic groups.

The study's findings impact social work practice by providing insight into the need for effective collaboration and communication among social workers and the community. This creates positive relationships between social workers and the patients

including their families leading to improved access to community resources. The symbiotic relationship promotes positive caregiving outcomes for both the elderly and the Hispanic caregivers or any other healthcare professional in the field of social work (Bruno et al., 2022). Collaboration promotes social support which remains accessible and beneficial for Hispanic caregivers, promoting their well-being and resilience throughout the caregiving journey.

Recommendations for Social Work Practice

This section presents recommendations for practice and policy and recommendations for future research. In addition, limitations are also discussed. The first recommendation is for healthcare leaders to implement training and skills development programs and provide enough resources for quality caregiving. Social workers need knowledge and skills in diverse areas to develop cultural competency, a critical factor in caregiving duties. The lack of skills, resources, and support makes caregiving challenging, especially when elderly individuals with dementia are resistant to caregiving. Thus, offering appropriate and continuous development programs may help caregivers develop effective skills and knowledge in providing care to older patients with dementia. Healthcare policymakers should ensure effective guidelines to provide direction for social workers to engage in continuous learning for enhanced caregiving.

Local authorities can create community support programs to enhance communication and collaboration between social workers and community leaders. This will foster a positive relationship between social workers and the community, helping social workers provide effective and quality caregiving to the elderly (Van Assche et al.,

2019). By engaging multiple perspectives and expertise, social workers can develop more comprehensive and effective interventions.

By comprehending the importance of cultural values and practices, including the importance of family, music, and food among Hispanic caregivers, effective culturally sensitive programs can be integrated into social work practices like caring for dementia patients. Music therapy, as the current study found, evokes memories and emotions, providing therapeutic benefits for dementia patients. Similarly, the study highlighted the importance of family care, which advanced practitioners can leverage to provide patients with support and resources based on their family values.

Understanding the challenges to caregiving, such as verbal abuse and resistance to care among patients, plays a key role in developing educational caregiving programs that focus on the management of dementia patients. Since dementia patients are functionally dependent, caregivers require more resources to provide increased supervision and personal care. Furthermore, the current findings can be used to advocate for support network programs and offer training programs to help caregivers cope with the challenge of taking care of dementia patients.

The current findings can be transferred to other contexts. While these results apply to Hispanic caregivers, caregivers from other cultural backgrounds and contexts can also benefit from the culturally sensitive programs and interventions that enhance caregiving practices. Social workers may use these findings to develop and implement intervention programs and practices to address global challenges to caregiving, including

insufficient resources and resistance to change. Moreover, the findings may be applicable to support caregiving for patients with different chronic conditions.

Dissemination of the findings is an important process, which ensures that researchers share their findings with the target audience. The process increases awareness, builds trust, contributes to policy debates, and informs future research. The current study's findings will be disseminated by publishing in established journals and presenting at conferences. The results will be shared in academic journals, which involve peer reviews.

Limitations and Recommendations for Future Research

The current study was limited to patients with dementia during the COVID-19 pandemic who resided in the United States. This limitation impacted the transferability of the study to other populations or patients with different illnesses who may require the service of social workers. Additionally, the study was limited to the United States during the COVID-19 pandemic. Focusing on the COVID-19 pandemic with one location might have limited the transferability of the findings to post-COVID-19, in which social workers may report different experiences. Thus, based on these limitations, future research should be conducted in different geographical locations, post-COVID-19, and with elderly patients with different illnesses to enhance the transferability of the findings.

Implications for Social Change

This study has implications in the field of clinical social work. The findings may help researchers in various fields of social work, medicine, nursing, public health, and psychology design more effective interventions to improve patients' quality of life.

Effective communication and collaboration with the community is a suitable strategy Hispanic caregivers use to provide care to dementia patients during the COVID-19 emergency. Understanding the different forms of support on caregivers' experiences and outcomes may guide the development of effective support interventions (Yoon et al., 2022). Therefore, the current study has provided effective caregiving interventions, including proper communication and collaboration with the community, engaging in self-care practices, and maintaining resilience despite patients' negative behaviors. The current study has also provided insights into the social problem of providing care to dementia patients, contributing to improved quality of life both for individuals with dementia and their caregivers. Social workers are considered part of the broader social systems, including family dynamics, community resources, cultural factors, and societal structures that impact the individual's well-being (Yoon et al., 2022).

Specifically, the three research questions explored in this study present unique implications for social change. The first research question explored how Hispanic family caregivers described their experiences providing care to dementia patients during the COVID-19 pandemic. The participants described their accounts of caregiving experiences by explaining what strategies were used to approach their work, including careful time management, striving for a collaborative environment with adequate levels of communication, patience, and resilience obtained through means such as religious faith. The second research question explored the barriers and challenges associated with COVID-19 restrictions at the family, cultural, and societal levels. The participants generally indicated COVID-19 introduced a multitude of new challenges, including

challenges with scheduling appointments and accessing relevant medication, requiring more advanced organizational tools to meet patient and institutional demands. Patients relied on aforementioned strategies such as resilience and a sense of shared responsibilities to overcome their challenges, as per the responses to RQ3.

Summary

This study has provided significant insights into the challenges experienced by Hispanic caregivers and the strategies used to overcome these challenges during the COVID-19 pandemic. The findings can help inform and develop targeted interventions, policies, and support systems to address caregivers' specific needs effectively. Social workers need effective communication and collaboration with the community for social and emotional support, effective self-care practices, and training programs for dementia patients. This study's findings addressed the research problem and purpose by highlighting diverse strategies and interventions that can be implemented by Hispanic social workers and other healthcare professionals to enhance the quality of caregiving. Further research should consider replicating this study in the post-COVID-19 era with different locations. This study has offered significant insight into how Hispanic family caregivers can effectively provide care to dementia patients. The findings inform and support social workers like Hispanic caregivers and help develop targeted interventions to address their specific needs effectively to help dementia patients, especially during upheavals.

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Appendix: Interview Questions in English and Spanish

English

1. How has your cultural background influenced your approach to caregiving for your family members with dementia during the pandemic?
2. What specific challenges have you faced as a Hispanic family caregiver that may differ from other cultural or ethnic groups?
3. Can you share any cultural traditions or practices that have helped you cope with the stress and responsibilities of caregiving during COVID-19?
4. How do you navigate the intersection of caregiving responsibilities with other family obligations or expectations, especially within the Hispanic community?
5. What strategies or coping mechanisms have you found most effective in managing the emotional toll of caring for a loved one with dementia at home during these uncertain times?
6. How have you balanced your own needs for self-care and mental health with the demands of caregiving during the pandemic?
7. Have you encountered any unique challenges or situations as a Hispanic family caregiver that you didn't anticipate before taking on this role?
8. Can you share a particularly meaningful or impactful experience you've had as a Hispanic family caregiver for your family member with dementia, and how it has shaped your journey?

Spanish

1. ¿Cómo ha influenciado tu trasfondo cultural en tu enfoque al cuidar de un familiar con demencia durante la pandemia?
2. ¿Cuáles retos específicos has enfrentado como cuidador familiar hispano que pueden ser distintos de otros grupos culturales o étnicos?
3. ¿Puedes compartir alguna tradición o práctica cultural que te haya ayudado a sobrellevar el estrés y las responsabilidades del cuidado durante la COVID-19?
4. ¿Cómo manejas la intersección de las responsabilidades del cuidado con otras obligaciones o expectativas familiares, especialmente dentro de la comunidad hispana?
5. ¿Qué estrategias o mecanismos de afrontamiento has encontrado más efectivos para manejar la carga emocional de cuidar a un ser querido con demencia en casa durante estos tiempos inciertos?
6. ¿Cómo has logrado equilibrar tus propias necesidades de autocuidado y salud mental con las demandas del cuidado durante la pandemia?
7. ¿Has enfrentado desafíos o situaciones únicas como cuidador familiar hispano que no anticipaste antes de asumir este rol?
8. ¿Puedes compartir alguna experiencia particularmente significativa o impactante que hayas tenido como cuidador familiar hispano de un miembro de tu familia con demencia, y cómo ha moldeado tu trayectoria?