BEHAVIORAL HEALTH, MENTAL HEALTH, AND OVERALL WELL-BEING OF INFORMAL CAREGIVERS BEFORE AND AFTER THE COVID-19 PANDEMIC

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A dissertation submitted in partial fulfilment
of the requirements for the

Doctor of Philosophy - Public Health

Healthcare Administration and Policy
School of Public Health
The Graduate College

University of Nevada, Las Vegas
May 2024

UNLV | GRADUATE COLLEGE

Dissertation Approval

The Graduate College
The University of Nevada, Las Vegas

March 24, 2024

This dissertation prepared by

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entitled

Behavioral Health, Mental Health, and Overall Well-Being of Informal Caregivers Before and After the Covid-19 Pandemic

is approved in partial fulfillment of the requirements for the degree of

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Abstract

Informal caregivers, such as relatives or close friends, are vital for maintaining the welfare of the individuals they provide care for. However, caregiving can be difficult and stressful that adversely impacts caregivers' health. The extra stress brought on by the COVID-19 pandemic can potentially aggravate health problems, particularly mental health. The current research aimed to nationally analyze whether the COVID-19 pandemic was significantly associated with behavioral health (physical activity and smoking), mental health (worrying, nervousness, hopelessness, little interest, and psychological distress score), and the perception of overall well-being among informal caregivers in the United States. Whether behavioral health could mediate mental health and overall well-being was also investigated.

The Health Information and National Trends Survey (HINTS), spanning the pre-pandemic period (2017–2019) and the post-pandemic era (2020, 2022), was the data source. Weighted multivariable survey logistic regression models were employed for all outcomes. Predictors for mental health and overall well-being were behaviors, including smoking and physical activity. All models were additionally adjusted to account for sociodemographic factors.

Post-pandemic, caregivers exhibited significantly higher odds of reporting "worrying" (OR = 1.43, 95% CI: 1.10-1.87, p = 0.0081) and overall unwell-being (OR = 1.33, 95% CI: 1.05-1.69, p = 0.0159). Caregivers who had insufficient physical activity compared to their physically active counterparts had higher odds of perceiving their overall well-being as diminished (OR=2.16, 95% CI: 1.65-2.82, p<0.0001). Compared to non-smokers, current smokers also had

higher odds of perceiving their overall well-being as diminished (OR=1.80, 95% CI: 1.17-2.79, p=0.0077). Smoking and insufficient physical activity had significant association with all mental health issues studied here, except for insufficient physical activity for “nervous”.

This research revealed that informal caregivers experienced a decline in the mental health and overall well-being in the United States following the COVID-19 pandemic. Behavioral health, including smoking and insufficient physical activity, were significantly associated with mental health and overall well-being. This research provides updated insights for policymakers on the importance of addressing the mental health and overall well-being of informal caregivers during a crisis. Tailored interventions are required to address these health issues among informal caregivers. Targeted policies are also recommended, prioritizing the behavioral health of informal caregivers to enhance their mental health and overall well-being.

Acknowledgments

I would like to express my cordial appreciation to my dissertation chair committee, Dr. Jay Shen, for his consistent support throughout the research process. His knowledge, encouragement, and mentorship have been crucial for the development and completion of this dissertation. Additionally, I extend my sincere appreciation to Dr. Yeunkyung Kim, Dr. Manoj Sharma, Dr. Ji Yoo, and Dr. Ian McDonough for their contributions as committee members and Graduate College Faculty Representative. Their constructive input and scholarly insights have enriched the quality and rigor of this dissertation.

Furthermore, I am profoundly appreciative to my son, Alireza, for his patience, understanding, and unwavering belief in me during this journey. His love and encouragement have been my greatest source of motivation and inspiration.

This dissertation became possible with the support and encouragement of the School of Public Health staff and faculties who have supported me along the way. I am deeply thankful for their encouragement, understanding, and belief in my abilities, particularly Dr. Karen Callahan, Dr. Miguel Fudolig, and Dr. Neeraj Bhandari.

Lastly, I would like to extend my appreciation to the academic and research community for their contributions to the field of public health, which have inspired and informed my work.

Zahra Mojtahedi

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Chapter 1: Introduction

Background

Informal caregiving has a tremendous impact on public health, but it also can negatively affect caregivers' own health. This negative impact must be addressed with appropriate policies. Informal caregivers can reduce the rising need for long-term care facilities for elderly care (Feinberg, 2011). They also play a crucial role in mitigating healthcare costs by offering personalized care at home. Home care often prevents the need for expensive institutional care (Feinberg, 2011; Ferraris et al., 2022). Informal caregiving can hugely reduce the cost of healthcare system, estimated at approximately $450 billion per year in the United States, but they are not often paid (Feinberg, 2011). It has been shown that informal caregivers not only alleviate the burden on public health systems but also contribute to better health outcomes for care recipients (Feinberg, 2011; Ferraris et al., 2022). There are about 50 million informal caregivers in the country. They have huge contribution to public health and reducing healthcare costs, which underscores the significance of addressing their health (Feinberg, 2011). Informal caregivers may experience diminished health due to the demands of their roles, which could be exacerbated by public health disasters, like the latest pandemic. Gaining insights into the health of caregivers is essential for designing policies that promote their health. Obviously, a healthy informal caregiver can effectively provide care to their loved ones, ultimately benefiting the whole community (Feinberg, 2011).

Caregivers critically take part in preserving welfare of those they care for. However, it is

critical to acknowledge that caregiving can be a difficult and stressful task that necessitates patience, empathy, and resilience (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Cohen, Ahmed, Brown, Meucci, & Greaney, 2022). The COVID-19 pandemic was investigated in terms of behavioral and mental health in the general population. Certain behavioral health measures, like smoking and drinking, have been reportedly found to be aggravated, while healthy behaviors, such as food and vegetable consumption and exercise as coping behaviors, were grown among the general population (Bianchi et al., 2023; Ryan, Gibbs, & Sehgal, 2023). Mental health issues, e.g., anxiety and sadness, have increased during the COVID-19 pandemic (Bianchi et al., 2023; Ryan et al., 2023). Caregivers might have been especially stressed during the COVID-19 pandemic since several patient facilities, including respite care and even physical contact with physicians, were unavailable. As a result, caregivers' coping behaviors, mental health, and overall well-being perception may have been adversely influenced during the COVID-19 pandemic.

Informal caregivers frequently adopt unhealthy behaviors and experience negative health outcomes (Adelman et al., 2014; Cohen et al., 2022; Swoboda, Walker, & Huerta, 2021), which might have become worse during the pandemic. Framed by Lazarus theory of stress and coping (Lazarus 1984), this study will investigate (i) coping behaviors (physical activity and smoking), (ii) mental health (worrying, nervous, hopeless, little interest, and a composite psychological distress score), and (iii) perceptions of the overall well-being of informal caregivers before and after the COVID-19 pandemic through analyzing a well-recognized, national dataset.

Caregivers provide assistance and support to those who are unable to fully care for themselves, such as elderly, or people with disabilities or chronic illnesses (e.g., cancer or multiple sclerosis) (Perenc, Podgorska-Bednarz, Guzik, & Druzbicki, 2023; Rozensztrauch,

Dzien, & Smigiel, 2023). Caregiving can be rewarding since caregivers serve their loved ones. However, it is usually quite opposite. Caregivers often have to spend their own time and energy alongside other commitments, and caregiving takes a toll on different aspects of health of informal caregivers (Ashikali et al., 2023; Rozensztrauch et al., 2023).

Two main types of caregivers exist, including informal caregivers and professional caregivers. Informal caregivers are usually unpaid relatives, notably spouses, children, parents, or cousins. Professional caregivers, on the other hand, are paid employees. They often work for healthcare facilities, such as nursing homes or home health agencies. Professional caregivers are always trained and held certificates or degrees (Dedzoe, Malmgren Fange, Christensen, & Lethin, 2023; Wen, Xing, Ding, Xu, & Wang, 2023).

Caregiving, particularly for informal caregivers, can be a challenging and stressful experience. Informal caregivers often have to juggle their caregiving responsibilities alongside other commitments, like employment and family obligations (Liu, Ye, Jiang, Zhong, & Zou, 2023). Informal caregivers may also experience financial strain, as caregiving often involves significant costs, such as medical expenses and lost wages (Rawat, Sehar, Bisht, & Reddy, 2023). All of these can be burdensome for the mental and physical health of caregivers.

Berry and colleagues investigated the overall well-being and mental health of caregivers compared to non-caregivers using data from the 2017 HINTS (Berry, Disckind, Reichard, & Ruiz, 2020). No differences in reported overall well-being between caregivers and non-caregivers were detected (Berry et al., 2020). However, caregivers' psychological distress levels were found to be significantly diminished compared to those in non-caregivers (Berry et al., 2020). When compared to people who were not caregivers, 40% of child caregivers had depression or anxiety diagnoses (Berry et al., 2020). The authors stressed that some findings with

p-values over 0.05 might be due to the low number of cases in subgroups of caregivers (Berry et al., 2020).

Secinti and colleagues compared caregivers to non-caregivers and found the odds of engaging in both negative (smoking) and positive behaviors (physical activity and healthy diet) were higher for caregivers (Secinti., 2018). However, their findings, except smoking, were not replicated by another independent study that found caregivers were less likely to avoid fast-food and soda consumption, smoking, and general negative health behaviors (Hoffman, Lee, & Mendez-Luck, 2012). Discrepant results could be due to different time periods, non-generalizable samples, different definitions of behaviors, or adjustments for different controls, which should be clarified in future studies from a nationally representative sample.

The COVID-19 infection, which was initially diagnosed right before Jan 2020 and spread globally afterward, profoundly challenged many aspects of society, including informal caregivers. The COVID-19 pandemic created inimitable challenges for informal caregivers (Chen et al., 2021). Here are some key aspects that the pandemic could have influenced informal caregivers:

1. During the pandemic, many healthcare services and facilities were shut down. Informal caregivers have to go above and beyond their routine responsibilities in order to take care of their patients in a safe way, considering the immunosuppressed immune system of their patients. Additionally, healthcare facilities were overwhelmed with COVID-19 patients, and they were not able to serve non-COVID-19 cases (Beach, Schulz, Donovan, & Rosland, 2021; Chen et al., 2021).
2. Informal caregivers may have faced increased risks of infection with COVID-19. This might be true for particularly those caring for individuals who were elderly or had

underlying health conditions. Caregivers usually have very close contact with their patients. There should be additional stress for caregivers with activities such as shopping or doing their in-person jobs because of fear of infection, which could have posed a threat to their patients (Beach et al., 2021; Chen et al., 2021).

3. The COVID-19 pandemic could have hammered mental health of informal caregivers. Caregivers have frequently experienced exacerbation of anxiety and depressive symptoms as they navigate an array of challenges of caregiving during the pandemic. Social isolation, changes in routine, and fear of their loved one contracting the virus can all contribute to increased emotional strain on caregivers (Beach et al., 2021; Chen et al., 2021).
4. Informal caregivers might have faced financial challenges during the pandemic. Some might have lost their jobs loss or reduced work hours (Beach et al., 2021; Chen et al., 2021). However, we should note that some caregivers might have benefited financially from some federal funds for unemployed during the pandemic.
5. Informal caregivers might have been more stressed than the general population since certain groups of care recipients (e.g., the elderly) experienced increased vulnerability to COVID-19. Care- recipients might also have had heightened anxiety and depression because of isolation and disruptions in their routine. All of these patient-recipient-related illnesses could have created more mental health issues among informal caregivers (Beach et al., 2021; Chen et al., 2021).

Quantitative publications on informal caregivers' mental health and overall well-being after the COVID-19 pandemic in the USA are usually derived from local and small sample sizes. For example, Beach and colleagues (2021) in Pittsburgh, PA, surveyed informal caregivers and

non-caregivers in 2020, during the second quarter. The number of caregivers were 576 and of non-caregivers were 2,933. Informal caregivers experienced exacerbation of anxiety and depression after controlling for sociodemographic factors (Beach et al., 2021). In 2020, another study involving U.S. adults (caregivers and non-caregivers) found that caregivers (N=1,362) experienced a greater rate of negative mental health symptoms compared to non-caregivers (N=3,649). The rates of anxiety or depressive symptoms were 57.6% among caregivers, in contrast to 21.5% among non-caregivers. Additionally, caregivers vs. non-caregivers had lower rates of experiencing suicidal ideation (33.4% vs. 3.7%). These differences were statistically significant (Czeisler et al., 2021). However, a national investigation from the USA conducted by Ngamasana and colleagues reported that there was no statistically significant difference in the incidence rate of days with diminished mental health between informal caregivers who provided care before the pandemic and those who provided care after the pandemic (Ngamasana, Zarwell, & Gunn, 2023). These conflicting findings and research gaps underscore the need for further investigation to fully comprehend the potential adverse effects of the pandemic on the mental health as well as overall well-being of informal caregivers.

Scarce quantitative literature has been published regarding the behavioral health of American informal caregivers post-COVID-19, as studies have predominantly concentrated on the general population. Knell and colleges (2020) surveyed positive (exercise, sleep) and negative (alcohol, drug, and tobacco use) health behaviors. The convenience sample was from1809 adults (April-May 2020). A greater decline in physical activity was reported, whereas the negative health behaviors were not changed (Knell, Robertson, Dooley, Burford, & Mendez, 2020). In 2020, another survey study revealed caregivers compared to non-caregivers significantly used less substance use as a behavior to cope with the pandemic (vs. 6.3%) and

experienced lower rate of suicidal ideation as revealed by its percentage, 33.4% among caregivers vs. 3.7% among non-caregivers ($p < 0.0001$) (Czeisler et al., 2021), though they did not make any comparison before the pandemic. Despite preliminary evidence that the COVID-19 pandemic has made worse negative behaviors among informal caregivers in the USA (Czeisler et al., 2021), quantitative, large sample size studies on this topic remain scant, and therefore, further research on informal caregivers' behavioral health after the COVID-19 pandemic is needed to clarify these health outcomes and identify relevant policies.

Concluding, there is a gap in the literature comparing different aspects of caregivers' behavioral and mental health and overall well-being before and after the COVID-19 pandemic, using nationally representative data with more generalizable findings. This study, with a national scope, has therefore enabled us to examine whether the caregiver's behavioral health, mental health, and overall well-being have worsened or not since the pandemic. Information gained from such a study can offer insight to policymakers in developing and strengthening evidence-based policies and interventions, such as promoting regular exercise and regular mental health and well-being check-ups, among others, to help informal caregivers maintain their health and well-being when facing challenges resulting from future pandemics and public health emergencies and crises.

Purpose of the Study

Given the literature gap on knowledge in terms of comparing behavioral health, mental health, and overall well-being of caregivers before and after the pandemic, the purpose of this study was to examine behavioral health, mental health, and the overall well-being of informal

caregivers (2017-2019) and after the pandemic (2020, 2022) in the USA. The measures for behavioral health were (i) insufficient physical activity and (ii) smoking. The measures for mental health were (i) “worrying,” (ii) “nervous,” (iii) “hopeless,” (iv) “little interest,” and (v) a composite score of these four conditions, called the psychological distress score. The measure for overall well-being was (i) perceived overall well-being. This research employed a quantitative, retrospective, and pooled cross-sectional design, utilizing the secondary dataset of HINTS.

Theoretical Framework

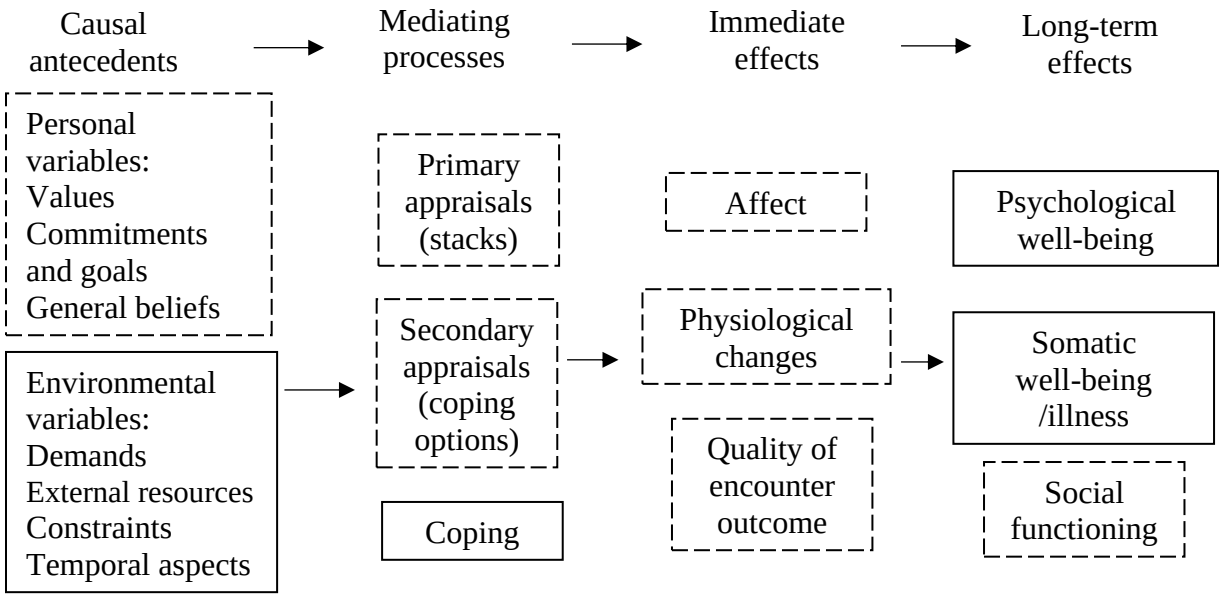
Lazarus theory of stress and coping

Lazarus proposed one of the most popular models describing stress pathways as early as 1984 (Lazarus, & Folkman, 1984). Lazarus theory of stress and coping, famously called the Transactional Model of Stress and Coping Theory, has been extensively used in the literature to explain how stress in different individuals can lead to different coping strategies that result in different well-being outcomes (Gerain & Zech, 2019; Grace Yi, Adamek, Hong, Lu, & Wilkerson, 2023; Lazarus & Folkman, 1984; Obbarius, Fischer, Liegl, Obbarius, & Rose, 2021). According to this theory, stress outcomes are determined by individual and environmental factors. Relationships between stressor exposure and stress outcome are mediated by the individual's assessment of how benign, threatening, harmful, or challenging those factors are (primary appraisal) and to what extent the individual feels capable of dealing with threatening, harmful, or challenging appraisals (secondary appraisal). These appraisals are then mediated by the coping techniques that the individual employs for non-neutral appraisals (Gerain & Zech,

2019; Grace Yi et al., 2023; Lazarus & Folkman, 1984; Obbarius et al., 2021).

Figure 1 depicts this theory, which is constituted of causal antecedents, mediating processes, and outcomes. Antecedents are personal variables (e.g., commitments or beliefs) and environmental variables (e.g., demands). Mediating processes are appraisals of the situation and personal coping strategies. Coping can be problem-focused (i.e., adapted to solve the conflict between individual and environment) or emotion-focused (i.e., adapted to handle the emotional challenge created by the situation) (Bianchi et al., 2023; Gerain & Zech, 2019; Grace Yi et al., 2023; Lazarus & Folkman, 1984; Obbarius et al., 2021; Schwarzer, 1998). Stress and coping outcomes have immediate impacts, such as affects or physiological changes, as well as long-term effects on psychological well-being, somatic health, and social functioning (Bianchi et al., 2023; Graven, Grant, & Gordon, 2015; Kyle, Blendon, Findling, & Benson, 2021; Lazarus & Folkman, 1984; Schuster, 2006; Schwarzer, 1998).

Figure 1: Lazarus and Folkman Theory (Bianchi et al., 2023; Graven et al., 2015; Lazarus, & Folkman, 1984; Obbarius et al., 2021; Schwarzer, 1998). Continuous Frames Represent Parts of the Theory Being Tested Here.



Conceptual framework model of the current study

Lazarus theory has provided a valuable framework for understanding how stress, such as the COVID-19 pandemic, can impact coping responses and ultimately affect the mental health of individuals (Acoba et al., 2022; Andrews 2022; Bianchi et al., 2023; Burke-Garcia et al., 2023). However, most studies tend to omit key components, such as appraising or short-term outcomes (Cannuscio et al., 2002; Elsayed et al., 2023; Leon-Campos et al., 2023; Lumley, 2018; Obbarius et al., 2021). Lazarus theory will be used to conceptualize our study model. As indicated in Figures 1 and 2, environmental, coping, psychological well-being (mental health), and somatic health (overall well-being) constructs from Lazarus theory were used here.

Adapted from Lazarus theory of stress and coping, the COVID-19 pandemic has been used as an environmental variable in several research studies (Acoba et al., 2022; Andrews 2022; Bianchi et al., 2023; Burke-Garcia et al., 2023) similar to the current study. In the present study, coping measures include insufficient physical activity and smoking. These variables have been identified as coping strategies after the COVID-19 pandemic in studies guided by the Lazarus theory (Acoba et al., 2022; Andrews 2022; Bianchi et al., 2023; Burke-Garcia et al., 2023).

Mental health measures in the current study are “worrying,” “nervous,” “hopeless,” “little interest,” and a composite score of these four conditions, called the psychological distress score, which have been used in prior studies as mental health measures (Acoba et al., 2022; Andrews 2022; Bianchi et al., 2023; Burke-Garcia et al., 2023). The measure of somatic health is the perception of overall well-being. Figure 2 depicts a schematic of the current research project.

Research Questions

This study investigates the subsequent research questions (Figure 2):

R1: Was the COVID-19 pandemic adversely associated with the coping behaviors of informal caregivers?

H1: Informal caregivers tend to have negative coping behaviors when encountering adverse environmental variables.

R2a: Was the COVID-19 pandemic adversely associated with the mental health of informal caregivers?

H2. Informal caregivers tend to have worse mental health when encountering adverse environmental variables.

R2b: Was the COVID-19 pandemic adversely associated with the overall well-being of informal caregivers?

H2b: Informal caregivers tend to have worse overall well-being when encountering adverse environmental variables.

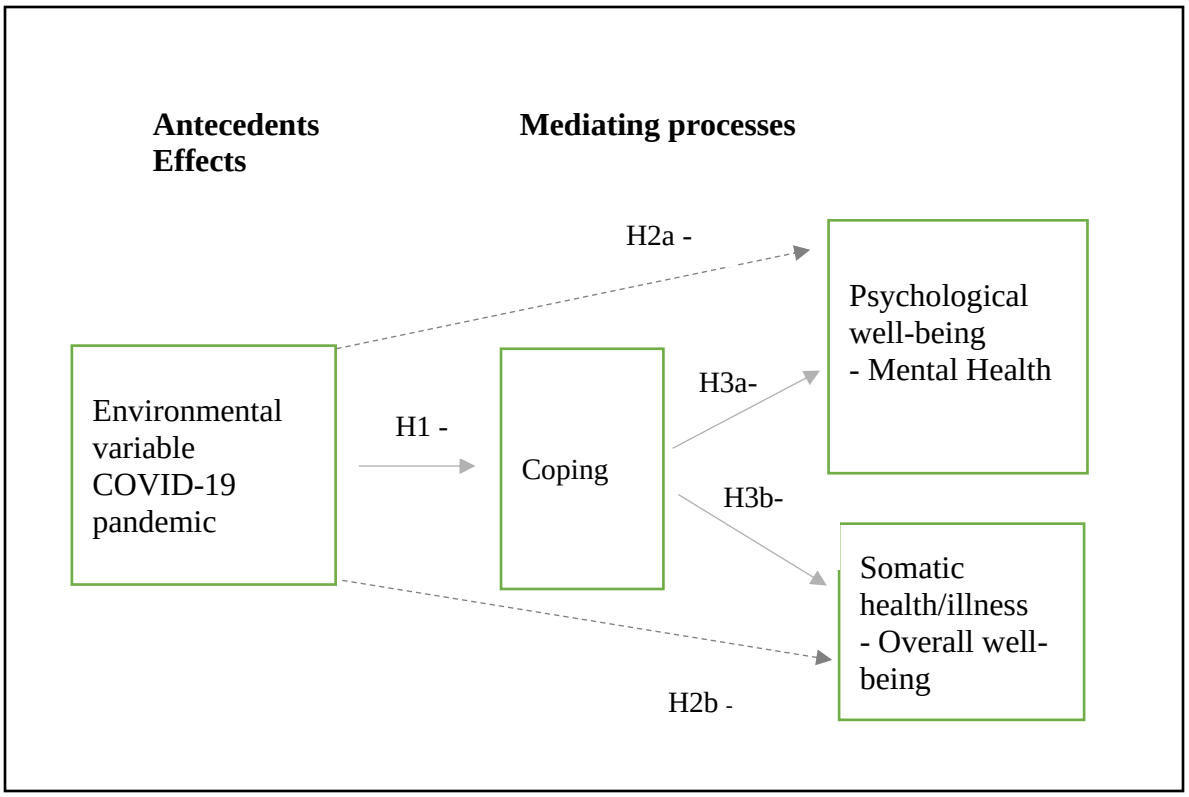
R3a. Did coping behaviors mediate mental health issues?

H3a: When encountering adverse environmental variables, informal caregivers tend to have worse mental health, mediated by coping behaviors.

R3b. Did coping behaviors mediate overall well-being?

H3b: When encountering adverse environmental variables, informal caregivers tend to have worse overall well-being, mediated by coping behaviors.

Figure 2: A summary of conceptual framework of the current study based on Lazarus and Folkman theory of stress and coping. Dash lines are not based on the original theory.



Significance of the Study

The significance of this study can be reflected in several aspects. The study is comprehensive both in terms of the number of health outcomes (8 outcomes) and also the length of the study. The data source is the well-recognized HINTS survey, collected periodically by the NIH (Berry et al., 2020; Burke-Garcia et al., 2023). The current study aimed to address a significant gap in our current knowledge on behavioral health, mental health, and overall well-being of informal caregivers in the aftermath of the COVID-19 pandemic as opposed to the period before the pandemic. Despite the critical role played by informal caregivers and the

potential influence of a global crisis on their routines and health, limited publications are available nationally examining the specific challenges they face in the USA.

The study investigated five mental health outcomes. It focuses on key mental health symptoms associated with anxiety and depression, including "worrying," "nervous," "hopeless," and "little interest" (Kroenke, Spitzer, Williams, & Lowe, 2009; Reeves et al., 2011). A composite score from these four mental health conditions, called the psychological distress score, was also taken into account. The aims of this study were to increase knowledge about several aspects of the health of informal caregivers, including mental health, after the pandemic.

Furthermore, the study aimed to investigate the perception of overall well-being among informal caregivers. Overall well-being recognizes that health is multidimensional encompassing physical, emotional, and social well-being (Clément Desmouceaux, 2022). Exploring the association of the pandemic on this holistic aspect of health, enabled us to offer a thorough understanding of informal caregivers' health after the pandemic.

The exploration of behavioral health, including smoking and physical activity, also enabled us to reveal potential coping mechanisms adopted by informal caregivers during stressful conditions (Bianchi et al., 2023; Obbarius et al., 2021). Understanding the association of these behaviors with the pandemic is vital for developing targeted interventions aimed at promoting healthier coping behaviors among informal caregivers during a crisis.

The study aimed to reveal the behavioral health, mental health, and overall well-being of a diverse and generalizable sample of informal caregivers across the USA. By using a national survey (Berry et al., 2020; Burke-Garcia et al., 2023). A national approach allows for a broad examination of the effects of the pandemic on the health of informal caregivers, accounting for potential regional disparities. The HINTS study includes both caregivers of the elderly and

caregivers of children (Berry et al., 2020; Burke-Garcia et al., 2023), setting it apart from other caregiver surveys that focus solely on the elderly (Riffin, Van Ness, Wolff, & Fried, 2019).

The study used available the HINTS dataset from 2017 to investigate the behavioral health, mental health, and perceived overall well-being of informal caregivers. It employed three available years before the COVID-19 pandemic (2017-2019) and two years after the pandemic (2020 and 2022) to investigate the difference before and after the pandemic. Investigating a long period of time (from 2017) will generate more robust and reliable findings to facilitate and assist in better informed policy and program development that, in turn, will improve the health and wellbeing of informal caregivers.

There is a scarcity of quantitative studies on the health of informal caregivers, post-pandemic, and the existing studies are limited in number and may present contradictory findings (Ngamasana et al., 2023; Rosenberg & Eckstrom, 2023). The study clarifies whether caregivers' health in terms of behavioral, mental, and overall well-being after the pandemic compared to pre-pandemic has worsened or not. Some initiatives were designed during the pandemic to address mental health and feelings of grief, worry, and stress, such as the How Right Now communication initiative (HRN), in the general population in the USA (Burke-Garcia et al., 2023). Whether informal caregivers need specific initiatives during lockdown crises needs more investigation.

Additionally, behavioral health (insufficient physical activity and smoking), as coping mechanisms (Bianchi et al., 2023; Obbarius et al., 2021), is used to predict mental health and overall well-being, providing an update about the association of behavioral health, mental health, and overall well-being among informal caregivers.

This study provided latest knowledge to policymakers. It emphasized the significance of

addressing the mental and overall well-being of informal caregivers in times of crisis. It also emphasized on the importance of behavioral health interventions in improving mental and overall well-being outcomes. The ultimate goal was to identify evidence-based interventions that can enhance mental health and the well-being of informal caregivers.

Summary

This chapter (Chapter 1) summarizes the aim, background, and significance of the study, the research questions, as well as the health theory that guided this study. Chapter 2 consists of a thorough review of the literature on the current knowledge on behavioral health, mental health, and the overall well-being of informal caregivers. Chapter 3 details the conceptual framework and its constructs. Chapter 4 (method) describes the secondary dataset, research design, statistical method employed in the current study, variables, and definition of each variable. Chapter 5 details the results, and Chapter 6 explains and interprets the findings of the current study.

Chapter 2: Literature review

Introduction

Policies, support programs, and payment for informal caregivers are evolving in the USA. Congress has recently approved tax credit for certain caregivers. For the 2022 tax year, individuals are eligible to request reimbursement for caregiving expenses up to $3,000 for a single qualifying individual or up to $6,000 for two or more qualifying individuals (AARP, 2023). The need for caregivers is projected to increase as the population of older adults is increasing. Policies ought to take into account the crucial contribution of informal caregivers to the healthcare system and be directed toward promoting this type of care (Tur-Sinai et al., 2020). However, caregiving can suppress mental health and overall well-being of caregivers (Ashikali et al., 2023; Rozensztrauch et al., 2023). To care for caregiver's health, a lot more needs to be accomplished in the way of policy, regulation, and support. Evidence-based policies are built on updated and comprehensive information (Brownson, Chriqui, & Stamatakis, 2009), which is not thoroughly available regarding caregivers in the USA.

Caregivers critically took part in providing essential support to those in need (de Araujo Gueiros Lira, Pontes da Silva, & Sarinho, 2023). They may help with tasks such as bathing, food preparation, eating, transportation, shopping, other routines, financial management, and administering medication, as well as provide emotional support and companionship (de Araujo Gueiros Lira et al., 2023). Caregiving is categorized into informal and formal (professional)

caregiving. Informal caregivers are usually relatives who are not paid or less paid. However, formal caregivers are professional caregivers who received wages for their services (van den Berg, Brouwer, & Koopmanschap, 2004).

Informal Caregivers

Informal caregivers are typically relatives or friends who provide care without receiving financial compensation, and their contributions can have a noteworthy influence on the physical and mental health of those they care for. Informal caregivers often undertake a unique form of on-the-job training, acquiring essential caregiving skills through firsthand experience rather than formal education. Their training is dynamic and responsive, evolving as the care recipient's needs change (van den Berg et al., 2004).

Role of informal caregivers

Informal caregivers offer a broad spectrum of support to their family members, aiding with daily tasks like eating, along with additional essential activities, like shopping, transportation, and finance management (Rakoski et al., 2012; Spigelmyer & Schreiber, 2019). Besides these practical tasks, informal caregivers also are a source of emotional support, companionship, and advocacy for their loved ones. They may also be responsible for managing medications, coordinating healthcare services, and communicating with healthcare providers (Rakoski et al., 2012; Spigelmyer & Schreiber, 2019).

The role of an informal caregiver can be demanding, both physically and emotionally.

Caregivers often juggle multiple responsibilities, including work, household tasks, and caring for their loved one. They may experience financial hardship, isolation, and sleep deprivation. Demands of caregiving can also hammer their own physical and mental health, leading to negative coping behaviors, depression, anxiety, and other health problems (Rakoski et al., 2012; Spigelmyer & Schreiber, 2019).

Challenges faced by informal caregivers

A huge challenge faced by informal caregivers is the inadequate support and resources available to them. Many caregivers feel that they are alone in their caregiving journey and do not know where to turn for help. They might also experience feelings of guilt when prioritizing personal time for themselves or seeking outside support, believing that they should be able to handle everything on their own. This can lead to physical and mental exhaustion of caregivers that creates serious concern for the caregiver as well as the care recipient (Spigelmyer & Schreiber, 2019; Ueshima, Yozu, Takahashi, Noguchi, & Tamiya, 2020).

Another challenge faced by informal caregivers is the economic weight of caregiving. Caregiving often involves out-of-pocket expenses such as transportation, home modifications, and medical equipment. Also, caregivers might need to work fewer hours or resign their jobs entirely in order to provide care, which would mean losing out on pay and benefits (van den Berg et al., 2004).

Emotional aspects of caregiving can also be significant. Caregivers may feel overwhelmed, stressed, and anxious about their loved one's health and well-being. They may also experience feelings of guilt, resentment, and frustration, especially if they feel that their

efforts are not appreciated or if they are not able to meet all of their loved one's needs (Spigelmyer & Schreiber, 2019; Ueshima et al., 2020).

Rewards of informal caregiving

Some informal caregivers find their role rewarding and fulfilling despite many challenges. Providing informal care can instill a sense of meaning as well as strengthen the relationship between the caregiver and their loved one (Andren & Elmstahl, 2005; Quinn, Clare, & Woods, 2015). Caregivers may also experience personal growth. They learn new skills, from communication to health care. They also gain a deeper understanding of themselves and their loved ones (Andren & Elmstahl, 2005; Quinn et al., 2015).

Caregiving can also provide opportunities for social connection and support. Caregivers may connect with other caregivers and share their experiences, providing a sense of community and belonging. They may also receive support from family and friends. Such support ranges from assisting with caregiving obligations to providing emotional support (Andren & Elmstahl, 2005; Quinn et al., 2015).

Another reward for caregivers can be financial support provided by the state and federal government. An example is tax credit for informal caregivers that has gone recently into effect (AARP, 2023). The tax credit not only financially supports informal caregivers but also it will remind them that they are seen and cared.

Informal caregivers: Importance of their support

Informal caregivers are frequently patients' relatives or friends who offer care without being paid for their services. While the role of an informal caregiver can be rewarding, it can also be physically and emotionally demanding (Quinn et al., 2015). Evidence indicates that supportive policies significantly impact informal caregivers' health. CalvoÂ -Perxas and colleagues (2018) examined the association of supportive policies for caregivers with their health (Calvo-Perxas et al., 2018). The study was originated from 12 European countries with a sample size of 13,507 caregivers. These countries were categorized as family-based or service-based car (Calvo-Perxas et al., 2018). The analysis revealed that caregivers in family-based care countries and those with higher caregiving intensity reported poorer health and worse health outcomes. Notably, non-financial support measures demonstrated a more significant protective effect on caregivers' health compared to financial support measures (Calvo-Perxas et al., 2018). Such information further highlights the significant influence of support policies on caregiver health, and, therefore, it is fundamental to offer support for informal caregivers to ensure they can provide the optimum care while also maintaining their well-being.

One reason why support for informal caregivers is important is that caregiving can suppress various health aspects of caregivers (Quinn et al., 2015). Caregivers may encounter too much stress, anxiety, depression, and fatigue, which can suppress overall well-being. Without adequate support, caregivers may become overwhelmed. They may not then be able to provide the optimum care for their loved ones. This viscous cycle can have longstanding harmful consequences for the caregiver's health and well-being (Liu et al., 2023; Quinn et al., 2015).

Another reason why support for informal caregivers is important is that caregiving can be the whole day and overnight. Many caregivers may have to juggle their caregiving

responsibilities with work and other family obligations (Liu et al., 2023; Pinquart & Sorensen, 2003). This can be challenging and can lead to financial strain, particularly if the caregiver cannot work more that part time or even resign from their job to provide optimum care to their loved ones. Providing support to caregivers, such as respite care, financial assistance, or flexible work arrangements, can help alleviate some of these stressors (Liu et al., 2023; Pinquart & Sorensen, 2003).

Support for informal caregivers can also help ensure that individuals who need care receive high-quality care (Quinn et al., 2015). Caregivers who receive support are better equipped to manage their loved one's care needs and are probably to seek help and ask for resources and information related to care recipients (Quinn et al., 2015). This can lead to better health outcomes for individuals who need care and can help reduce the burden on the healthcare system (Quinn et al., 2015).

Support for informal caregivers is crucial to ensure that individuals who need care receive high-quality care while also maintaining the caregiver's health and well-being (Litzelman, 2019). This support can come in many forms, including financial assistance, respite care, flexible work arrangements, and emotional support. By providing support to caregivers, we can help ensure that they can provide continuous and efficient care to the care recipients while also taking care of their own needs (Litzelman, 2019). This support can come in many forms, including:

Education and training: Informal caregivers may benefit from education and training on caregiving skills and strategies. This can instill more confident feeling and capability in their tasks, as well as reduce the risk of caregiver burnout (Gaspar, Raimundo, de Sousa, Barata, & Cabrita, 2023).

Respite Care: Informal caregivers are temporarily relieved by respite care, allowing them to relax and refuel. Respite care can take many forms, such as hiring a home health aide, arranging for short-term care at an assisted living facility, or finding a volunteer who can help with caregiving tasks (Burke-Garcia et al., 2023).

Emotional Support: Caregiving can be an isolating and emotionally draining experience. Offer support by being a listening ear, checking in on them regularly, and providing encouragement. Sometimes just having someone to talk to can make a big difference (Courtin, Jemiai, & Mossialos, 2014; Leon-Campos et al., 2023).

Practical Support: Caregiving can be overwhelming, and caregivers may need help with tasks such as grocery shopping, transportation, or running errands. Offering practical support can take some of the burden off of caregivers and allow them to focus on their caregiving responsibilities (Olesen, la Cour, Thorne, With, & Handberg, 2023).

Recognition and Appreciation: Caregiving can be a thankless job, and caregivers often do not receive the recognition they deserve. Showing appreciation by acknowledging their efforts, expressing gratitude, and offering to help is critical in supporting informal caregivers (Plothner, Schmidt, de Jong, Zeidler, & Damm, 2019).

Financial Support: Caregiving can be expensive, and many caregivers may be struggling to make ends meet. Offering financial assistance can help ease the financial burden of caregiving (Courtin et al., 2014).

In summary, there are many ways to support informal caregivers, including respite care, emotional support, practical support, education, recognition and appreciation, and financial support. Offering supportive policies, can help caregivers experience valued, supported, and capable in their caregiving responsibilities (Courtin et al., 2014).

Health of Caregivers

Caregiving can hugely influence behavioral health, mental health, and overall well-being of the caregivers themselves (Hoffman et al., 2012). Caregiving is a demanding and challenging role, and it can take a toll on the health and wellbeing of those who take on this responsibility (Cohen et al., 2022). Understanding these challenges is very important from a policy standpoint.

Behavioral health

The behavioral health of informal caregivers is a critical aspect that can be shaped by the demanding and often emotionally challenged nature of their role. The emotional toll of witnessing a loved one's health decline and physical burden can contribute to negative coping strategies and behavioral issues. Caregivers may use negative and risky behaviors, such as smoking, drinking alcohol, or insufficient physical activity, as a way to emotionally cope with the stress and their responsibilities (Hoffman et al., 2012; Polen & Green, 2001).

Physical activity

The association of caregiving with insufficient physical activity is a matter of controversy. While Freedman and colleagues did not find significant association of caregiving with physical activity (Fredman, Bertrand, Martire, Hochberg, & Harris, 2006), some studies found the tendency of informal caregivers toward inadequate physical activity as opposed to non-caregivers (Hiel et al., 2015). Similarly, a scholarly published article found that caregivers

experienced lower levels of physical activity and fitness (Lambert et al., 2016).

The reasons for caregivers and non-caregivers to possibly differ in physical activity levels are multifactorial. Caregivers may find themselves with reduced opportunities and energy for physical exercise owing to the demands of their caregiving duties, which can be physically and emotionally demanding. Additionally, caregivers may experience heightened levels of stress, which has been related to a decrease in physical activity (Baik et al., 2021; Lambert et al., 2016).

Critically, caregivers' levels of physical activity can tightly be related to both their own health and the health of the care recipient. Regular physical exercise increases the likelihood that caregivers will benefit from better cardiovascular health, a lower chance of developing chronic diseases, and enhanced well-being (Baik et al., 2021; Lambert et al., 2016). Furthermore, physically fit caregivers may be better able to handle the physical burden of caregiving, lowering the likelihood of burnout (Baik et al., 2021; Lambert et al., 2016).

Interventions targeting physical activity among caregivers may be an important strategy for improving the well-being of caregivers in addition to care recipients. For example, home-based exercise program was effective in enhancing physical activity levels and advancing physical function among older caregivers (Braz de Oliveira et al., 2023; Lambert et al., 2016). Similarly, systematic reviews found that exercise interventions among caregivers can improve physical function, reduce stress, and improve life quality (Baik et al., 2021; Braz de Oliveira et al., 2023; Lambert et al., 2016)

Smoking

Informal caregivers may be at an increased risk of tobacco smoking due to the stresses associated with caregiving (Cohen et al., 2022). Studies have also shown that informal caregivers

who smoke are likely to have more health complications as opposed to non-smoking caregivers, as well as non-caregivers (Cohen et al., 2022).

A study conducted by Gottschalk and colleagues found that informal caregivers had higher odds of smoking (1.34 times) than non-caregivers (Gottschalk, Konig, & Brettschneider, 2020). Another study by Wu and Lu Found similar results. Moreover, informal caregivers who were current smokers also reported higher levels of perceived stress compared to non-smoking caregivers or non-caregivers who smoked (Wu & Lu, 2017).

In summary, compared to informal caregivers who do not smoke and non-caregivers, informal caregivers who smoke have higher rates of experiencing mental and physical health issues. (Gottschalk et al., 2020). Also, compared to the overall population, informal caregivers may have a greater smoking prevalence. Given that smoking cessation programs can help improve different aspects of health, it is critical to emphasize the importance of detecting and addressing tobacco use among informal caregivers.

Mental health

The association of caregiving with deterioration in mental health has been demonstrated in prior literature (Berry et al., 2020; Hoffman et al., 2012). Informal caregiving contributes to worsening mental health. For example, Berry and colleagues using the 2017 HINTS dataset found higher mental health composite scores in caregivers as opposed to non- caregivers (Berry et al., 2020). Schulz and colleagues compared the mental health state of informal caregivers *vs.* non-caregivers. They found that caregivers reported greater levels of depressive symptoms and life dissatisfaction than non-caregivers. The study also found that caregivers who reported

greater burden and stress were more likely to experience depression compared to the group who reported suppressed burden and stress (Schulz, O'Brien, Bookwala, & Fleissner, 1995). In a meta-analysis on 84 articles on comparing caregivers and non-caregivers in terms of physical and mental health outcomes, Pinquart & Sörensen reported the largest differences were found with regard to depression (Pinquart & Sorensen, 2003). Lee and colleagues investigated the mental health of informal caregivers *vs.* non-caregivers using a nationwide sample (USA). They revealed that caregivers had greater levels of depressive symptoms and life dissatisfaction than non-caregivers (Lee, Colditz, Berkman, & Kawachi, 2003).

Caregivers may experience mental health deterioration due to the demands and challenges of caregiving. Caregivers may experience social isolation, as their caregiving responsibilities may limit their ability to participate in social events and maintain relationships. Caregiving stress can result in burnout, a state of physical, emotional, and mental overtiredness (Cannuscio et al., 2002). It is critical to acknowledge the significant contribution of informal caregivers to the healthcare system and to deliver them adequate support to maintain their overall well-being status.

Overall well-being

Perceived overall well-being is an individual's subjective assessment of their overall well-being and happiness. It contributes to a variety of factors, notably physical health, mental health, emotional health, social support, and life fulfilment (Netemeyer, 2018). One's perception of their overall well-being can be influenced by their own personal experiences and circumstances. For example, someone who has good physical health, fulfilling relationships, and a sense of purpose may perceive their overall well-being to be high. On the other hand, someone who is struggling

with chronic pain, social isolation, or financial stress may perceive their overall well-being to be lower (Netemeyer, 2018). Perceived overall well-being is often used as an indicator of quality of life (Netemeyer, 2018).

Berry and colleagues using the 2017 HINTS dataset found no significant differences in overall well-being in caregivers as opposed to non-caregivers (Berry et al., 2020), while they did not rule out the possibility that the low sample size contributed to the non-significant results. Research has shown that a higher perceived overall well-being contributes to a range of positive outcomes, notably enhanced physical health, greater life satisfaction, and productivity. It can also be associated with enhanced sense of purpose and fulfillment in life (Netemeyer, 2018), making its address crucial among caregivers.

Socioecological factors of informal caregivers

Informal caregivers were frequently found to be middle aged white women with higher graduation levels (Berry et al., 2020; Wajnberg et al., 2016). The sociodemographic factors, notably, age groups, gender, educational levels, health insurance, and marital status, and geographic region were also found to affect behavioral health, mental health, and overall well-being of informal caregivers (Berry et al., 2020; Wajnberg et al., 2016). For example, Wajnberg and colleagues investigated 49 informal caregivers and found that the mean age was 58 years. Women constitute 78% of caregivers. Approximately, 60% of caregivers experienced some levels of caregiver burden while 30% suffered depressive symptoms. More burdens fell on White caregivers than on Black and Latino caregivers (Wajnberg et al., 2016). Using the 2017 HINT dataset, Berry and colleagues discovered that the odds for caregivers of children with disabilities

to be between the ages of 35 and 49 were doubled compared to non-caregivers (52% versus 27%). It was discovered that caregivers for persons with disabilities were older than non-caregivers. Seventy one percent of caregivers for children and 58% of caregivers for adults were women. Compared to non-caregivers, caregivers of children and adults were more likely to be married (Berry et al., 2020). Hoffman and colleagues also found that those informal caregivers were slightly older than non-caregivers, more likely to be women and had higher income levels and education (Hoffman et al., 2012). Other publications also demonstrated the influence sociodemographic factors e on different aspect of caregiver's health (Abidova, Silva, & Moreira, 2021; Cohen, Sabik, Cook, Azzoli, & Mendez-Luck, 2019; National., 2010).

COVID-19 Pandemic and Caregivers

The COVID-19 pandemic profoundly influenced societies around the world, and one group of individuals who have been significantly affected were informal caregivers (Beach et al., 2021; Chen et al., 2021). After the pandemic, informal caregivers faced unique challenges and responsibilities. A lot of business stores were shut down, but caregivers had to continue their services and faced many challenges (Beach et al., 2021; Chen et al., 2021). Challenges might have mediated the deterioration of different aspects of the health of informal caregivers. Exploring these multifaceted aspects through comprehensive research is essential to developing targeted interventions and support systems for this invaluable health workforce group.

The pandemic introduced unique stressors for informal caregivers. As such, there are increased caregiving responsibilities due to the unavailability of healthcare systems for non-COVID-19 cases and a heightened risk of infection for themselves and their patients. Other

sources of extra stress could be decreased access to resources and support services, financial issues, social isolation, and the uncertainty surrounding the pandemic (Beach et al., 2021; Chen et al., 2021).

A significant challenge faced by informal caregivers after the COVID-19 pandemic was the augmented risk of exposure to the virus (Beach et al., 2021; Chen et al., 2021). The majority of caregivers provide care to individuals with a suppressed immune system, notably older adults or those with underlying health issues, who are at an augmented risk of a severe illness or complications if they contract COVID-19. Informal caregivers had to take extra precautions to protect both themselves and the individuals they care for, such as wearing personal protective equipment (PPE), practicing hygiene measures, and minimizing social interactions to suppress the risk of transmission (Beach et al., 2021; Chen et al., 2021).

Financial strain is another area that hit hard by the pandemic. Caregivers may have faced job loss or reduced work hours, which resulted in heightened financial strain for both the care recipient and caregivers and subsequently diminished mental health and overall well-being issues (Budnick et al., 2021). Disruptions in healthcare, which occurred during the pandemic, had an impact on informal caregivers. Caregivers had to navigate changes in healthcare access and services, including cancellations or delays of appointments, procedures, and treatments for the individuals they care for. This added additional stress and uncertainty to their caregiving responsibilities (Beach et al., 2021; Chen et al., 2021).

Furthermore, the social isolation measures implemented after the pandemic are likely to have had a significant impact on informal caregivers (Beach et al., 2021; Chen et al., 2021). Caregivers had to limit their social interactions to mitigate the risk of transmission. The absence of access to support groups, respite care, and other resources could have further exacerbated their

challenges (Beach et al., 2021; Chen et al., 2021). Informal caregivers immediately found themselves and their patients alone in the midst of the pandemic.

Through above mechanisms, the pandemic could have led to negative coping behaviors, augmentation of anxiety and depressive symptoms, and overall unwell-being among informal caregivers. To cope with these stressors, the COVID-19 pandemic could have potentially exacerbated negative coping behaviors informal caregivers (Beach et al., 2021; Chen et al., 2021), which could have subsequently contributed to augmentation mental health problems and deteriorating the overall well-being of informal caregivers.

Coping strategies after the COVID-19 pandemic

Less evidence is available regarding coping strategies by caregivers after the COVID-19 pandemic. However, evidence exists regarding the general population. Guided by Lazarus theory of stress and coping, coping strategies after the COVID-19 pandemic for the general population were mainly found to be engaging in exercise, consumption of alcohol, substance use, healthy eating, gaming, reading book, and socializing through Internet. Some are positive like engaging in exercise, and some are maladaptive, notably consumption of alcohol and/or substance use (Alexopoulos et al., 2021; Bianchi et al., 2023; Ogueji, Okoloba, & Demoko Ceccaldi, 2022; Ryan et al., 2023). Caregivers might have had experienced more negative behaviors as trying to cope with overstressed conditions, a claim that needs to be clarified.

Mental health and overall well-being after the COVID-19 pandemic

Limited quantitative publications are available regarding caregivers' health after the COVID-19 pandemic in the US, which are usually derived from local and low sample sizes and focused on mental health rather than overall well-being. For example, Beach and colleagues in a study from April to May 2020 in Pittsburgh, Pennsylvania, found that family caregivers as opposed to non-caregivers experienced an augmentation of anxiety, depression, and exhaustion after controlling for sociodemographic characteristics (Beach et al., 2021). While the insights provided by Beach and colleagues, along with similar studies (Ngamasana et al., 2023), have revealed the potential significant effects of the pandemic on the health of caregivers, there is a need for national research that comprehensively incorporates several mental health outcomes, examines overall well-being, and investigates the association of behavioral health with mental health and overall well-being. Addressing the needs of informal caregivers during a crisis is crucial in order to maintain their essential services in an effective way.

Literature Gap

The COVID-19 pandemic hugely influenced societies, and one area that has been particularly affected is informal caregiving (Rodriguez-Mora, Mateo Guirola, & Mestre, 2023). There is a literature gap when it comes to understanding and comparing the behavioral health, mental health, and overall well-being of informal caregivers before and after the COVID-19 pandemic in the USA, as being summarized as follows.

(1) paucity of quantitative research on comparing behavioral health of informal caregivers before and after the COVID-19 pandemic; (2) paucity of quantitative study on mental

health of informal caregivers before and after the COVID-19 pandemic, and sometimes contradicting results (Beach et al., 2021; Ngamasana et al., 2023); (3) paucity of quantitative research on comparing overall well-being of informal caregivers before and after the COVID-19 pandemic; (4) paucity of an updated research on the association of behavioral health with mental health; and (5) paucity of an updated research on the association of behavioral health with overall well-being. These literature gaps highlight the necessity for additional research to comprehend the unique health challenges and its predictors among informal caregivers during this unprecedented crisis (Budnick et al., 2021). It is essential to identify the detailed influences of the pandemic on caregivers' health and to develop evidence-based interventions and care systems to address their health issues.

Hypothetically, the pandemic had a weighty negative impact on mental health and overall well-being of informal caregivers, and this association was partially mediated by coping behaviors notably insufficient physical activity and smoking. The pandemic caused widespread fear, anxiety, and uncertainty, leading to an increase in mental health disorders notably depression and anxiety. Social isolation, financial stress, and the loss of loved ones further exacerbated these issues. As a result, individuals might have turned to coping mechanisms like insufficient physical activity, smoking, and drinking as a way to manage their distress and escape from challenging circumstances. However, these behaviors can have detrimental effects on mental health and overall well-being. By filling the literature gap, researchers, policymakers, and healthcare providers can better comprehend the health of informal caregivers during a crisis and develop strategies to support them effectively.

Summary

This chapter reviewed the literature on informal caregivers. Challenges faced by caregivers were also summarized, including financial strain, social isolation, and a lack of training or support. The tasks and demands of caregiving can also contribute to the neglect of one's own needs and well-being. It also discussed unique challenges faced by informal caregivers after the COVID-19 pandemic, such as difficulty accessing essential resources like medical supplies, increased risk of infection, social distancing practices, and visitation restrictions. All of these challenges could have led to negative coping behaviors, mental health issues, and overall well-being, which were thoroughly reviewed. Finally, the gap in the literature and lack of a quantitative study to examine the behavioral health, mental health, and overall well-being of informal caregivers nationwide before and after the COVID-19 pandemic were explained. The next chapter reviews the conceptual framework of this study.

Chapter 3: Conceptual Framework

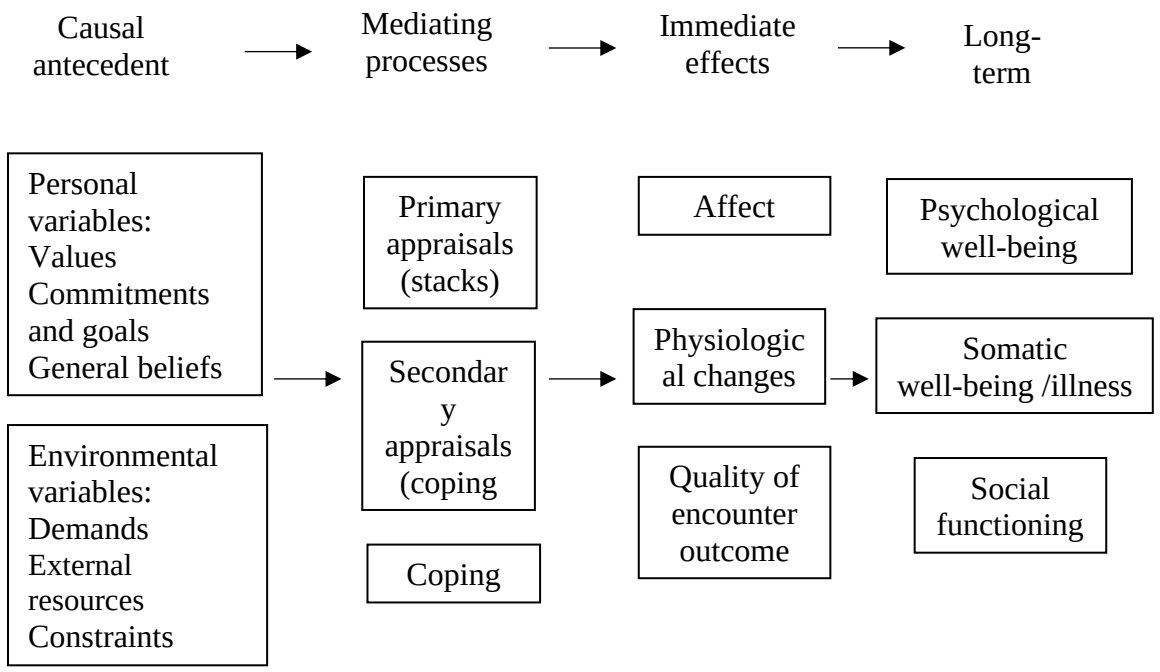
This study employs Lazarus theory of stress and coping to compare the behavioral health, mental health, and overall well-being of informal caregivers before and after the COVID-19 pandemic, which placed an unprecedented burden on informal caregivers, resulting in an elevated levels of stress and psychological distress. Moreover, caregivers who relied on maladaptive coping mechanisms, such as smoking, might have had worse mental health. This study will clarify the possible significant impact of an environmental variable (the COVID-19 pandemic) on coping strategies (behavioral health), psychological well-being (mental health), and somatic health (overall well-being) of informal caregivers.

Lazarus Theory of Stress and Coping

Lazarus theory of stress and coping, also known as the transactional model of stress and coping, was developed by psychologist Richard Lazarus and Susan Folkman. It focuses on how individuals perceive and cope with stress (Lazarus & Folkman, 1990). According to this theory, stress is not solely determined by external events, but also by an individual's appraisal of those events and their ability to cope with them. The theory includes several key components: Antecedents (Personal variables and environmental variables), mediating processes, and effects (immediate and long-term) (Bianchi et al., 2023; Graven et al., 2015; Krohne, 2022; Lazarus, &

Folkman, 1990; R. S. Lazarus & Folkman, 1984; Lumley, 2018; Obbarius et al., 2021). A schematic of Lazarus theory of stress and coping is shown in Figure 3.

Figure 3: Lazarus Theory of Stress and Coping (Lazarus and Folkman, 1984)



Antecedents

According to Lazarus and Folkman's stress and coping theory, two significant antecedent elements exist that affect the later appraisal and coping: personal variables and environmental variables. They suggested that a variety of personal and environmental variables can influence a

person's cognitive appraisals when confronted with any event. These factors all interact in intricate ways (Benness, 1989; Lazarus & Folkman, 1984; Schwarzer, 1998).

Personal variables

Personal variables are the first group of antecedents that influence appraisal and coping. Personal variables, according to Lazarus and Folkman's stress and coping theory, are important in grasping the significance of an event, appreciating what is vital for an individual's well-being, and evaluating outcomes (Benness, 1989; Krohne, 2022; R. S. Lazarus, & Folkman, S. . , 1984; Schwarzer, 1998). Commitments and beliefs are the most significant personal factors for Lazarus and Folkman when it comes to appraisal. Commitment is a responsibility or obligation to commit time and effort in order to achieve a specific goal. Lazarus proposes that people make commitments to specific Goals and values (Lazarus & Folkman, 1984; Schwarzer, 1998). A strong commitment to a specific goal signal that the goal is a priority and is likely to have a greater effect on the appraisals a person makes (Benness, 1989; Lazarus & Folkman, 1984; Schwarzer, 1998). A person's belief is about how much they have control over the outcome of events. For instance, to be successful in a school, a student must have innate ability (e.g., IQ) as well as suitable skills (e.g., test-taking skills). Nevertheless, if the student believes that he or she lacks the potential to succeed, he or she might not attempt to learn the skills. Subsequently, the student will perform poorly due to a lack of test-taking abilities (Benness, 1989; Lazarus & Folkman, 1984; Schwarzer, 1998). This subpar performance will be blamed on a lack of IQ, reinforcing the student's notion that he or she is incapable. This is one example of how beliefs might influence appraisal and coping (Benness, 1989; Lazarus & Folkman, 1984; Schwarzer, 1998). Adapted from this theory, sociodemographic characteristics have also been extensively

used in research studies as personal variables (Gerain & Zech, 2019; Grace Yi et al., 2023; Lumley, 2018; Mojtahedi et al., 2021; Obbarius et al., 2021; Sanguanklin et al., 2014; Siteman, 2023).

Environmental variables

When making assessments, the individual considers a number of environmental variables, according to Lazarus stress and coping theory (Benness, 1989; Lazarus, & Folkman, 1984; Schwarzer, 1998). They notably mentioned demands and temporal aspects of the stressful conditions. Demands that are complex, unclear, unexpected, and must be worked on both for a long time and under time constraints are more likely to produce threat perceptions than simple activities that can be adequately prepared for and done at a suitable pace and time. Temporal aspect refers to stress as an ever-changing process that occurs across time (Benness, 1989; Cerin, Szabo, Hunt, & Williams, 2000; Lazarus & Folkman, 1984; Schwarzer, 1998). Adapted from this theory, a stressor, an external event, have been extensively used as an environmental variable in conceptual framework in research studies (Acoba et al., 2022; Andrews 2022; Lazarus & Folkman, 1990; Miles, Khambaty, Petersen, Naik, & Cully, 2018; Wong, 1993).

Mediating Processes

Mediating processes are the cognitive and emotional processes that occur between antecedents and the outcomes of stress. The mediating processes in Lazarus and Folkman's stress and coping theory are appraisal and coping (Bianchi et al., 2023; Camilleri, Fogle, O'Brien, & Sammut, 2021; Lazarus & Folkman, 1984; Ogueji et al., 2022).

Appraisals

Appraisal refers to the evaluation of a stressor, including the assessment of its significance, threat, harm, and challenge. Appraisals have two components: primary and secondary appraisals.

Primary and secondary appraisals influence how an individual perceives and responds to a stressful situation (Benness, 1989; Lazarus & Folkman, 1984; Schwarzer, 1998).

Primary Appraisal

Primary Appraisal: Primary appraisal involves the initial evaluation of a situation to determine its relevance and significance for the individual. During primary appraisal, an individual assesses whether a situation is threatening, benign, or irrelevant. If the situation is perceived as threatening, it can trigger a stress response. For example, if someone receives a poor performance review at work, they may appraise it as threatening to their job security or self-esteem, which can trigger a stress response (Benness, 1989; Lazarus & Folkman, 1984; Schwarzer, 1998).

Secondary Appraisal

Secondary Appraisal: After the primary appraisal, the individual engages in secondary appraisal, which involves evaluating their coping resources and options for dealing with the situation. Secondary appraisal is a more detailed assessment of the situation and the individual's

perceived ability to cope with it. It involves evaluating the available resources, notably social network, problem-solving skills, and personal strengths, to determine if they are sufficient to cope with the perceived threat. If the individual believes they have adequate coping resources, they may feel more in control and capable of managing the stressor. However, if they perceive a lack of resources, they may experience increased stress and may need to seek additional support or develop new coping strategies (Benness, 1989; Lazarus & Folkman, 1984; Schwarzer, 1998). It is important to note that primary and secondary appraisals are subjective. What one person perceives as threatening, another person may perceive as manageable (Benness, 1989; Lazarus & Folkman, 1984; Schwarzer, 1998).

Coping

Coping includes the strategies and behavioral efforts of an individual in order to handle an stressor. The theory recognizes two main categories of coping strategies: problem-focused coping and emotion-focused coping (Bianchi et al., 2023; Camilleri et al., 2021; Lazarus & Folkman, 1984; Ogueji et al., 2022). Problem-focused coping involves efforts to actively address the stressor, such as problem-solving, seeking information, or taking action to alter the situation. Emotion-focused coping, on the other hand, involves efforts to regulate one's emotional response to the stressor, such as seeking social support, using relaxation techniques, or engaging in distraction (Bianchi et al., 2023; Lazarus & Folkman, 1984; Ogueji et al., 2022; Stults-Kolehmainen & Sinha, 2014). Emotion-focused coping strategies try to handle the emotional distress associated with a stressor, rather than changing the stressor itself. Coping methods can be positive, notably exercise and healthy diet, or maladaptive, such as alcohol consumption and

substance use (Bianchi et al., 2023; Camilleri et al., 2021; Lazarus & Folkman, 1984; Ogueji et al., 2022; Stults-Kolehmainen & Sinha, 2014).

Effects

Immediate effects

Immediate effects: The immediate effects in Lazarus and Folkman stress and coping theory refers to the initial response or reaction to a stressor. It can include physiological and emotional responses, such as increase in heart rate or crying (Bianchi et al., 2023; Graven et al., 2015; Lazarus & Folkman, 1984; Lumley, 2018; Obbarius et al., 2021). Immediate effects have been frequently deleted from the model in non-longitudinal studies (Acoba et al., 2022; Andrews 2022; Grace Yi et al., 2023).

Long-term effects

Long-term effects: The long-term effects in Lazarus stress and coping theory refers to the effects of stress on an individual's well-being. The outcomes of real-life situations can vary depending on an individual's appraisal and coping strategies according to the Theory (Bianchi et al., 2023; Lazarus & Folkman, 1984; Ogueji et al., 2022). Problem-focused coping strategies generally contribute to positive outcomes. By directly addressing the stressor, individuals can gain a sense of control and actively reduce the demands of the stressor (Bianchi et al., 2023; Lazarus & Folkman, 1984; Ogueji et al., 2022). For example, mental health outcomes can vary

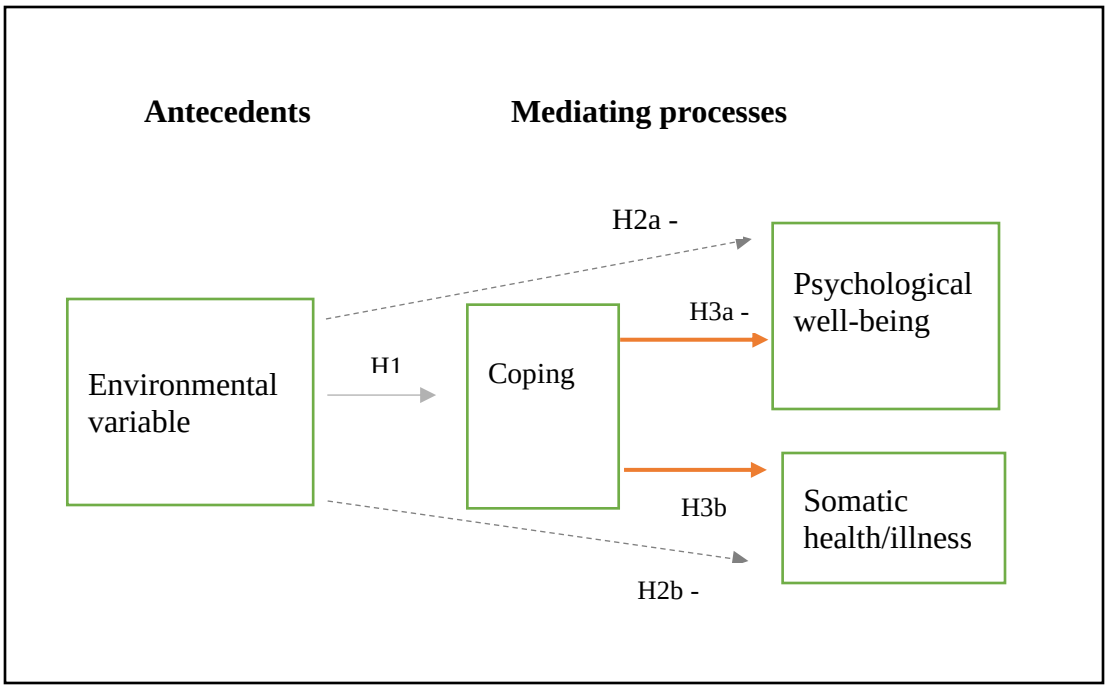
based on an individual's appraisal and coping abilities in response to the same stressor (Cohen et al., 2022; Sanguanklin et al., 2014). If an individual appraises a stressor extremely challenging but has effective coping strategies, it may not result in negative mental health outcomes (Cohen et al., 2022; Sanguanklin et al., 2014).

Collectively, Lazarus and Folkman stress and coping theory is a useful theory for explaining how environmental stressors can be linked to individual wellbeing. According to this model, stress through individual's appraisals and coping responses can influence the individual's wellbeing (Grace Yi et al., 2023). Identifying related factors can help policymakers to create interventions that promote positive outcomes.

Conceptual Framework Model of the Current Study

Lazarus theory of stress and coping has provided a framework for understanding how the COVID-19 pandemic has influenced mental health in prior studies (Acoba et al., 2022; Andrews 2022; Camilleri et al., 2021; J. H. Kim, Shim, Y., Choi, I., & Choi, E., 2022). A conceptual framework adapted from Lazarus theory of stress and coping will be used to guide this study, as shown in Figure 4. This study will only focus on relationships among Environmental Variables (under the Antecedents category), coping (under the Mediating Processes category), and psychological well-being and Somatic health/illness (under the Effects category), as shown in Figure 4.

Figure 4. Conceptual Framework of the Study Adapted from Lazarus theory of Stress and Coping.



H1: Relationships between environmental variables and coping

In the context of COVID-19 pandemic, several studies, guided by Lazarus theory of stress and coping, have investigated coping strategies. Both positive and maladaptive coping strategies have been identified (Bianchi et al., 2023; J. H. Kim, Shim, Y., Choi, I., & Choi, E., 2022; Ogueji et al., 2022). Several effective coping strategies were identified, including spending time with close family and friends (for example, through video calls), participating in physical activities, focusing on academic pursuits, steering clear of negative COVID-19 news, and practicing meditation. The maladaptive coping strategy were mainly found to be consumption of alcohol, smoking, and substance use (Bianchi et al., 2023; Burke-Garcia et al., 2023; J. H. Kim, Shim, Y., Choi, I., & Choi, E., 2022; Ogueji et al., 2022). Some of these coping strategies,

including smoking and insufficient physical activity, are negative behavioral coping strategies used by caregivers (Adelman et al., 2014; Cohen et al., 2022; de Araujo Gueiros Lira et al., 2023; Farzan et al., 2023; Fredman et al., 2006) and are included in the HINT surveys from 2017 to 202. Some research, but not all, have found that caregivers are more likely to have insufficient physically activity or smoke (Adelman et al., 2014; Cohen et al., 2022; de Araujo Gueiros Lira et al., 2023; Farzan et al., 2023; Fredman et al., 2006). This study will investigate whether informal caregivers had more negative coping behaviors after the pandemic compared to pre-pandemic period.

H2a. Relationships between environmental variable and psychological well-being (Mental health: “worrying,” “nervous,” “hopeless, “little interest,” and their composite score)

Despite the extensive evidence on the psychological consequences of the COVID-19 pandemic, there remains a limited knowledge of the psychological consequences of providing informal care during the pandemic in the USA. A recent publication from the UK explored the effects of COVID-19 on informal caregivers. Thy used the UK Household Longitudinal Study from 2016 until 2021. They analyzed 4,698 respondents. Their findings indicate deterioration in mental well-being of informal caregivers during the pandemic (Costi, Hollingsworth, O'Sullivan, & Zucchelli, 2023). There is an evident literature gap comparing psychological well-being of informal caregivers before and since the COVID-19 pandemic in the USA. The current research compares informal caregivers' psychological well-being (mental health) before and after the pandemic. The measures are “worrying,” “nervous,” “hopeless,”, and “little interest”, as well as a composite score of these four mental health issues, which is available in the HINTS dataset.

H2b. Relationships between environmental variables and somatic health/illness (overall well-being)

The COVID-19 pandemic was a major international crisis affecting the well-being of people across the world. This study used perceived overall well-being as a measure for somatic health/illness. Perceived overall well-being denotes an individual's subjective assessment of their own level of well-being (Netemeyer, 2018). Several studies have investigated the association of overall well-being and COVID-19 pandemic using different measures and samples. For instance, a study by Dai and colleagues on general population in China found that the pandemic has led to worsening of overall well-being (Dai et al., 2021). Here, the relation of COVID-19 with overall well-being among informal caregivers is investigated (comparing before and after the COVID-19 pandemic).

H3a. Coping behaviors mediates psychological well-being

Coping behaviors significantly contribute to shaping mental health outcomes. Effective coping strategies, notably seeking social support, problem-solving, and involving in adaptive forms of emotion regulation, contribute to improved mental health and resilience in the face of challenges (Panicker & Ramesh, 2019). Conversely, maladaptive coping mechanisms, notably avoidance and substance use can impact the development or augmentation of mental health disorders, including anxiety and depression (Panicker & Ramesh, 2019). Additional to the direct effect of behaviors on mental well-being, behaviors functioning as coping mechanisms may

serve as an indirect effect of environmental stressors on psychological well-being.

According to Lazarus and Folkman theory of stress and coping, coping behaviors, notably physical activity and smoking, can affect psychological well-being (S. Y. Kim, Guo, Won, & Lee, 2020; Liu et al., 2023). In fact, mental health (e.g., anxiety and depression) has been extensively studied using Lazarus theory of stress and coping, and behavioral health as coping strategies have been frequently predicted mental health (Crego, Yela, Gomez-Martinez, Riesco-Matias, & Petisco-Rodriguez, 2021; Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005; Shea et al., 2021). Moreover, mental health and behavioral health have also been studied using Lazarus theory of stress and coping after the COVID-19 pandemic in the general population (Acoba et al., 2022). The current study investigates whether coping behaviors were significantly associated with mental health of informal caregivers.

H3b. Coping behaviors mediates somatic health/illness

Some coping behaviors are unhealthy and maladaptive, such as insufficient physical activity and smoking. These behaviors may provide temporary relief, but they can also harm one's well-being (Tomas, Sancho, Melendez, & Mayordomo, 2012). Several studies have demonstrated the association of coping behaviors like insufficient physical activity and smoking with worse well-being (Dai et al., 2021; Kosendiak et al., 2021). Here, the measure of somatic health or illness is overall well-being. Perceived overall well-being as an effect has been explained using Lazarus stress and coping theories in prior studies (Vander Elst, De Cuyper, Baillien, Niesen, & De Witte, 2016). For instance, the relationship between job insecurity and perceived overall well-being has been previously investigated using Lazarus stress and coping

theory as an effect (Vander Elst et al., 2016). Well-being has also been investigated using Lazarus and Folkman's theory of stress and coping in the context of the COVID-19 pandemic. For example, the impact of the COVID-19 pandemic on consumers' well-being and coping strategies was investigated by Nath et al. in India (Nath, Jamshed, & Shaikh, 2022). The current study investigates whether coping behaviors were significantly associated with overall well-being of informal caregivers.

Collectively, the conceptual framework illustrates relationships among Environmental variables, Coping, Psychological well-being, and Somatic health/illness. Thus, the general hypotheses of this study, based on the conceptual framework indicated in Figure 4, are stated as follows:

H1: Informal caregivers tend to have negative coping behaviors when encountering adverse environmental variables.

H2a: Informal caregivers tend to experience psychological well-being issues when encountering adverse environmental variables.

H2b: Informal caregivers tend to experience somatic health issues when encountering adverse environmental variables.

H3a: Informal caregivers tend to experience psychological well-being issues mediated by coping behaviors.

H3b: Informal caregivers tend to experience somatic health issues mediated by coping behaviors.

Chapter 4: Methods

Study Design and Data

This is a retrospective, pooled, cross-sectional study. The data was extracted from the publicly available Health Information National Trends Survey (HINT) dataset from 2017 to 2020 and 2022 (Burke-Garcia et al., 2023; National cancer Institute [NCI], 2023). National Cancer Institute (NCI) initiated the Health HINTS two decades ago. The HINTS is designed to gather information on health-related subjects, such as behaviors health, mental health, and overall well-being among adult American population. The survey is conducted periodically to monitor the trends of health-related issues, such as mental health, and to inform the development of health communication and education programs (Berry et al., 2020; NCI, 2023; Mojtahedi, Sun, & Shen, 2023).

Within the HINTS 6 dataset, a full sample weight and a set of 50 replicates are available. Each adult surveyed receives a full-sample weight as well as a set of 50 replicate weights generated through the 'delete one' jackknife (JK1) replication method (NCI, 2023). The full-sample weight is utilized for determining population and subgroup estimates, while the replicate weights are employed for calculating standard errors associated with these estimates. The application of sampling weights was crucial for accurate extrapolation of findings from the respondent sample to the broader population, mitigating nonresponse biases. The person-level weights are calibrated to population counts, known as control totals, utilizing data from the United States Census Bureau American Community Survey, incorporating variables such as age,

gender, education, marital status, race, ethnicity, and census region (Berry et al., 2020; NCI, 2023).

The data collected from the HINTS survey is mostly publicly available, and it is used by researchers, public health officials, and policymakers to inform their decisions on health communication and education initiatives. Each year, there are about 4000 respondents. Of whom, around 700 are informal caregivers (Berry et al., 2020; NCI, 2023). This study used the HNITS information from 2017 to 2020 and 2022. The 2021 HINTS was excluded since it only included cancer patients and was therefore not representative of the US population (2023). The University of Nevada Las Vegas determined that the secondary analysis of deidentified, publicly accessible data was exempt from formal review.

Definition of Informal Caregivers in the Current Study

Caregiving status was identified by this question: "Are you currently caring for or making health care decisions for someone with a medical, behavioral, disability, or other condition?" (Berry et al., 2020; Kent et al., 2020; H. Kim et al., 2021; J. Kim, Dove, & Dang, 2022; S. Y. Kim et al., 2020; Mahmood et al., 2024; Mojtahedi et al., 2023). Those who responded "yes" were defined as caregivers. Professional caregivers were defined as those who responded "yes" to the following question: "(For the individual to whom you provide the most care) Do you provide any of this care professionally as a part of a job (for example, as a nurse or professional home health aide)?". Among caregivers, professional caregivers were excluded. The remaining caregivers were defined as informal caregivers (Mojtahedi et al., 2023).

Measures and Variables

In the present study, variables in the HINTS dataset were identified to measure constructs of the conceptual framework (Figure 4). A summary of measures and their definitions has been indicated in Table 1 and explained in detail below:

Environmental variable

The environmental variable was COVID-19 pandemic, which was the main independent variable (predictor) of this study. Our study period spanned 2017-2020 and 2022. Data from 2017 to 2019 were coded as COVID = 0 (before the COVID-19 pandemic). The 2020 and 2022 data were coded as COVID = 1 (after the COVID-19 pandemic).

Coping (behavioral health measures)

Coping (behavioral health) was measured by insufficient physical activity and cigarette smoking. These two variables, in addition to serving as outcomes, were used as predictors in multivariable models in which mental health and overall well-being were outcomes.

Insufficient physical activity

The definition of physical activity, which has been previously used by other researchers (Swoboda et al., 2021), was based on publicly available information from the HINTS codebook, as below:

"In a typical week, how many days do you do any physical activity or exercise of at least moderate intensity, such as brisk walking, bicycling at a regular pace, swimming at a regular pace, and heavy gardening?". Physical activity 5 days or more was considered meeting guidelines. Physical activities less than 5 days were considered insufficient physical activity (Swoboda et al., 2021).

Smoking

"Smoking status" was defined by the "smokestat" question, which was derived from other smoking-related questions. This question had 3 categories: Current; Former; Never (2023). Those whose responses were recorded as "current" were categorized as "smokers." Those whose responses were recorded as "former" or "never" were categorized as "non-smokers".

Mental health

The definition of mental health was based on previous publications (Walia et al., 2021) and the information that is available in the HINTS codebook (Westat, 2023). Psychological well-being was measured by four mental health variables, as well as the composite score of the four variables – called Psychological Distress score. The four mental health variables were "worrying", "nervous", "hopeless", and "little interest". Therefore, there are five outcomes for mental health in the present study.

"Worrying", "nervous", "hopeless", and "little interest"

"Worrying" was defined by this question: "Over the past 2 weeks, how often have you been bothered by: Not being able to stop or control worrying?". "Nervous" was defined by this question: "Over the past 2 weeks, how often have you been bothered by: feeling "nervous", anxious, or on edge?". "Hopeless" was defined by this question: "Over the past 2 weeks, how often have you been bothered by: feeling down, depressed, or hopeless? ". "Little interest" was defined by this question: "Over the past 2 weeks, how often were you bothered by: little interest or pleasure in doing things?" (2023).

Feeling "worrying", "nervous", "hopeless", and "little interest" were coded in the HINTS dataset on a 4-point Likert scale, 1 = nearly every day; 2 = more than half the days; 3 = several days; 4 = not at all (2023). In the present study, those who responded to these questions with "not at all" were categorized as informal caregivers whose responses were "no" to that particular question. Others who responded "nearly every day", "more than half the days", or "several days" were categorized as informal caregivers whose responses were "yes" to that particular question.

Psychological distress score

The HINTS dataset included total composite scores for these four mental health conditions, which were inverted (0 = not at all: 3 = nearly every day) and added, ranging from 0 to 12, with higher scores showing a more negative emotional state (2023; Kosendiak et al., 2021). This composite psychological distress score has been successfully employed to screen for anxiety and depression (Grace Yi et al., 2023; Kroenke et al., 2009). In addition to a continuous variable outcome (0-12), we categorized the composite psychological distress score based on

previous publications, where scores 0–2 was considered normal (Kroenke et al., 2009). We created binary categories for this variable (normal 0–2; mental health issues 3–12).

Overall well-being

"Overall well-being" was defined by this question: "In general, would you say your health is..." (2023). Those who responded "excellent" or "very good were categorized as informal caregivers with no or minimal overall well-being issues. Caregivers who responded "good," "fair," or "poor" were categorized as informal caregivers with general health issues. We also used this variable as a continuous outcome (1-5).

Conceptual framework with measures and operationalized hypotheses

According to the conceptual framework of this study (Figure 4) and general hypotheses stated in Chapter 3, the conceptual framework of this study with measures is displayed in Figure 5. We have three hypotheses and several sub hypotheses to shed light on behavioral health (coping), mental health, and overall well-being of informal caregivers before and after the COVID-19 pandemic.

Figure 5: Operationalized Conceptual Framework of This Study.

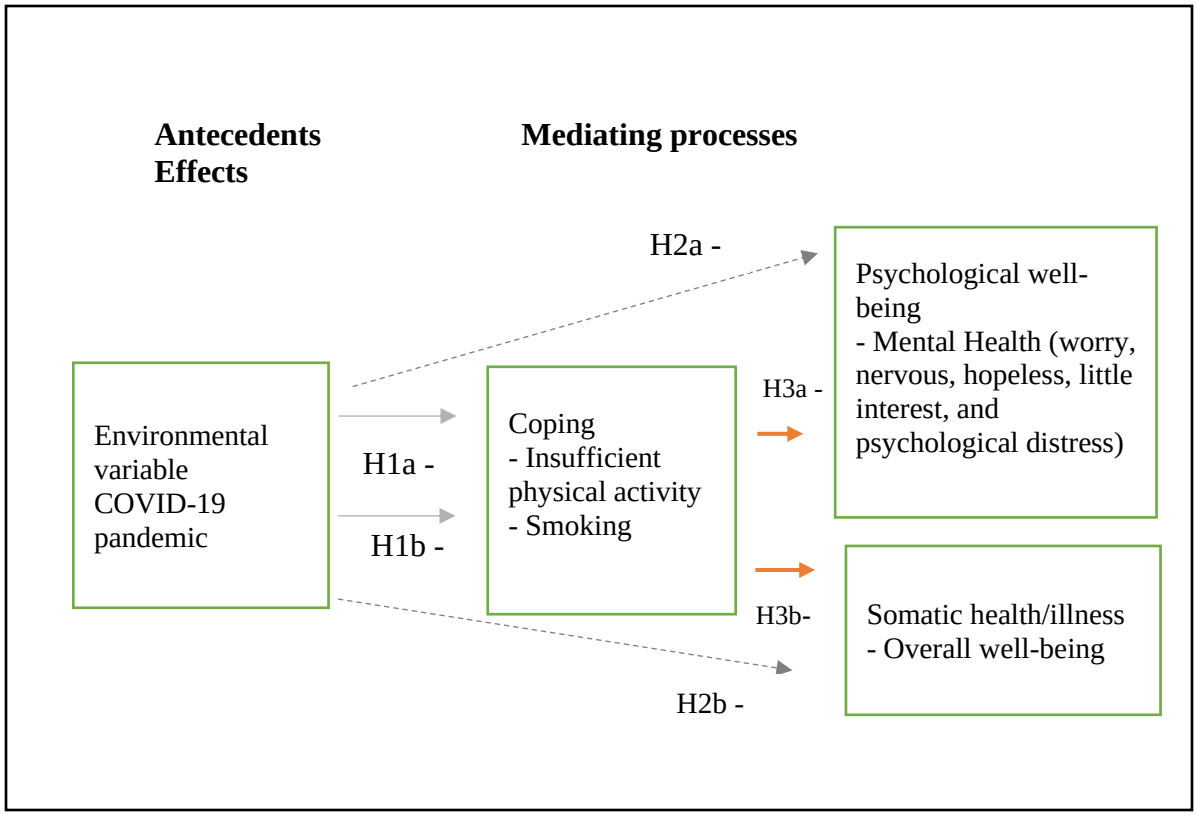


Table 1: Measures of the current study

Measures	Definition	Levels	Hypothesis
Environmental variables			
COVID-19 pandemic	2017-2019 vs 2020, 2022	Binary	H1-H3
Coping			
Insufficient physical activity	In a typical week, how many days do you do any physical activity or exercise of at least moderate intensity, such as brisk walking, bicycling at a regular pace, swimming at a regular pace, and heavy gardening?" and exercise less than 5 days considered inactivity	Binary	H1, H3
Smoking	"Do you now smoke cigarettes?"	Binary	H1, H3
Effects			
Mental health			
worrying	Over the past two weeks, how often have you been bothered by: worrying. The answers included not at all, several days, more than half days, nearly every day	Binary	H2, H3
nervous	Over the past two weeks, how often have you been bothered by: anxious. The answers included not at all, several days, more than half days, nearly every day	Binary	H2, H3
hopeless	Over the past two weeks, how often have you been bothered by: depressed. The answers included not at all, several days, more than half days, nearly every day	Binary	H2, H3
little interest	Over the past 2 weeks, how often have you been bothered by: Little interest or pleasure in doing things?. The answers included not at all, several days, more than half days, nearly every day	Binary	H2, H3
Psychological distress score	Psychological distress score are assessed using a combined score from these four separate questions. The new ordinal variable will be categorized based on total PHQ-4 score interpretation as 0-2 as none; 3-5 as mild; 6-8 as moderate; and 9-12 as severe psychological distress	Binary	H2, H3
Overall well-being	In general, would you say your health Is excellent, very good, good, fair or poor.	Binary	H2, H3
Covariates			H1-H3
Age			
Gender			
Marital status			
Educational level			
Health insurance			
Census Region			

Hypotheses:

The hypotheses of this study are listed below, and a schematic of hypotheses is shown in Figure 5. The Environmental variable was the COVIC-19 pandemic. Three years before the pandemic (2017-2019) are compared to two years after the pandemic (2020, 2022). Coping was measured by behavioral health. Psychological well-being is measured by mental health. Somatic health is measured by overall well-being. Thus, operationalize hypotheses of the study are listed as follows:

H1: Informal caregivers tend to have more negative coping behaviors when encountering adverse environmental variables.

H1a: Informal caregivers tend to be more physically inactive when encountering adverse environmental variables.

H1b: Informal caregivers tend to smoke more when encountering adverse environmental variables.

H2a: Informal caregivers tend to have worse mental health when encountering adverse environmental variables.

H2a.1: Informal caregivers tend to experience more “worrying” when encountering adverse environmental variables.

H2a.2: Informal caregivers tend to experience more “nervous” when encountering adverse environmental variables.

H2a.3: Informal caregivers tend to experience more “hopeless” when encountering adverse environmental variables.

H2a.4: Informal caregivers tend to experience more “little interest” when encountering

adverse environmental variables.

H2a.5: Informal caregivers tend to have a worse physiological distress when encountering adverse environmental variables.

H2b: Informal caregivers tend to have worse overall well-being when encountering adverse environmental variables.

H3a: Informal caregivers' mental health are mediated by coping behaviors.

H3a.1: “Worrying” is mediated by coping behaviors.

H3a.2: “Nervous” is mediated by coping behaviors.

H3a.3: “Hopeless” is mediated by coping behaviors.

H3a.4: “Little interest” is mediated by coping behaviors.

H3a.5: “Psychological distress” is mediated by coping behaviors.

H3b: “overall well-being” is mediated by coping behaviors.

Statistical Analyses

All data were analyzed using the free version of the SAS software, called SAS OnDemand for Academics. The handbook of the HINTS was the guideline for creating the codes (2023). All SAS codes are available in Appendix A. P-values smaller than 0.05 were considered to be statistically significant. Statistical estimates, such as odds ratios (ORs), along with their corresponding 95% confidence intervals (CIs), were calculated for binary outcomes in regression

models. These estimates were used to reveal the strength and direction of associations between variables.

Descriptive analysis

Frequencies were computed for all variables. Descriptive analysis and frequencies are the initial steps in looking at the data. It gives researchers an idea about the possible association of the same variables with each other (Martens, Turkowyd, & Endesfelder, 2021). Descriptive statistics provide a concise summary of key characteristics of a dataset. Frequencies, specifically, help in quantifying the occurrence of different values within a dataset, enabling researchers to identify prevalent trends or outliers (Martens et al., 2021). These analytical techniques not only aid in exploring data comprehensively but also facilitate effective communication of findings, assisting stakeholders in making informed decisions based on empirical evidence (Martens et al., 2021).

Binary logistic regression

Regression models are widely used for predicting the value of an outcome based on one or more predictors. These models analyze the relationship between outcomes and predictors (Schwender & Ruczinski, 2010). Once a regression model is developed and the assumptions are met, it can be used to predict the association of variables (Cacola & Pant, 2014; Xia et al., 2023). The output of the analysis calculates P-values, beta-coefficients, OR, and CI based on this relationship (Schwender & Ruczinski, 2010). Subsequently, ORs and CIs are frequently used to explain the relationships between variables.

The logistic regression model estimates the relationship between the predictors and the log-odds of the outcome occurring. This enables researchers to make predictions about the probability of the outcome occurring based on the values of the predictors (Schwender & Ruczinski, 2010). Binary logistic regression analyzes the relationship between one or more independent variables (predictor) and a binary dependent variable (outcome), where the dependent variable can take only two possible outcomes, typically coded as 0 and 1 (Schwender & Ruczinski, 2010). The logistic regression model estimates the probability of the outcome by employing the logistic function to transform the linear combination of predictors into a probability score between 0 and 1 (Schwender & Ruczinski, 2010). The coefficients derived from the model represent the change in the log-odds of the event occurring for a one-unit change in the predictor, facilitating interpretation and prediction (Schwender & Ruczinski, 2010).

The basic equation for a logistic model is as follows (Schwender & Ruczinski, 2010):

$$\text{logit}(p) = \beta_0 + \beta_1 * X_1 + \beta_2 * X_2 + ... + \beta_n * X_n$$

logit(p): This represents the log-odds of the probability of the outcome occurring. The logit function is the natural logarithm of the odds ratio, where the odds ratio is the ratio of the probability of the event occurring to the probability of it not occurring (Schwender & Ruczinski, 2010).

p: This represents the probability of the outcome occurring. In binary logistic regression, the dependent variable is binary (e.g., 0 or 1, yes or no), and the logistic regression model estimates the probability of the outcome being equal to 1 given the values of the predictors (Schwender & Ruczinski, 2010).

β_0: This is the logistic regression model intercept term, indicating the log-odds of the outcome occurring when all predictors are equal to zero (Schwender & Ruczinski, 2010).

$\beta_1, \beta_2, \ldots \beta_n$: These are the coefficients (or slopes) associated with each predictors (denoted as $X_1, X_2, .., X_n$), indicating the change in the log-odds of the dependent variable (outcome) for a one-unit change in the corresponding independent variable (predictors), after adjusting for controls (Schwender & Ruczinski, 2010).

$X_1, X_2, .., X_n$: These are the or predictors included in the model. Each predictor represents a different aspect or characteristic that may influence the probability of the outcome occurring (Schwender & Ruczinski, 2010).

A multivariable binary logistic regression model using **PROC SURVEYLOGISTIC** was used with the response as a dichotomous 0-1 variable (Westat, 2023) in the current study.

Mediation regression models

Mediation regression analysis measures if a predictor variable (here the COVID-19 pandemic) affects outcome variables (here mental health and overall well-being) through mediating variables (here behaviors) (MacKinnon, Fairchild, & Fritz, 2007). It helps in comprehending the indirect effects of the predictor on the outcome through one or more intervening variables, known as mediators (here behavioral health including physical activity and smoking). In another word, in a mediation model, the predictor variable (X) affects the outcome variable (Y) both directly and indirectly through one or more mediators (M) (MacKinnon et al., 2007; Rijnhart, Valente, Smyth, & MacKinnon, 2023). The fundamental mediation model comprises three regression equations.

Equation 1 (tests H1):

$$\textbf{logit (Pr (M=1|x)) = } \beta_{0M} + \beta_{1M}X$$

where β_{0M} represent regression intercepts, and β_{1M} terms signify regression slopes for the association of M and X (here behavioral health with COVID-19 pandemic). This equation elucidates the relationship between the predictor variable (X) and the mediator (M) (Rijnhart et al., 2023). An Example of this equation for the current study is:

logit ($Y_{smoking}$ =1) = β_0+ $\beta_1 I(X_{Covid\text{-}19}=1)$

Equation 2 (tests H2):

$$\textbf{Logit (Pr (Y=1|x)) =} \boldsymbol{\beta_{0Y}+\beta_{1Y}X}$$

where β_{0Y} represents the intercept of the regression, and β_{1Y} signifies the slope coefficient representing the association the X and Y (here mental health conditions (Y) and overall health (Y) with COVID-19 pandemic). This overall effect characterizes the relationship between X and Y independently of the mediator. The equation indicates the direct and indirect effects into a single regression coefficient, called total effect (Rijnhart et al., 2023). An Example of this equation for the current study is:

logit ($Y_{worrying}$ =1) = β_0+ $\beta_1 I(X_{Covid\text{-}19}=1)$

Equation 3 (tests H3):

$$\textbf{Logit (Pr (Y=1|x, m)) = } \beta_{0Y*} + \beta_{1Y*}X + \beta_{2Y}M$$

where β_{0Y*} represent regression intercepts, and the β_{1Y*} and β_{2Y} signify regression slopes. The asterisks in Equation 3 indicates that the coefficients differ from those in Equation 2. Specifically, in Equation 3, β_{1Y*} denotes the impact of X on Y after controlling for the mediator

(direct effect), whereas β_{1Y} in Equation 2 represents the relationship between X and Y without controlling for mediators, total effect (Rijnhart et al., 2023). An Example of this equation for the current study is:

$$\text{logit}\,(Y_{worrying}=1) = \beta_0 + \beta_1 I(X_{Covid\text{-}19}=1) + \beta_2 I(X_{smoking}=1)$$

In a mediation model, all three equations should demonstrate significance to provide evidence for mediation. A significant X → M relationship indicates that the predictor affects the mediator. a significant X → Y relationship indicates a direct effect of the predictor on the outcome variable (MacKinnon et al., 2007). Finally, a significant M → Y relationship suggests that the mediator influences the outcome variable (Rijnhart et al., 2023). If these three-regression equation are significant, then the indirect effect of the predictor through mediator will be significant. Several different methods have been proposed to calculate the mediation effect, notably the production of coefficients for logit models (Rijnhart et al., 2023). The production of coefficients refers to the process of calculating the indirect effect of an independent variable on a dependent variable through a mediator variable (Rijnhart et al., 2023). The production of coefficients involves multiplying the coefficients associated with the paths from the independent variable to the mediator and from the mediator to the dependent variable.

Indirect effect= $\boldsymbol{\beta_{1M} \times \beta_{2Y}}$

Where:

$\boldsymbol{\beta_{1M}}$ is the coefficient associated with the equation from the independent variable (X) to the mediator (M).

$\boldsymbol{\beta_{2Y}}$ is the coefficient associated with the equation from the mediator (M) to the dependent variable (Y) (Rijnhart et al., 2023).

Akaike Information Criterion (AIC)

When comparing statistical models, the Akaike Information Criterion (AIC) assists with model selection by balancing goodness of fit in complex models (Wagenmakers & Farrell, 2004). Lower AIC values indicate better-fitting models relative to their complexity, making them preferable choices (Wagenmakers & Farrell, 2004). By comparing AIC values across competing models fitted to the same data, researchers can identify the most suitable model that achieves an optimal balance between explanatory power and parsimony, facilitating robust inference and prediction (Wagenmakers & Farrell, 2004).

Control Variables (Covariates)

Age, gender, education, marital status, health insurance, and census region were the sociodemographic characteristics examined, and all had less than 5% missing values. They were defined according to existing groupings in the HINTS codebook as well as current literature on caregivers from the HINTS dataset (Berry et al., 2020; 2023). Missing data were most common in income and race/ethnicity, accounting for more than 10% of all missing values. They were excluded from regression models. Using sociodemographic control variables in a regression model predicting the behavioral health, mental health, and overall well-being of informal caregivers is important because they can influence impact behavioral health, mental health, and overall well-being (Berry et al., 2020).

Age

The association between age and behavioral health, mental health, and overall well-being has been well-known. Age serves as an important control variable due to its potential confounding effects on well-being measures. Older individuals may experience different health challenges compared to younger individuals (Berry et al., 2020). Older individuals often demonstrate resilience against mental health challenges (Berry et al., 2020; Ngamasana et al., 2023). By accounting for age-related variations, researchers can better understand the distinct contributions of informal caregiving to behavioral health, mental health, and overall well-being.

Gender

Gender differences can influence behavioral health, mental health, and overall well-being through various biological, psychological, and socio-cultural mechanisms. For example, females tend to have greater incidence for depressive disorders and anxiety disorders, while males may be more prone to behaviors like alcohol drinking and smoking (Berry et al., 2020). Including gender and other related factors as a control variable in regression models predicting health of informal caregivers allows researchers to examine the unique contributions of informal caregivers on health while accounting for the potential confounding effects of gender.

Education

Education levels can provide insights into socioeconomic status, knowledge, and skills that may influence different facets of health, notably behavioral health, mental health, and

overall well-being. Education significantly contributes to individual behaviors, knowledge, and access to resources that impact different aspects of health (Berry et al., 2020; Ngamasana et al., 2023). More advanced education is often associated with enhanced health outcomes, notably lower occurrence of mental health disorders and healthier lifestyle choices. Education can also influence factors like socioeconomic levels, social support networks, and health literacy, all of which have implications for health. By including education as a control variable in regression models predicting health of informal caregivers, researchers can better isolate the consequence of informal caregiving on health while accounting for potential educational attainment confounding effects (Zhang, Chen, McCubbin, McCubbin, & Foley, 2011).

Health insurance

Health insurance coverage can be directly related to mental health and overall well-being since it is directly related to health service access and quality. There is solid evidence indicating individuals with reliable health coverage have better health outcomes. Health insurance coverage plays a significant role in preventive care and mental health services (Berry et al., 2020; Ngamasana et al., 2023). Health insurance as a control variable in regression models predicting the health of informal caregiver's accounts for the potential confounding effects of insurance coverage on health, enabling the analysis of an association between informal caregiving and health in a more exact manner (Zhang et al., 2011).

Marital status

Marital status can be related to many aspects of health through several pathways, including notable social support and economic stability. For example, couples (those who are married or in stable partnerships) often enjoy enhanced levels of social support, which can be linked to protection against mental health issues (Berry et al., 2020; Ngamasana et al., 2023). Marital status can also be related to positive, healthy behaviors. There is solid evidence to indicate that married individuals often have healthier behaviors, such as lower rates of smoking and drinking. Therefore, marital status should be included as a control variable in regression models. This inclusion helps more accurately predict health-related variables. In our study, its inclusion enabled us to examine the association of COVID-19 on mental health and overall well-being since marital status as a potential confounding factor was taken into account (Berry et al., 2020; Kaggwa et al., 2023).

Census region

The impact of the census region on the behavioral health, mental health, and overall well-being of informal caregivers reflects the complicated interaction of many culturally known and unknown factors in different geographical areas (Kalb et al., 2021). Regional disparities in access to healthcare services, community support systems, and socio-economic resources may significantly influence various aspects of informal caregivers' health, including behavioral health, mental health, and overall well-being. For instance, caregivers residing in urban areas of densely populated regions might face heightened stress due to greater caregiving responsibilities coupled with the limited availability of mental health services (Kalb et al., 2021). Conversely,

caregivers residing in rural or remote regions may encounter unique challenges; of them, geographic isolation, limited healthcare infrastructure, and reduced availability of respite care options are notable. All of these can exacerbate mental health issues (Kalb et al., 2021).

Sociodemographic categories

The sociodemographic characteristics were defined according to the categories within the HINTS in addition to current publications derived from the HINTS dataset on informal caregivers (Berry et al., 2020; NCI, 2023). These categories encompass gender, with individuals identified as either women or men; age, segmented into distinct groups spanning from 18 to 34, 35 to 49, 50 to 64, and those aged 65 years and above; educational attainment, stratified into four groups comprising individuals with less than high school degrees, graduated from high school, some college education, as well as possessing college degrees or higher; health insurance coverage, denoted as either present or absent; and geographic location, defined by Census regions (Northeast, Midwest, South, and West (Berry et al., 2020; NCI, 2023).

Limitations

Our study was based on a solid, national survey. However, all studies based on surveys have more or less certain limitations. Surveys are self-reported. Therefore, participants should have the ability to respond to the survey in the correct way. Their willingness to provide accurate responses also matters (Brenner & DeLamater, 2016). Moreover, respondents may unintentionally provide inaccurate information due to memory lapses. All of these can lead to

potential errors in the data collection (Brenner & DeLamater, 2016; Fincham, 2008). Memory lapses are particularly important for retrospective surveys like the present study.

Furthermore, individuals may not be comfortable telling the truth about sensitive or personal information. This can result in underreporting responses to negative behaviors or conditions, such as smoking or mental health issues. In addition, social desirability bias should be considered. Participants may underreport their behaviors or conditions due to the social stigma surrounding the health conditions (Fincham, 2008; Newman et al., 2002).

The cross-sectional design of the study also restricts conclusions on causation. The 2021 survey, which was during the pandemic, was not representative of the USA population (2023) and was not included in the present study.

Additionally, surveys may not contain the full range of variables that enrich a study (Brenner & DeLamater, 2016; Fincham, 2008). Our study primarily focused on mental health symptoms related to anxiety and depressive disorders, with an emphasis on feelings of “worry,” “nervous,” “hopeless,” and “little interest." However, this focus might not fully capture the complexity of mental health conditions. Data regarding the duration of caregiving—a potential predictor of our outcomes—was not available, potentially limiting the depth of the findings. Secondary data analysis inherently confines studies to predefined, available variables (Cole & Trinh, 2017), and this study could not explore all predictors. We only included predictors available in the HINTS dataset during the study period (2017–2020, 2022) with the fewest missing values (less than 5%).

Chapter 5: Results

Descriptive analysis

Table 2 depicts the descriptive analysis of sociodemographic characteristics, behavioral health (physical activity and smoking), mental health, and overall well-being perception among American informal caregivers before (2017-2019) and after the COVID-19 pandemic (2020, 2022). Regarding behavioral health, the weighted percentage of current smokers showed a decrease from 13.9% before the pandemic to 12.8% after the pandemic. Sufficient physical activity increased from 24.8% before the pandemic compared to 26.6.% after the pandemic.

Regarding mental health measures, increases were observed in the percentages of informal caregivers reporting feelings of "worrying," "nervous," "hopeless," and "little interest" after the pandemic. The percentage of informal caregivers with a normal psychological composite score (0-2) decreased after the pandemic (59.8%) compared to pre-pandemic (65.2%). The perception of overall well-being also decreased after the pandemic. The percentage of those who reported excellent or very good on overall well-being decreased from 46.2% before the pandemic to 39.8% for diminished overall well-being after the pandemic.

Table 2. Descriptive analysis of informal caregivers before (2017-2019) and after the COVID-19 pandemic (2020, 2022)

	Before the pandemic			After the pandemic		
Characteristics	**Frequency**	**Weighted Frequency**	**(%)**	**Frequency**	**Weighted Frequency**	**(%)**
Age groups, years						
18–34	151	12,663,011	11.64	126	9,626,802	13.06
35–49	446	37,602,822	34.57	325	21,863,942	29.66
50–64	642	39,680,778	36.49	469	28,715,124	38.96
65 +	477	18,796.359	17.28	398	13,494,579	18.31
Gender						
Male	574	40,306,399	36.33	420	29,901,399	40.77
Female	1151	70,616,648	63.66	882	43,426,866	59.22
Race/Ethnicity						
White	994	67,640,307	64.22	715	44,787,528	63.70
None-White	614	37,685,202	35.77	521	25,521,056	36.29
Household income levels						
< $20,000	248	16,903,521	16.39	193	10,337,972	14.98
$20,000 - less than $35,000	190	12,026,576	11.66	144	7,750,465	11.233
$35,000 - less than $50,000	224	15,983,655	15.50	160	8,046,420	11.66
$50,000 - less than $75,000	275	14,316,696	13.88	222	12,897,338	18.69
≥ $75,000	661	43,849,129	42.5391	497	29,961,536	43.42
Education						
Less than high school	82	6,513,309	5.90	68	4,509,260	6.13
High school	252	20,912,691	18.96	202	12,744,640	17.35
Some college	524	43,323,617	39.27	409	33,149,990	45.13
College Graduate or More	864	39,549,307	35.85	622	23,050,512	31.38
Insured						
Yes	1.642	102,070,147	93.07	1.251	69,653,671	92.45
No	88	7,593,756	6.92	92	56,86,840	7.54
Marital status						
Married/living with a partner	1.128	74,183,181	68.06	847	50,292,609	68.86
Others	585	34,798,469	31.93	450	22,736,919	31.13
Census Regions						
Northeast	262	19,797,357	17.69	211	15,788,007	20.91
Midwest	322	21,415,910	19.14	217	14,366,019	19.03
South	778	45,608,126	40.76	606	28,359,690	37.56
West	393	25,047,749	22.39	313	16,972,839	22.48
Smoking status						
Current smoker	213	15,508,178	13.91	144	93,82,376	12.8
Former or Never smoker	1,522	95,914,486	86.08	1,163	63,888,342	87.19
Sufficient Physical activity						
No	1,313	83,125,929	75.19	950	54,484,322	73.83
Yes	418	27,427,183	24.80	359	19,311,808	26.16
Worrying						
Yes	605	41,540,576	37.65	564	33,840,875	45.55
No	1123	68,766,057	62.34	767	40,448,973	54.44
Nervous						
Yes	747	49,746,561	45.16	625	36,761,539	49.61
No	981	60,394,235	54.83	697	37,328,005	50.38
Hopeless						
Yes	571	38,188,592	34.74	480	28,515,680	38.54
No	1,152	71,728,307	65.25	842	45,467,021	61.45
Little interest						
Yes	605	41,540,576	37.65	542	30,867,132	41.64
No	1,123	68,766,057	62.34	781	43,246,848	58.35
Psychological distress						
No	1,157	71,366,980	65.23	808	44,163,355	59.86
Yes	557	38,040,516	34.76	504	29,609,499	40.13
Perceived overall well-being						
Excellent or very good	842	51,322,411	46.26	553	29,747,001	39.81
Good, fair, poor	894	59,618,683	53.73	780	44,972,732	60.18

Coping Behavioral health: Insufficient Physical Activity and Smoking (Hypothesis 1)

As is indicated in Table 3, comparing the post-COVID-19 pandemic with the pre-pandemic, behavioral health, including insufficient physical activity (OR = 0.89; 95% CI. 0.68-1.16; p = 0.4059) and smoking (OR = 0.90; 95% CI, 0.60-1.36; p = 0.6336), were not significantly associated with the pandemic in regression models adjusted for sociodemographic characteristics (Table 3A). This table is related to the H1a and H1b of the current study. Unadjusted models also did not demonstrate any significant differences in insufficient physical activity and smoking before and after the pandemic (Table 3B). The models of fits indicated that AIC of the adjusted models were lower than the unadjusted ones (Appendix B, TableS1). SAS codes for these models are available in Appendix A. Due to the absence of statistically significant associations between behavioral health and the COVID-19 pandemic, mediation analyses were not pursued (MacKinnon et al., 2007).

Table 3A (RQ1): Comparing insufficient physical activity and smoking before and after the COVID-19 pandemic among informal caregivers using regression models adjusted for covariates (HINTS*)

	Insufficient physical activity (N=2,889)			**Smoking (N=2,895)**		
Characteristics	**Odds ratio**	**95% confidence interval**	**p**	**Odds ratio**	**95% confidence interval**	**p**
Period						
Before the pandemic (ref)						
After the pandemic	0.89	0.68-1.16	0.4059	0.90	0.60-1.36	0.6336
Gender						
Women (ref)						
Men	0.57	0.43-0.76	0.0001	1.42	0.95-2.13	0.0855
Age groups, years						
Ref, 18–34						
35–49	0.88	0.51-1.51	0.6545	1.53	0.74-3.17	0.2443
50–64	0.76	0.45-1.30	0.3267	1.31	0.64-2.68	0.4511
65 +	0.86	0.50-1.46	0.5799	0.35	0.17-0.74	0.0061
Education						
<high school (ref)						
High school	1.37	0.63-2.98	0.4138	0.44	0.21-0.93	0.0336
Some college	1.07	0.50-2.30	0.8500	0.30	0.15-0.58	0.0004
≥ College graduate	0.66	0.30-1.42	0.2898	0.10	0.05-0.20	<.0001
Marital status						
Others (ref)						
Married/live with a partner	0.94	0.69-1.28	0.7038	0.45	0.29-0.68	0.0002
Health insurance						
No (ref)						
Yes	1.60	0.91-2.83	0.0997	0.74	0.40-1.37	0.3473
Census region						
West (ref)						
Northeast	1.37	0.86-2.18	0.0218	0.97	0.46-2.01	0.9403
Midwest	1.53	1.00-2.35	0.5633	2.09	1.03-4.23	0.0395
South	1.09	0.76-1.57	0.6677	1.34	0.73-2.45	0.3337

*HINTS, Health Information and National Trends Survey.

Table 3B: Comparing insufficient physical activity and smoking before and after the COVID-19 pandemic among informal caregivers in unadjusted regression models (HINTS)*

	Insufficient physical activity N=3,040			**Smoking N=3,042**		
Characteristics	**Odds ratio**	**95% Confidence interval**	**p-value**	**Odds ratio**	**95% Confidence interval**	**p-value**
Period						
Before the pandemic (ref)						
After the pandemic	0.93	0.72-1.19	0.5716	0.90	0.62-1.31	0.6107

*HINTS, Health Information and National Trends Survey.

Mental Health: “Worrying,” “Nervous,” “Hopeless,” “Little Interest”, and Psychological Distress (Hypotheses 2a and 3a)

Table 4A demonstrates mental health models of “worrying,” “nervous,” “hopeless,” “little interest”, and psychological distress, before and after the COVID-19 pandemic adjusted only for sociodemographic characteristics, which relates to the H2a of the current study. Table 4B compares mental health conditions of feeling “worrying,” “nervous,” “hopeless,” “little interest”, and psychological distress before and after the COVID-19 pandemic among informal caregivers using multivariable logistic models adjusted for all variables including behavioral health, (smoking and physical activity) and covariates, which relates to the H3a of the current study. Table 4C demonstrates unadjusted models for mental health conditions of “worrying,” “nervous,” “hopeless,” “little interest”, and psychological distress before and after the COVID-19 pandemic among informal caregivers. “Worrying” was significantly associated with the pandemic in all these three models. The AIC of the models adjusted for both behavioral health and sociodemographic characteristics were lower than the other two models followed by the model adjusted only for sociodemographic characteristics and unadjusted model (Appendix B, Table S2), indicating the fully adjusted model is the best model in the current study.

Table 4A (RQ2a): Comparing mental health conditions before and after the COVID-19 pandemic among informal caregivers using models adjusted for covariates without behaviors (HINTS)*

	Worrying N=2,848			**Nervous N=2,846**			**Hopeless N=2,843**			**Little interest N=2,849**			**Psychological distress N=2,830**		
Factors	**OR** **	**CI** **	**p**	**OR** **	**CI** **	**p**	**OR** **	**CI** **	**p**	**OR** **	**CI** **	**p**	**OR** **	**CI** **	**p**
Period															
Pre-pandemic (ref)															
Post-pandemic	1.41	1.08-1.83	0.0094	1.22	0.96-1.56	0.0932	1.18	0.89-1.57	0.2380	1.15	0.88-1.52	0.2852	1.27	0.97-1.66	0.0756

*HINTS, Health Information and National Trends Survey. ** OR, odds ratio. *** CI, 95% confidence interval.

Table 4B (RQ3a): Comparison of mental health conditions (worrying, nervous, hopeless, little interest, and psychological distress) before and after the COVID-19 pandemic among informal caregivers in models included behaviors and covariates

	Worrying N=2,848			**Nervous N=2,846**			**Hopeless N=2,843**			**Little interest N=2,849**			**Psychological distress N=2,830**		
Factors	**OR***	**CI****	**p**	**OR**	**CI**	**p**	**OR**	**CI**	**p**	**OR**	**CI**	**p**	**OR**	**CI**	**p**
Period (pre-pandemic (ref)															
Post-pandemic	1.43	1.10-1.87	0.0081	1.24	0.97-1.58	0.0829	1.20	0.90-1.60	0.2073	1.18	0.89-1.56	0.2311	1.29	0.98-1.70	0.0632
Sufficient physical activity (yes, ref)															
No	1.47	1.09-1.97	0.0110	1.20	0.92-1.57	0.1598	1.51	1.12-2.03	0.0062	2.11	1.57-2.84	<.0001	1.67	1.24-2.26	0.0007
Current smokers (no, ref)															
Yes	1.690	1.10-2.59	0.0164	1.91	1.28-2.83	0.0014	1.70	1.16-2.49	0.0062	1.63	1.07-2.47	0.0210	1.79	1.19-2.68	0.0048
Gender (Women, ref)															
Men	0.60	0.44-0.80	0.0006	0.62	0.46-0.83	0.0013	0.73	0.54-0.98	0.0367	0.82	0.617-1.09	0.1752	0.69	0.51-0.93	0.0155
Age groups (18-34, ref)															
35–49	0.69	0.43-1.09	0.1181	0.68	0.42-1.11	0.1265	0.69	0.42-1.11	0.1265	0.61	0.37-1.01	0.0569	0.54	0.33-0.90	0.0177
50–64	0.61	0.38-0.97	0.0374	0.57	0.36-0.90	0.0167	0.53	0.33-0.86	0.0104	0.50	0.30-0.82	0.0062	0.44	0.27-0.71	0.0009
65 +	0.47	0.29-0.74	0.0016	0.43	0.27-0.69	0.0005	0.37	0.22-0.62	0.0002	0.41	0.25-0.67	0.0005	0.34	0.21-0.55	<.0001
Education (<high school, ref)															
High school	0.66	0.35-1.27	0.2205	0.87	0.49-1.53	0.6367	1.32	0.7-2.47	0.3810	1.018	0.51-2.01	0.9581	0.84	0.43-1.66	0.6326
Some college	0.63	0.34-1.17	0.1494	0.97	0.56-1.67	0.9171	1.425	0.77-2.62	0.2534	0.868	0.44-1.68	0.6754	0.79	0.40-1.52	0.4832
≥ College graduate	0.50	0.27-0.91	0.0247	0.80	0.46-1.38	0.4213	0.90	0.50-1.62	0.7419	0.529	0.27-1.01	0.0554	0.50	0.26-0.97	0.0422
Marital status (others, ref)															
Married or live with a partner	0.775	0.59-1.01	0.0672	0.96	0.73-1.26	0.7992	0.65	0.49-0.85	0.0021	0.598	0.45-0.79	0.0004	0.64	0.49-0.84	0.0015
Health insurance (no, ref)															
Yes	0.60	0.37-0.94	0.0279	0.85	0.53 1.37	0.5209	0.897	0.53-1.49	0.6757	1.04	0.62-1.75	0.8552	0.77	0.46-1.29	0.3295
Census region (West, ref)															
Northeast	0.971	0.62-1.49	0.8931	1.08	0.72-1.62	0.6815	0.757	0.51-1.11	0.1621	0.656	0.44-0.98	0.0394	0.66	0.43-1.02	0.0673
Midwest	1.117	0.74-1.66	0.5862	1.37	0.94-1.99	0.0939	0.833	0.56-1.220	0.3468	0.785	0.53-1.15	0.2148	0.83	0.56-1.24	0.3778
South	0.830	0.58-1.17	0.2913	0.92	0.65-1.29	0.6339	0.810	0.56-1.15	0.2433	0.84	0.59-1.19	0.3321	0.78	0.55-1.10	0.1629

*OR, odds ratio; ** CI, 95%confidence interval.

Table 4C: Comparing mental health conditions before and after the COVID-19 pandemic among informal caregivers in unadjusted models (HINTS)*

	Worrying N=3,057			**Nervous N=3,050**			**Hopeless N=3,045**			**Little interest N=3,051**			**Psychological distress N=3,026**		
Characteristics	**Odds ratio**	**CI**	**p-value**	**Odds ratio**	**CI**	**p-value**	**Odds ratio**	**CI**	**p-value**	**Odds ratio**	**CI**	**p-value**	**Odds ratio**	**CI**	**p-value**
Period															
Before pandemic (reference)															
After the pandemic	1.34	1.06 - 1.69	0.0127	1.19	0.95 - 1.49	0.1119	1.17	0.90 - 1.53	0.2237	1.18	0.92 - 1.51	0.1869	1.25	0.98 - 1.60	0.0633

*HINTS, Health Information and National Trends Survey. ** CI, 95% confidence interval.

“Worrying”

The odds of experiencing “worrying” significantly increased after the pandemic compared to the pre-pandemic using adjusted regression models only for covariates (OR = 1.41; 95% CI: 1.08-1.83; p = 0.0094), (Table 4A, relates to H2a), fully adjusted regression models for covariates and behavioral health (OR = 1.43; 95% CI: 1.10; 1.87; p = 0.0081) (Table 4B, relates to H3a), and unadjusted model (Table 4C). The models of fit and AIC of the unadjusted and adjusted model are displayed in Appendix B, Table S2. The AIC was lowest for the fully adjusted model (equation 3a), indicating it was the best model. Table 4B (H3a) indicates that insufficient physical activity and smoking were significantly associated with the pandemic. Informal caregivers with insufficient physical activity had higher odds of reporting “worrying” (OR = 1.47; 95% CI, 1.09-1.97; p = 0.0110). Current smokers compared to former/never smokers had higher odds of reporting “worrying” (OR = 1.69; 95% CI, 1.10-2.59; p = 0.0164) (Table 4B). Due to the absence of statistically significant associations between behavioral health and the COVID-19 pandemic, mediation analysis was not pursued (MacKinnon et al., 2007).

“Nervous”

“Nervous” had no significant association with the pandemic in adjusted regression models only for covariates (Table 4A, relates to H2a), fully adjusted regression models for covariates and behavioral health (Table 4B, relates to H3a), or unadjusted model (Table 4C) (p > 0.05). The models of fit and AIC of these three models are displayed in Appendix B, Table S2. The AIC was lowest for the fully adjusted model (relates to H3a), indicating it was the best

model. Table 4B (relates to H3a) indicates that current smokers compared to former/never smokers had significantly higher odds of feeling “nervous” (OR = 1.91, 95% CI: 1.29-2.83, p = 0.0014).

“Hopeless”

“Hopeless” had no significant association with the pandemic in adjusted regression models only for covariates (Table 4A, relates to H2a), fully adjusted regression models for covariates and behavioral health (Table 4B, relates to H3a), or unadjusted model (Table 4C) (p > 0.05). The models of fit and AIC of these three models are displayed in Appendix B, Table S2. The AIC was lowest for the fully adjusted model (relates to H3a), indicating it was the best model. Table 4B (relates to H3a indicates that those not engaged in sufficient physical activity had significantly higher odds of reporting “hopeless” (OR = 1.51, 95% CI: 1.12, 2.03, p = 0.0062). Current smokers compared to former/never smokers had significantly higher odds of feeling “hopeless” (OR = 1.70, 95% CI: 1.16, 2.49, p = 0.0062).

“Little interest”

“Little interest” had no significant association with the pandemic in adjusted regression models only for covariates (Table 4A, relates to H2a), fully adjusted regression models for covariates and behavioral health (Table 4B, relates to H3a), or unadjusted model (Table 4C) (p > 0.05). The models of fit and AIC of these three models are displayed in Appendix B, Table S2. The AIC was lowest for the fully adjusted model (relates to H3a), indicating it was the best

model. Table 4B (relates to H3) indicates that those not engaged in sufficient physical activity had significantly higher odds of feeling "little interest" (OR = 2.11, 95% CI: 1.57, 2.84, $p < 0.0001$). Current smokers compared to former/never smokers had significantly higher odds of "little interest" (OR = 1.63, 95% CI: 1.07, 2.47, $p = 0.0210$).

Psychological distress

"Psychological distress" had no significant association with the pandemic in adjusted regression models only for covariates (Table 4A, relates to H2a), fully adjusted regression models for covariates and behavioral health (Table 4B, relates to H3a), or unadjusted model (Table 4C) ($p > 0.05$). Table 4B (relates to H3a) indicates that insufficient physical activity as well as current smoking were significantly associated with psychological distress. Physically inactive caregivers had significantly higher odds of an unfavorable psychological composite score (OR=1.67, 95% CI: 1.24-2.26, p=0.0007). Current smokers also had higher odds of an unfavorable psychological composite score (OR=1.79, 95% CI: 1.19-2.68, p=0.0048). The models of fit and AIC of the unadjusted and adjusted model are displayed in Appendix B, Table S3. The AIC was the lowest for fully adjusted model (relates to H3a). All the SAS codes are available in Appendix A.

Overall Well-Being Perception (Hypotheses 2b and 3b)

The odds of diminished overall well-being significantly increased after the pandemic compared to the pre-pandemic using adjusted regression models only for covariates (OR = 1.29,

95% CI: 1.03-1.63, p = 0.0116) (Table 5A, relates to H2b), fully adjusted regression models for covariates and behavioral health (OR=1.33, 95% CI: 1.05-1.69, p=0.0159) (Table 5B, relates to H3b), and unadjusted model (Table 5C). The models of fit and AIC of the unadjusted and adjusted model are displayed in Appendix B, Table S2, and the AIC was lowest for the fully adjusted model (relates to H3b), indicating it was the best model. Table 5B (relates to H3b) indicates that informal caregivers who had insufficient physical activity compared to their physically active counterparts had higher odds of perceiving their overall well-being as diminished (OR=2.16, 95% CI: 1.65-2.82, p<0.0001). Current smokers, compared to non-smokers, also demonstrated had higher odds of perceiving their overall well-being as diminished (OR=1.80, 95% CI: 1.17-2.79, p=0.0077). All the SAS codes are available in Appendix A.

Table 5A (RQ2b): Comparing overall well-being before and after the COVID-19 pandemic among informal caregivers in adjusted models for covariates without behaviors (HINTS*)

	Diminished overall well-being perception N=2,855		
Characteristics	**OR****	**95% CI*****	**p-value**
Period			
Before the pandemic (reference)			
After the pandemic	1.29	1.03-1.63	0.0116

*HINTS, Health Information and National Trends Survey. ** OR, odds ratio. *** CI, confidence interval.

Table 5B (RQ3b): Comparing overall well-being perception before and after the COVID-19 pandemic among informal caregivers in models included behaviors and covariates (HINTS*)

	Diminished overall well-being perception N=2,855		
Characteristics	**OR****	**95% CI*****	**p-value**
Period			
Before the pandemic (reference)			
After the pandemic	1.33	1.05-1.69	0.0159
Sufficient physical activity			
Yes (reference)			
No	2.16	1.65-2.82	<.0001
Current smokers			
No (reference)			
Yes	1.80	1.17=2.79	0.0077
Gender			
Female (reference)			
Male	0.87	0.66-1.14	0.3113
Age groups, years			
Reference, 18–34			
35–49	0.78	0.51-1.21	0.2776
50–64	0.74	0.47-1.16	0.1924
65 +	0.73	0.47-1.14	0.1677
Education			
<high school (reference)			
High school	0.87	0.45-1.68	0.6939
Some college	0.88	0.48-1.63	0.7037
≥ College graduate	0.35	0.19-0.64	0.0008
Marital status			
Others (reference)			
Married or live with a partner	0.94	0.70-1.24	0.6679
Health insurance			
No (reference)			
Yes	1.02	0.62-1.68	0.9119
Census region			
West (reference)			
Northeast	0.62	0.41-0.93	0.0218
Midwest	1.10	0.78-1.57	0.5633
South	1.06	0.79-1.43	0.6677

*HINTS, Health Information and National Trends Survey. ** OR, odds ratio. *** CI, confidence interval.

Table 5C: Comparing overall well-being perception before and after the COVID-19 pandemic among informal caregivers in unadjusted models (HINTS*)

	Diminished overall well-being perception N=3,069		
Characteristics	**OR****	**95% CI*****	**p-value**
Period			
Before the pandemic (reference)			
After the pandemic	1.30	1.05-1.61	0.0155

*HINTS, Health Information and National Trends Survey. ** OR, odds ratio. *** CI, confidence interval.

Chapter 6: Discussion

Main Findings

When assessing mental health symptoms, surveys commonly inquire about feelings such as "worrying" and "nervous," which are typically linked to anxiety disorders. Symptoms like "hopeless" and "little interest" are often explored in relation to depressive disorders. These survey items provide insights into individuals' experiences and help professionals identify potential signs of anxiety or depression, facilitating early intervention and appropriate treatment strategies for improved mental health (Nagata et al., 2021; Vahratian, Blumberg, Terlizzi, & Schiller, 2021; Y. Wang, Ye, Chen, & Zhang, 2023). A campsite score of these four groups of symptoms was also frequently used to assess psychological distress (Gupta, Puyat, Ranote, Vila-Rodriguez, & Kazanjian, 2021; Kroenke et al., 2009; Reeves et al., 2011; Vos et al., 2022).

Here, using the HINTS national dataset, we found that “worrying” and the perception of overall well-being have been significantly exacerbated after the COVID-19 pandemic among informal caregivers. Overall well-being encompasses not only mental health but also physical, emotional, and social dimensions. It reflects an individual's overall state of health and satisfaction across various aspects of life, including physical fitness, emotional resilience, and social connections (Clément Desmouceaux, 2022; Gonzalez-Zamar, Ortiz Jimenez, Sanchez Ayala, & Abad-Segura, 2020; Hernandez-Torrano et al., 2020; Luthra et al., 2023). Behavioral health (physical activity and smoking) was found to predict mental health and overall well-being, but not mediators through the pandemic since they had no significant association with the

pandemic. Sociodemographic characteristics as covariates also had significant associations with both mental health and overall well-being.

Coping Behaviors

Most of the current knowledge on behavioral health during the COVID-19 pandemic comes from the general population. Changes in behavioral health, including smoking and physical inactivity, before and after the pandemic has shown mixed results in terms of their decrease or increase as revealed by a systematic review of more than 30 original research articles (Nindenshuti & Caire-Juvera, 2023). Moreover, according to a survey of the general population in the US, when compared to the pre-pandemic, the time spent on exercise decreased and heavy smoking, defined as using 11 cigarettes or more per day, saw an increase among smokers during the pandemic (Chen et al., 2021).

Changes in coping behaviors in the USA among informal caregivers during the COVID-19 pandemic needs more clarification. Most of the knowledge about coping behaviors of informal caregivers during the pandemic originates from other countries. Maxwell and colleagues (2023) investigated caregivers of seniors regarding their coping behaviors during the COVID-19 pandemic in Canada (Maxwell et al., 2023). The study employed a cross-sectional and longitudinal survey design, involving informal caregivers of seniors in Canada. Conducted twice, the online survey collected data on caregiver coping behaviors (seeking counseling, initiating psychotropic drug use, and substance use) during the pandemic (Maxwell et al., 2023). Among the initial 673 surveyed caregivers, the most common coping behaviors during the first wave were alcohol consumption and taking psychotropic drug (both more than 10%). This was

followed by smoking and/or cannabis use (8.0%) and counseling (7.4%) (Maxwell et al., 2023). Only alcohol use exhibited a significantly lower occurrence during the second wave with a p-value of 0.02 (11.7% *vs*. 15.1%) in the longitudinal sample (Maxwell et al., 2023). Some other reports also indicate that informal caregivers adopted more unhealthy behaviors compared to the general population (Hiyoshi, Rostila, Fall, Montgomery, & Grotta, 2023), while others found quite the opposite (Gottschalk et al., 2020).

We did not detect any association at significant levels between the pandemic and behavioral health, including smoking and insufficient physical activity among informal caregivers, indicating that informal caregivers might not have used smoking and physical activity as coping mechanisms during the COVID-19 pandemic. These two behaviors are among those regarded as negative coping mechanisms employed during stressful conditions (Bianchi et al., 2023; Obbarius et al., 2021). From a theoretical standpoint, it could be argued that smoking and insufficient physical activity as coping mechanisms would have been exacerbated among informal caregivers during the pandemic. The absence of an increase in unhealthy behaviors may be due to improved awareness of behavioral health and the adoption of initiatives designed to enhance caregivers' behavioral health (The National Alliance for Caregiving [NAC], 2021). Another contributing factor may be the increased occurrence of remote working during the pandemic, which potentially allowed individuals more flexibility in managing their schedules and buffering the undesirable impact of the COVID-19 pandemic on coping behaviors. Furthermore, considering the respiratory nature of the pandemic, informal caregivers who were providing support to loved ones may have been particularly attentive to negative behaviors such as smoking, which can exacerbate respiratory symptoms or contribute to their onset. As they cared for their loved ones, they might have been conscious about the possible danger associated

with smoking, thereby consciously influencing their decision towards smoking.

Mental Health and Overall Well-Being

The descriptive analysis illuminated an increase in mental health issues and a decline in the perception of overall well-being after the pandemic compared to pre-pandemic among informal caregivers. These differences reached statistical significance only for “worrying” (a symptom of anxiety disorders) as well as for the perception of overall well-being. A comprehensive review article conducted a search across five electronic databases in terms of original articles published until the midst of March, 2021, encompassing diverse regions globally. Notably, no studies from the United States were identified within that time frame (Hughes, Liu, & Baumbach, 2021). This rapid review focused on the impact of the pandemic on the informal caregivers who were taking care of dementia patients, a group requiring substantial caregiving support (Hughes et al., 2021). The studies consistently reported mental health issues among informal in the context of the COVID-19 pandemic (Hughes et al., 2021). Notably, Altieri & Santangelo (2021) found a substantial rise in anxiety, with an OR of 1.75 (95% CI: 1.32-2.32) (Altieri & Santangelo, 2021). The psychological distress experienced by informal caregivers was also a common theme across the studies (Hughes et al., 2021). Alexopoulos and colleagues (2021) highlighted that caregivers' distress was increased during the pandemic with an OR of 1.92 and 95% CI of 1.17-3.15 (Alexopoulos et al., 2021). Borges-Machado and colleagues (2020) reported a rise in caregiver burden with diminishing overall well-being, particularly for those caring for individuals with advanced stages of dementia (Borges-Machado, Barros, Ribeiro, & Carvalho, 2020). Several studies from European countries indicated a positive

association between poor mental health and the COVID-19 pandemic among caregivers (Costi et al., 2023; Fleitas Alfonzo, Taouk, Emerson, & King, 2023; Zwar, Konig, & Hajek, 2023). Collectively, the psychological findings from these articles underscore the substantial effects of the pandemic on the mental health of informal caregivers (Alexopoulos et al., 2021; Altieri & Santangelo, 2021; Borges-Machado et al., 2020; Costi et al., 2023; Fleitas Alfonzo et al., 2023; Zwar et al., 2023). However, findings from the USA have indicated some controversies.

Sheth and colleagues (2021) assessed the effect of the COVID-19 pandemic on American caregivers, focusing on English-speaking populations. The study explored caregivers' depressive symptoms, stress, overall well-being, and pain using surveys administered online. Compared to pre-COVID19 period, caregiver stress ($p = 0.002$) and pain ($p = 0.009$) levels were significantly higher during the pandemic. The eight-item Patient Health Questionnaire depression scale (PHQ-8) was used for assessing depression. PHQ-8 depression scores and overall health did not exhibit statistically significant differences between pre-pandemic and pandemic periods, with p-values of 0.156 and 0.095, respectively (Sheth, Lorig, Stewart, Parodi, & Ritter, 2021).

Another study explored disparities in mental and physical health among the U.S. population in the early phases of the COVID-19 pandemic among non-caregivers and caregivers. Utilizing data from the Understanding America Study, the study analyzed group distinctions in the reporting of psychological distress and somatic symptoms (Park, 2021). Outcome measures were any psychological distress and bodily symptoms, including headaches, abdominal discomfort, fatigue, and body aches (Park, 2021). The mental and physical health of adults showed notable variations based on caregiver status. Caregivers consistently experienced poorer mental health and increased fatigue compared to non-caregivers, while long-term caregivers were more prone to reporting headaches, body aches, and abdominal discomfort than both short-

term caregivers and non-caregivers, even after accounting for various control (Park, 2021). Higher proportions of poorer health outcomes were observed among caregivers compared to non-caregivers. Psychological distress was prevalent among 35.2% of non-caregivers, 42.3% of short-term caregivers, and 46.5% of long-term caregivers (Park, 2021). Disparities in somatic symptoms were more pronounced among long-term caregivers, ranging from 44% to 60% higher. In summary, this study, which was conducted after the COVID-19 pandemic in the USA, found that, caregivers compared to non-caregivers, had worse mental health and physical health (Park, 2021).

A national study from the USA conducted by Ngamasana and colleagues using the Behavioral Risk Factor Surveillance System survey found no statistically significant difference in the incidence rate of days with poor mental health between informal caregivers who provided care before the pandemic and those who provided care after the pandemic (Ngamasana et al., 2023).

Discrepancies in Ngamasana findings with ours and also others could stem from variations in methods used to assess mental health, inclusion criteria, and the percentage of male/female (Ngamasana et al., 2023). The male/female in our study is closer to what was expected from the national average (Spillman, 2021), and women may experience more depression and anxiety issues than men (Berry et al., 2020).

The same national study indicated that, compared to the pre-pandemic period, informal caregivers had a 26% reduced incidence rate of days with poor physical health ($p = 0.001$) after the COVID-19 pandemic (Ngamasana et al., 2023). Though we did not investigate physical health, the perception of overall well-being, which is about holistic health and covers physical health and beyond, was diminished in the present study. The COVID-19

pandemic had the potential to induce mental health challenges and overall well-being concerns in various ways. One way is related to uncertainties surrounding the pandemic, which could be a significant source of stress for many people, including informal caregivers (Costi et al., 2023; Fleitas Alfonzo et al., 2023; Zwar et al., 2023). Every day or even hour, news, sometimes fake, was evolving., and the situation seemed really unpredictable. Another way could be related to concerns about personal health, the health of loved ones, and uncertainty about the duration and severity of the pandemic. All could contribute to worsening mental health issues and overall well-being (Costi et al., 2023; Fleitas Alfonzo et al., 2023; Zwar et al., 2023). Second, the public health measures implemented to mitigate the spread of the virus, such as social isolation, quarantine, and physical distancing, could lead to increased feelings of loneliness and a lack of social support. In fact, many individuals found themselves struggling with feelings of loneliness, which could further exacerbate mental health issues (Costi et al., 2023; Fleitas Alfonzo et al., 2023; Zwar et al., 2023). The direct impact of the virus itself, including illness and the loss of loved ones, was another significant source of emotional distress. The inability to properly bury their loved ones, particularly early in the pandemic, due to restrictions on gatherings and funerals, added additional stress to communities (Costi et al., 2023; Fleitas Alfonzo et al., 2023; Zwar et al., 2023). Furthermore, individuals who have contracted the virus and experienced severe illness might have also faced long-lasting physical and psychological effects, further contributing to their emotional distress. The economic consequences of the pandemic could have also added fuel to flare mental health and overall well-being issues (Costi et al., 2023; Fleitas Alfonzo et al., 2023; Zwar et al., 2023).

Behavioral health predicting mental health and overall well-being

Another finding in the current study was the strong association of unhealthy behaviors with both mental health and overall well-being. Informal caregivers' smoking and insufficient physical activity significantly predicted all outcomes studied here, including "worrying," "hopeless," "little interest," psychological distress score, and overall well-being, with the exception of "nervous" for insufficient physical activity. Insufficient physical activity deprives the body of the positive effects of exercise, including the release of endorphins and the reduction of stress hormones, leaving individuals more vulnerable to depression and anxiety (Firth et al., 2020; Schoenfeld & Swanson, 2021). Smoking, beyond its well-documented physical health risks, has been associated with an elevated likelihood of mental health challenges, partly due to the neurobiological effects of nicotine (Corley et al., 2019). These behavioral risk factors can not only compromise physical health but also contribute significantly to the complex web of factors influencing mental health, emphasizing the importance of promoting a smoke-free, active lifestyle for informal caregivers. Consistently, physical activity and smoking have long been associated with mental health and overall well-being issues (Fox, 1999; E. S. Kim, Kubzansky, Soo, & Boehm, 2017), and our study provided the latest update on this matter.

Covariates (sociodemographic characteristics)

The current study also found that mental health issues as well as overall well-being were predicted by certain sociodemographic characteristics that were not necessarily the same. Multivariable regression analysis revealed that male informal caregivers exhibited significantly lower odds of feeling "worrying," "nervous," "hopeless," and a diminished psychological

distress score, suggesting potential gender-specific vulnerabilities for these mental health conditions. Older age groups were significantly associated with lower odds of all five mental health outcomes. College graduates had lower odds for “worrying,” an unfavorable psychological distress score, and diminished overall well-being. Health insurance emerged as a protective factor against “worrying,” but not with other outcomes. Being married or living with a partner was protective against depressive symptoms (hopeless and little interest), but not against other outcomes. These findings are similar to those of a recently published study that used national data to examine the association of mental health (days of poor mental health) with sociodemographic factors (Ngamasana et al., 2023).

We also found that the sociodemographic characteristics that were associated with overall well-being included educational attainment and census regions, emphasizing the distinction and overlap between overall well-being and mental health predictive factors and the importance of intervention for vulnerable sociodemographic groups, particularly those with lower educational attainment.

Summary of Findings

The study revealed the association of the COVID-19 pandemic with the mental health and overall well-being of informal caregivers. It emphasizes on the significance of research and addressing of health of informal caregivers during a crisis. Our findings indicated that feelings of "worrying," were significantly became worse among caregivers, after the COVID-19 pandemic. This can have policy implications for supporting mental health and over all well-being of informal caregivers during a crisis.

Moreover, the study reveals a decline in the perception of overall well-being among caregivers, post-pandemic. Overall well-being is about holistic health and covers social aspects of the life of informal caregivers in addition to mental health and physical health. These findings highlight the need for targeted interventions and support addressing caregivers' complex well-being needs during a crisis.

Furthermore, the study identifies sociodemographic characteristics and behavioral health factors, including physical activity and smoking, were significantly associated with mental health and overall well-being among caregivers. While previous research has examined the impact of these behaviors (Mohr, Burns, Schueller, Clarke, & Klinkman, 2013), limited attention has been given to their effects on caregivers, specifically post-pandemic. Understanding the association of these behavioral factors with mental health and overall well-being of caregivers is crucial for developing meaningful interventions for promoting the mental health and overall well-being of caregivers.

Regarding coping behaviors, existing literature predominantly originates from other countries and highlights the exacerbation of coping behaviors such as alcohol use and psychotropic drug use among caregivers (Maxwell et al., 2023). However, our study findings indicate no significant association between the pandemic and behavioral health, including smoking and physical activity, among informal caregivers in the USA. While the absence of an increase in unhealthy behaviors may reflect improved awareness and initiatives targeting caregivers' behavioral health (NCI, 2021), further research is warranted to elucidate coping mechanisms and their implications for well-being of caregivers.

Directions for Future Research

Future research on behavioral health, mental health, and overall well-being among informal caregivers should address the limitations of this study and focus on improving support systems during a crisis and beyond.

Conducting qualitative research provides more comprehensive answers to the behavioral health of informal caregivers during the pandemic in the USA. In our study, we focused on smokers and non-smokers. Qualitative research should focus on heavy smokers since a crisis can hit the most vulnerable people in a more severe way.

Trial studies are required in order to evaluate the mental health and overall well-being of informal caregivers with and without intervention. For example, provide useful information through some health apps to caregivers and compare their mental health and overall well-being to those caregivers without such apps. Supporting caregivers with technology can be an affordable and effective way to cope during a crisis since there is no in-person contact and it will reduce the chance of spreading any sort of disease. This technology support can expand to telehealth utilization, which can reduce the "worrying" levels of informal caregivers about their patients. The trial study should compare the level of "worrying" and "overall well-being" among the caregivers who have access to telehealth compared to those without such access. Future research on technology use for reducing mental health conditions should also take into account the quality of the internet, since it has been shown that telehealth quality is significantly associated with technological problems with telehealth (Mojtahedi et al, 2023).

Exploring the association of illnesses and health conditions of care recipients with the behavioral health, mental health, and overall well-being of informal caregivers is also another interesting topic for future research. It is essential to understand the impact of care recipient

health status on the behavioral and mental health and overall well-being of informal caregivers during a crisis in order to create appropriate policies. For example, there is a possibility that caregivers of cancer patients will be hit more severely than other caregivers during a crisis since the chemotherapy or radiotherapy of these patients might be impacted by lockdown and the unavailability of hospital beds. Similarly, caregivers of Alzheimer patients with 24-hour help needs might be hit in a more severe way during a crisis since a crisis might impede respite care. The relationship of other conditions of the patients with mental health and the overall well-being of caregivers during a crisis should also be explored to find out more about the impact of the nature of the patient disease on caregiver's health.

Future research comparing caregivers and non-caregivers regarding mental health, behavioral health, and overall well-being is important for understanding whether the experiences between these two groups differ in a significant way. Differences between these two groups can point to exact health problems specific to informal caregivers. Although our studies provide useful information about differences in behavioral health, mental health, and overall well-being of informal caregivers before and after the COVID-19 pandemic, there is a possibility that the same issues of the same magnitude existed among the general population. Even if the mental health and overall well-being of informal caregivers and non-caregivers are affected in similar ways during a pandemic, still more attention should be directed toward informal caregivers since it also affects patients. However, we should take into account that non-caregivers may not be an exact match for caregivers since their sociodemographic characteristics are significantly different from each other. Informal caregivers are mainly women, who tend to smoke less and have more depression and anxiety (Berry et al., 2020; Wajnberg et al., 2016).

Future research should focus on finding healthcare policies and social support systems to

support caregivers' mental health and overall well-being. Systematic barriers to health care services should be eliminated for informal caregivers during a crisis in order to promote the mental health and overall well-being of this valuable source of health care workforce.

Policy implications

Policymakers should take into account the integration of mental health support services into caregiver support programs, particularly during a crisis. These policies should address affordable access to mental health services. It should thorough mental health services, covering counseling, therapy, and medications. Investing in mental health resources can help reduce the heightened levels of anxiety experienced by informal caregivers during a crisis.

Healthcare professionals can play a critical role in the in the early diagnosis of mental health conditions in informal caregivers. These professionals include primary care physicians, nurses, and social workers. Nurses and social workers could provide a more accessible and affordable way for initial counseling. Policy initiatives should focus on providing training and education to this group of health professionals. They can provide appropriate referrals to mental health professionals after the initial diagnosis. This can help improve early diagnosis and intervention for caregivers experiencing mental health challenges.

Policies should take into account the expansion of respite care and support services for informal caregivers. Respite care provides caregivers with temporary relief from their caregiving responsibilities, which enables them to relax and take care of their own needs (Min, Currin, Razo, Connelly, & Shih, 2020). By increasing access to respite care services, policymakers can help promote mental health and overall well-being among caregivers during a crisis.

Public health initiatives should take into account bringing public attention to the needs of

informal caregivers and the importance of supporting them. An example of such policies could be raising awareness of the mental health challenges faced by caregivers. Another example could be providing information on available support services for informal caregivers during a crisis. A support system might be available, but caregivers might not be aware of it. All of these can improve the mental health and overall well-being of informal caregivers.

Limitations

This study used robust, repetitive, national surveys to conclude on the health of informal caregivers in the USA and found that certain health outcomes deteriorated after the COVID-19 pandemic. It also offered an update on sociodemographic characteristics and unhealthy behaviors that were predictive of mental health and overall well-being, emphasizing the need for targeted interventions to promote a healthier lifestyle, particularly for certain sociodemographic groups. Despite its strengths, this study has several limitations that should be taken into account when interpreting the findings, particularly those related to survey and secondary data studies.

Certain limitation of survey studies

Survey respondents may provide inaccurate or biased responses. Social desirability bias, where respondents provide answers, they think are socially acceptable (Brenner & DeLamater, 2016; Cole & Trinh, 2017). People may engage in unhealthy activities, such as smoking and insufficient physical activity, yet refuse to provide proper answers because they are not socially

acceptable. Because of the stigma associated with mental health concerns, they may also provide inaccurate information, and refuse to choose correct answer for mental health in surveys.

Surveys often rely on non-random sampling methods, such as convenience sampling or voluntary response sampling, which can result in sampling bias and limit the generalizability of findings to the broader population (Brenner & DeLamater, 2016; Cole & Trinh, 2017). However, our study used the HINTS dataset, which is representative of the US population (Westat, 2023). HINTS employs a robust sampling process is. It uses geography and address to choose only one member from each home. They send out multiple surveys to non-responders and offer incentives to respondents to boost their odds of responding (Westat, 2023).

Survey respondents may have difficulty accurately recalling past events or experiences, leading to memory bias and affecting the validity of responses, especially for retrospective surveys (Cole & Trinh, 2017). This is especially true for retrospective studies, like the HINTS survey. The survey questions are frequently from the same year or not too long ago (Westat, 2023). As a result, this imitation may not be serious in the HINTS dataset.

Surveys are limited in their ability to capture complex phenomena, particularly those that require in-depth exploration and qualitative research (Brenner & DeLamater, 2016; Cole & Trinh, 2017). We did not observe any association between behavioral health and the pandemic. This must be due to the survey questions. For example, we did not have information regarding heavy smokers, whose behaviors may have been aggravated by the pandemic.

Surveys administered in a language that respondents are not proficient in or that does not reflect their cultural context may result in misunderstandings, or underrepresentation of certain groups (Cole & Trinh, 2017). The HINTs survey was provided in both English and Spanish (Westat, 2023), but not other languages. The USA is diverse and multicultural, and some

minority groups might have been excluded unintentionally from the survey.

Certain limitations of studies on secondary data

Secondary datasets are typically collected for purposes other than our specific research questions. Secondary datasets often have limited scope and may not include all relevant variables or measures needed to thoroughly address the research questions. For example, the hint survey only includes question about “worrying” “nervous” “hopeless” and “little interest” which may not cover all mental health conditions.

Secondary data analysis inherently confines studies to predefined, available variables (Bin Hamdan, AlAmri, & Aldosari, 2024; Cole & Trinh, 2017; M. Kim, Hsu, Kwok, & Seo, 2018), and this study could not explore all predictors. We only included predictors available in the HINTS dataset during the study period (2017-2020, 2022) with the fewest missing values (less than 5%). In our study, information on the duration of caregiving —a potential predictor of our outcomes—was not available for all the years studied here, potentially limiting the depth of the findings. Moreover, we could not investigate some potential positive coping behaviors because of their unavailability in the HINTS. Lazarus's theory of stress and coping also underscores the possibility of positive coping behaviors under stressful conditions (Lazarus & Folkman, 1990). Positive coping behaviors aim at reducing or mitigating the perceived threat or harm posed by the stressor (Lazarus & Folkman, 1990). These behaviors may include seeking social support, engaging in problem-solving, and creating resilience through adaptive coping mechanisms. By adopting positive coping strategies, individuals can effectively navigate stressors, ultimately promoting overall well-being (Lazarus & Folkman, 1990).

Researchers may also struggle with data access and availability, as certain datasets may

be restricted, or require payment for access. However, this major limitation, possibly for PhD candidates, are not related to the HINTS dataset, which is publicly available (NCI, 2023), making it an ideal dataset for public health PhD candidates, in my opinion. Studies based on the HINTS are exempt from IRB approval since the HINTS survey is delivered as a deidentified file and is publicly available, and PhD students can download the data on their personal laptops.

Other limitations

Our study focused on mental health symptoms related to anxiety and depressive disorders, with an emphasis on feelings of "worrying," "nervous," "hopeless," and "little interest". However, this focus might not fully cover the complexity of mental health conditions. Some serious mental health conditions, such as suicidal ideation, were not investigated.

The 2021 survey, which was during the pandemic, was not representative of the USA population (2023), and was not included in the present study. 2021 was a very important year during the COVID-19 pandemic and possibly stressful for informal caregivers, much more so than 2022. If data for 2021 were available, they might have more significant findings.

Additionally, the cross-sectional nature of the study does not prove causation. In a cross-sectional study, we can conclude about the association but not make a prediction about causation. Despite the limitations regarding causal inference, cross-sectional studies can provide useful information for association and inform future research directions. We mentioned all interpretations of our results as an association, not a causation or prediction, and emphasized that longitudinal studies can establish causation and exact prediction. For example, we indicated that

behavioral health was associated with mental health, but this does not imply that behavioral health caused mental health or overall unwell-being.

The potential for low statistical power within a study is also another limitation that warrants consideration, particularly for non-significant findings, such as behavioral health in our study. Low power happens when a study fails to detect a significant association due to insufficient sample size (Serdar, Cihan, Yucel, & Serdar, 2021). Our study included less than 4,000 informal caregivers, which may not be large enough to detect some behaviors with a lower frequency, such as smoking.

Conclusions

The study can contribute to understanding the association of the COVID-19 pandemic with the behavioral health, mental health, and overall well-being of informal caregivers in the USA. It revealed that informal caregivers experienced more mental health symptoms, particularly feelings of "worrying," after the pandemic. This exacerbation indicates the need for future intervention addressing anxiety symptoms, and the importance of providing the right and information to informal caregivers during crises.

Moreover, the study reveals a decline in the perception of overall well-being among caregivers after the pandemic. Overall well-being is about the physical, emotional, and social aspects of life. These findings underscore the need for targeted interventions to cover different aspects of health during crises among caregivers, and not just mental health.

The study also identifies sociodemographic characteristics and behavioral health factors as significant predictors of mental health and overall well-being among caregivers. When

making policies or interventions for improving the mental health and overall well-being of informal caregivers, these sociodemographic characteristics can help tailor policies and interventions to the right groups.

The robust association of smoking and physical activity with mental health and overall well-being in our study emphasizes the importance of promoting a smoke-free, active lifestyle for informal caregivers. Any policy or intervention for improving the mental health and overall well-being of informal caregivers should take into account addressing these behaviors, independent of any pandemic or crisis.

However, our study has limitations, such as potential response and sampling biases and the cross-sectional nature of our research, which critically limits causal interpretation. Future research directions include qualitative research to better understand caregivers' health, intervention studies to evaluate the efficacy of support strategies, using technology and innovation to support caregivers, and examining the role of healthcare policies in supporting caregivers' mental health. Integrating mental health support services, providing training and education for healthcare professionals, expanding respite care and support services, promoting healthy lifestyle behaviors, and including caregiver support in public health initiatives can also be future interventions or policies.

This study contributes to our understanding of the behavioral health, mental health, and overall well-being of informal caregivers during a crisis. It underscores the importance of addressing the unique needs of informal caregivers during crises. By identifying the association between mental health and overall well-being and the pandemic, the study provides valuable guidance for policymakers in drafting policies to support informal caregivers during a crisis and beyond.

Publications or Submitted Manuscript Derived from HINT Dataset about Informal Caregivers

This dissertation encompasses three research articles derived from the HINTS datasets focusing on informal caregivers. These articles provide comprehensive insights into the behavioral health, mental health, and overall well-being of informal caregivers and the factors influencing their utilization of health technologies and telehealth services:

1. Article 1: Title: "Declining Mental Health and Overall Health, but Not Behavioral Health, of Informal Caregivers after the COVID-19 Pandemic: An Analysis of US National Trends". This study investigates the impact of the COVID-19 pandemic on the mental, behavioral, and overall health of informal caregivers in the USA. Using HINTS data spanning pre-pandemic (2017–2019) and post-pandemic periods (2020, 2022), the study examines various health outcomes and sociodemographic predictors. The findings reveal a decline in mental and overall health post-pandemic, with different sociodemographic factors influencing mental health and overall health outcomes (Appendix C).

2. Article 2: Title: "Sociodemographic Factors Predicting the Utilization of Electronic Health Technologies among Informal Caregivers: A Nationwide Study in the USA, 2022" This article investigates sociodemographic factors associated with the utilization of electronic health technologies among informal caregivers. Analyzing data from the 2022 HINTS survey, the study

identifies disparities in the adoption of health technologies based on education level, race, age, gender, and income satisfaction. The findings emphasize the need to address these disparities to ensure equitable access to electronic health technologies among informal caregiver populations (Appendix D).

3. Article 3: Title: "Telehealth Utilization and Good Care among Informal Caregivers: Health Information National Trends Survey, 2022" This study explores telehealth use and quality among informal caregivers, considering the inequalities in telehealth adoption and its impact on caregiving responsibilities. Using the 2022 HINTS dataset, the study identifies significant inequalities in telehealth utilization based on age, gender, race, and health insurance status. Furthermore, it examines factors influencing the quality of telehealth care provided by informal caregivers (Appendix E). This article has been published (Telehealth Utilization and Good Care among Informal Caregivers: Health Information National Trends Survey, 2022 - PubMed.

Appendix A

SAS Codes of the Current Study

```
libname longdata"/home/u60708413/EPY 747";
/* GENERATE USER FORMAT TO DELINEATE THE DIFFERENT SURVEY CYCLES */
proc format ;
   value survey
   1='HINTS 5 CYCLE 1'
   2='HINTS 5 CYCLE 2'
   3='HINTS 5 CYCLE 3'
   4='HINTS 5 CYCLE 4'
   5='HINTS 6'  ;
run;

/* PREP DATA FOR EACH SURVEY CYCLE and renaming variables */
data tempHINTS5CYCLE1;
   set longdata.hints5_cycle1_public (rename=genderc=birthgender) ;
   survey=1;
   format survey survey.;
run;
```

```
data tempHINTS5CYCLE2;
    set longdata.hints5_cycle2_public (rename=genderc=birthgender);
    survey=2;
    format survey survey.;
run;

data tempHINTS5CYCLE3;
    set longdata.hints5_cycle3_public (rename=genderc=birthgender);
    survey=3;
    format survey survey.;
run;
data tempHINTS5CYCLE4;
    set longdata.hints5_cycle4_public;
    survey=4;
    format survey survey.;
run;

data tempHINTS6;
    set longdata.hints6_public (rename= HealthInsurance2=HealthInsurance);
    survey=5;
    format survey survey.;
run;
```

```
/*adding column*/
data tempHINTS5CYCLE1;
    set tempHINTS5CYCLE1;
    newcolumn=.;
run;
data tempHINTS5CYCLE2;
    set tempHINTS5CYCLE2;
     NewColumn=.;
run;

data tempHINTS5CYCLE3;
    set tempHINTS5CYCLE3;
     NewColumn=.;
run;
data tempHINTS5CYCLE4;
    set tempHINTS5CYCLE4;
     NewColumn=.;
run;

data tempHINTS6;
    set tempHINTS6;
     NewColumn=.;
run;
```

```
/*recoding of new column*/
data tempHINTS5CYCLE1;
   set tempHINTS5CYCLE1;
   if NewColumn=.  then AftervsbeforeCOVID19=2;
run;
data tempHINTS5CYCLE2;
   set tempHINTS5CYCLE2;
    if NewColumn=.  then AftervsbeforeCOVID19=2;
run;

data tempHINTS5CYCLE3;
   set tempHINTS5CYCLE3;
    if NewColumn=.  then AftervsbeforeCOVID19=2;
run;
data tempHINTS5CYCLE4;
   set tempHINTS5CYCLE4;
    if NewColumn=.  then AftervsbeforeCOVID19=1;
run;

data tempHINTS6;
   set tempHINTS6;
   if NewColumn=.  then AftervsbeforeCOVID19=1;
```

```
    run;

    /*recoding for each data*/
   data tempHINTS5CYCLE1;
    set tempHINTS5CYCLE1;
    if NewColumn=.  then NewColumn2=1;
run;
data tempHINTS5CYCLE2;
    set tempHINTS5CYCLE2;
     if NewColumn=.  then NewColumn2=2;
run;

data tempHINTS5CYCLE3;
    set tempHINTS5CYCLE3;
     if NewColumn=.  then NewColumn2=3;
run;
data tempHINTS5CYCLE4;
    set tempHINTS5CYCLE4;
     if NewColumn=.  then NewColumn2=4;
run;

data tempHINTS6;
    set tempHINTS6;
```

```
    if NewColumn=.  then NewColumn2=5;
    run;

 /* STACK TOGETHER DATA FROM EACH SURVEY CYCLE AND GENERATE THE
APPROPRIATE NUMBER OF REPLICATE WEIGHTS USING THE RIZZO METHOD */
data merge_hints;
    length APP_REGION $2;
    set  tempHINTS5CYCLE1 tempHINTS5CYCLE2 tempHINTS5CYCLE3
tempHINTS5CYCLE4 tempHINTS6;
    array hints51wgts[50] person_finwt1-person_finwt50;
    array hints52wgts[50] person_finwt1-person_finwt50;
    array hints53wgts[50] tg_all_finwt1-tg_all_finwt50;
    array hints54wgts[50] PERSON_FINWT1-PERSON_FINWT50;
    array hints6wgts[50] PERSON_FINWT1-PERSON_FINWT50;
    array newWghts[250] nwgt1-nwgt250;

    if survey eq 1 then do i=1 to 50;
        nwgt0=person_finwt0;
        newWghts[i]= hints51wgts[i];
        newWghts [50 + i]= person_finwt0;
        newWghts [100 + i]= person_finwt0;
        newWghts [150 + i]= person_finwt0;
        newWghts [200 + i]= person_finwt0;
```

```
end;

else if survey eq 2 then do i=1 to 50;
    nwgt0=person_finwt0;
    newWghts[i]= person_finwt0;
    newWghts [50 + i]= hints52wgts[i];
    newWghts [100 + i]= person_finwt0;
    newWghts [150 + i]= person_finwt0;
    newWghts [200 + i]= person_finwt0;
end;

else if survey eq 3 then do i=1 to 50;
    nwgt0=tg_all_finwt0;
    newWghts[i]= tg_all_finwt0;
    newWghts [50 + i]= tg_all_finwt0;
    newWghts [100 + i]= hints53wgts[i];
    newWghts [150 + i]= tg_all_finwt0;
    newWghts [200 + i]= tg_all_finwt0;
end;

else if survey eq 4 then do i=1 to 50;
    nwgt0=person_finwt0;
    newWghts[i]= person_finwt0;
```

```
        newWghts [50 + i]= person_finwt0;
        newWghts [100 + i]= person_finwt0;
        newWghts [150 + i]= hints54wgts[i];
        newWghts [200 + i]= person_finwt0;
    end;

    else if survey eq 5 then do i=1 to 50;
        nwgt0=person_finwt0;
        newWghts[i]= person_finwt0;
        newWghts [50 + i]= person_finwt0;
        newWghts [100 + i]= person_finwt0;
        newWghts [150 + i]= person_finwt0;
        newWghts [200 + i]= hints6wgts[i];
    end;
run;

/*cleaning data*/

  data merge_hints1;
    set merge_hints;
    if Caregiving_no < 0   then delete;
    If drinkdaysperweek< 0 then drinkdaysperweek=.;
         If avgdrinsperweek < 0 then avgdrinsperweek=.;
```

```
        If smokenow < 0 then smokenow=.;
        If SmokeStat < 0 then SmokeStat=.;
        if hopeless < 0 then hopeless=.;
        if littleinterest < 0 then littleinterest=.;
        if nervous < 0 then nervous=.;
        if worrying < 0 then worrying=.;
        if Phq4 < 0 then phq4=.;
        if TimesModerateExercise < 0 then TimesModerateExercise=.;
        if worrying < 0 then worrying=.;
        if BirthGender < 0   then BirthGender=.;
      if  AgeGrpB < 0   then  AgeGrpB=.;
      if  EducA < 0   then  EducA=.;
      if  RaceEthn5 < 0   then  RaceEthn5=.;
      if  HHInc < 0   then  HHInc=.;
      if GeneralHealth< 0  then GeneralHealth=.;
    if HealthInsurance < 0  then HealthInsurance=.;
  if MaritalStatus< 0  then MaritalStatus=.;
  if Caregiving_Professional <0  then Caregiving_professional=.;
  run;

/*recoding varibles */
data merge_hints1;
          set merge_hints1;
```

```
        select (maritalstatus);
                when (1) _maritalstatus_=1;
                when (2) _maritalstatus_=1;
                when (3) _maritalstatus_=2;
                when (4) _maritalstatus_=2;
                when (5) _maritalstatus_=2;
                when (6) _maritalstatus_=2;
                otherwise _maritalstatus_=maritalstatus;
        end;
run;

data merge_hints1;
        set merge_hints1;
        select (generalhealth);
                when (1) _generalhealth_=1;
                when (2) _generalhealth_=1;
                when (3) _generalhealth_=2;
                when (4) _generalhealth_=2;
                when (5) _generalhealth_=2;
                otherwise _generalhealth_=generalhealth;
        end;
run;
```

```
 data merge_hints1;
        set merge_hints1;
        select (agegrpb);
                when (1) _agegrpb=1;
                when (2) _agegrpb=2;
                when (3) _agegrpb=3;
                when (4) _agegrpb=4;
                when (5) _agegrpb=4;
                otherwise _agegrpb=agegrpb;
        end;
run;

data merge_hints1;
        set merge_hints1;
        select (SmokeNow);
                when (1) _SmokeNow=1;
                when (2) _SmokeNow=1;
                when (3) _SmokeNow=2;
                otherwise _SmokeNow=SmokeNow;
        end;
run;
data merge_hints1;
        set merge_hints1;
```

```
        select (Smokestat);
                when (1) _Smokestat=1;
                when (2) _Smokestat=2;
                when (3) _Smokestat=2;
                otherwise _Smokestat=Smokestat;
        end;
run;




data merge_hints1;
        set merge_hints1;
        select (hopeless);
                when (1) _hopeless=1;
                when (2) _hopeless=1;
                when (3) _hopeless=1;
                when (4) _hopeless=2;
                otherwise _hopeless=hopeless;
        end;
run;

data merge_hints1;
```

```
        set merge_hints1;
        select (Nervous);
                when (1) _nervous=1;
                when (2) _nervous=1;
                when (3) _nervous=1;
                when (4) _nervous=2;
                otherwise _nervous=nervous;
        end;
run;


data merge_hints1;
        set merge_hints1;
        select (worrying);
                when (1) _worrying=1;
                when (2) _worrying=1;
                when (3) _worrying=1;
                when (4) _worrying=2;
                otherwise _worrying=worrying;
        end;
run;
data merge_hints1;
        set merge_hints1;
```

```
        select (TimesModerateExercise);
                when (0) _TimesModerateExercise=1;
                when (1) _TimesModerateExercise=1;
                when (2) _TimesModerateExercise=1;
                when (3) _TimesModerateExercise=1;
                when (4) _TimesModerateExercise=1;
                when (5) _TimesModerateExercise=2;
                when (6) _TimesModerateExercise=2;
                when (7) _TimesModerateExercise=2;
                otherwise _TimesModerateExercise=TimesModerateExercise;
        end;
run;

data merge_hints1;
        set merge_hints1;
        select (LittleInterest);
                when (1) _LittleInterest=1;
                when (2) _LittleInterest=1;
                when (3) _LittleInterest=1;
                when (4) _LittleInterest=2;
                otherwise _LittleInterest=LittleInterest;
        end;
run;
```

```
data merge_hints1;
        set merge_hints1;
                select (phq4);
                when (0) _phq4=1;
                when (1) _phq4=1;
                when (2) _phq4=1;
                when (3) _phq4=2;
                when (4) _phq4=2;
                when (5) _phq4=2;
                when (6) _phq4=2;
                when (7) _phq4=2;
                when (8) _phq4=2;
                when (9) _phq4=2;
                when (10) _phq4=2;
                when (11) _phq4=2;
                when (12) _phq4=2;
                when (13) _phq4=2;
                otherwise _phq4=phq4;
        end;
run;

data merge_hints1;
```

```
        set merge_hints1;
                select (RaceEthn5);
                when (1) _RaceEthn5_=1;
                when (2) _RaceEthn5_=2;
                when (3) _RaceEthn5_=2;
                when (5) _RaceEthn5_=2;
                when (4) _RaceEthn5_=2;
                otherwise _RaceEthn5_=RaceEthn5;
        end;
run;
 data merge_hints1;
        set merge_hints1;
                select (DrinkDaysPerWeek);
                when (0) _DrinkDaysPerWeek=1;
                when (1) _DrinkDaysPerWeek=2;
                when (2) _DrinkDaysPerWeek=2;
                when (3) _DrinkDaysPerWeek=2;
                when (4) _DrinkDaysPerWeek=2;
                when (5) _DrinkDaysPerWeek=2;
                when (6) _DrinkDaysPerWeek=2;
                when (7) _DrinkDaysPerWeek=2;
                otherwise _DrinkDaysPerWeek=DrinkDaysPerWeek;
        end;
```

```
run;
data merge_hints1;
        set merge_hints1;
                select (SmokeStat);
                when (1) _SmokeStat=1;
                when (2) _SmokeStat=2;
                when (3) _SmokeStat=2;
                otherwise _SmokeStat=SmokeStat;
                        end;
run;
/*defining informal caregivers*/
data merge_hints2;
   set merge_hints1;
      if Caregiving_No =1  then delete;
     run;

data merge_hints3;
   set merge_hints2;
      if Caregiving_Professional =1  then delete;
     run;

    /*frequency of charactertics*/
proc freq data = work.merge_hints3 ;
```

```
Tables   BirthGender Agegrpb _Agegrpb educa  _RaceEthn5_ RaceEthn5
HHinc _maritalstatus_ Generalhealth    _Generalhealth_
HealthInsurance CENSREG SmokeStat _Smokestat
DrinkDaysPerWeek   TimesModerateExercise _TimesModerateExercise
hopeless _hopeless littleinterest _littleinterest worrying _worrying
nervous _nervous phq4 _phq4 ;
run;

proc freq data = work.merge_hints3 ;
Tables   BirthGender Agegrpb _Agegrpb educa  _RaceEthn5_ RaceEthn5
HHinc _maritalstatus_ Generalhealth    _Generalhealth_
HealthInsurance CENSREG SmokeStat _Smokestat
DrinkDaysPerWeek   TimesModerateExercise _TimesModerateExercise
hopeless _hopeless littleinterest _littleinterest worrying _worrying
nervous _nervous phq4 _phq4  ;
Where AftervsbeforeCOVID19 =2 ;
run;

/*LOGISTIC REGRESSION ANALYSIS CODE USING NEWLY GENERATED REPLICATE
WEIGHTS FOR MULTIPLE SURVEY CYCLES*/
    /* unadjusted behavioral health*/
   proc surveylogistic data = merge_hints3 varmethod = jackknife;
   weight nwgt0;
```

```
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class  AftervsbeforeCOVID19 /param=REF;
    model _TimesModerateExercise (event="1") = AftervsbeforeCOVID19 /tech=newton
xconv=1e-8 CLPARM EXPB;
run;

/* unadjusted behavioral health*/
proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class  AftervsbeforeCOVID19 /param=REF;
    model _SmokeStat (event="1") = AftervsbeforeCOVID19 /tech=newton xconv=1e-8
CLPARM EXPB;
run;

/* adjusted behavioral health*/
proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
 /param=REF;
 model _TimesModerateExercise (event="1")= AftervsbeforeCOVID19 Birthgender _AgeGrpB
```

```
EducA
_maritalstatus_ HealthInsurance CENSREG /tech=newton xconv=1e-8 CLPARM EXPB;
run;



/*adjusted behavoiral health*/
proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
 /param=REF;
 model _SmokeStat (event="1")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG /tech=newton xconv=1e-8 CLPARM EXPB;
run;

/*overall health*/
/* unadjusted overall health*/
proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class  AftervsbeforeCOVID19 /param=REF;
    model _generalhealth_ (event="2") = AftervsbeforeCOVID19 /tech=newton xconv=1e-8
```

```
CLPARM EXPB;
run;

/* adjusted overall health only for SES*/
proc surveylogistic data = merge_hints3 varmethod = jackknife;
weight nwgt0;
repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /param=REF;
 model _generalhealth_ (event="2")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
 /tech=newton xconv=1e-8 CLPARM EXPB;
run;

/* adjusted overall health for SES and bahaviors*/
proc surveylogistic data = merge_hints3 varmethod = jackknife;
weight nwgt0;
repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /param=REF;
 model _generalhealth_ (event="2")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
```

```
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /tech=newton xconv=1e-8 CLPARM EXPB;
run;

/*overall health linear regression, unadjusted and adjusted*/
proc surveyreg data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class  AftervsbeforeCOVID19 ;
    model generalhealth =  AftervsbeforeCOVID19 /
 solution;
run;

proc surveyreg data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class  AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat;
    model generalhealth = AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat/
 solution;
```

```
run;

/*mental health, unadjusted and adjusted logistic regression models*/
proc surveylogistic data = merge_hints3 varmethod = jackknife;
   weight nwgt0;
   repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
   class  AftervsbeforeCOVID19 /param=REF;
   model _Worrying (event="1") = AftervsbeforeCOVID19 /tech=newton xconv=1e-8 CLPARM
EXPB;
run;

proc surveylogistic data = merge_hints3 varmethod = jackknife;
weight nwgt0;
repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /param=REF;
 model _worrying (event="1")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
/tech=newton xconv=1e-8 CLPARM EXPB;
run;

proc surveylogistic data = merge_hints3 varmethod = jackknife;
```

```
weight nwgt0;
repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /param=REF;
 model _worrying (event="1")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /tech=newton xconv=1e-8 CLPARM EXPB;
run;

proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class  AftervsbeforeCOVID19 /param=REF;
    model _hopeless (event="1") = AftervsbeforeCOVID19 /tech=newton xconv=1e-8 CLPARM
EXPB;
run;

proc surveylogistic data = merge_hints3 varmethod = jackknife;
weight nwgt0;
repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
```

```
_TimesModerateExercise _Smokestat /param=REF;
 model _hopeless (event="1")=AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
  /tech=newton xconv=1e-8 CLPARM EXPB;
run;

proc surveylogistic data = merge_hints3 varmethod = jackknife;
weight nwgt0;
repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise _Smokestat /param=REF;
 model _hopeless (event="1")=AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise _Smokestat  /tech=newton xconv=1e-8 CLPARM EXPB;
run;
proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class  AftervsbeforeCOVID19 /param=REF;
    model _nervous (event="1") = AftervsbeforeCOVID19 /tech=newton xconv=1e-8 CLPARM
EXPB;
run;
```

```
proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /param=REF;
 model  _nervous (event="1")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
  /tech=newton xconv=1e-8 CLPARM EXPB;
run;
proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /param=REF;
 model  _nervous (event="1")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat  /tech=newton xconv=1e-8 CLPARM EXPB;
run;

proc surveylogistic data = merge_hints3 varmethod = jackknife;
```

```
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class  AftervsbeforeCOVID19 /param=REF;
    model _littleinterest (event="1") = AftervsbeforeCOVID19 /tech=newton xconv=1e-8
CLPARM EXPB;
run;

proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /param=REF;
 model  _littleinterest (event="1")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
  /tech=newton xconv=1e-8 CLPARM EXPB;
run;

proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
```

```
_TimesModerateExercise  _Smokestat /param=REF;
 model  _littleinterest (event="1")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat  /tech=newton xconv=1e-8 CLPARM EXPB;
run;
proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
    class  AftervsbeforeCOVID19 /param=REF;
    model _phq4 (event="2") = AftervsbeforeCOVID19 /tech=newton xconv=1e-8 CLPARM
EXPB;
run;

proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /param=REF;
 model  _phq4 (event="2")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
  /tech=newton xconv=1e-8 CLPARM EXPB;
run;
```

```
proc surveylogistic data = merge_hints3 varmethod = jackknife;
    weight nwgt0;
    repweights nwgt1 - nwgt250 / df=245 jkcoefs = 0.98;
class AftervsbeforeCOVID19 Birthgender _AgeGrpB  (ref="1")  EducA (ref="1")
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat /param=REF;
 model  _phq4 (event="2")= AftervsbeforeCOVID19 Birthgender _AgeGrpB EducA
_maritalstatus_ HealthInsurance CENSREG
_TimesModerateExercise  _Smokestat  /tech=newton xconv=1e-8 CLPARM EXPB;
run;
```

Appendix B: Models of Fit

Table S1: Models Fit for physical activity in unadjusted and adjusted models (A and B, respectively) and smoking in unadjusted and adjusted models (C and D, respectively).

(A)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	208751759	208708602
SC	208751776	208708636
-2 Log L	208751757	208708598

(B)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	196746892	190513371
SC	196746909	190513609
-2 Log L	196746890	190513343

(C)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	146036670	145989452
SC	146036687	145989486
-2 Log L	146036668	145989448

(D)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	138242833	121743022
SC	138242850	121743260
-2 Log L	138242831	121742994

Table S2: Models Fit for: worrying in unadjusted model (A), adjusted model for all variables (B), and adjusted model for only covariates (C), nervous in unadjusted model (D), adjusted model for all variables (E), and adjusted model for only covariates (F), hopeless in unadjusted model (G), adjusted model for all variables (H), and adjusted model for only covariates (I) , and little interest in unadjusted model (J), adjusted model for all variables (K), and adjusted model for only covariates (L).

(A)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	249773038	248825137
SC	249773055	248825171
-2 Log L	249773036	248825133

(B)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	234396312	221510038
SC	234396329	221510310
-2 Log L	234396310	221510006

(C)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	234396312	223563091
SC	234396329	223563329
-2 Log L	234396310	223563063

(D)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	254714455	254362200
SC	254714472	254362234
-2 Log L	254714453	254362196

(E)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	239351563	230074075
SC	239351580	230074347
-2 Log L	239351561	230074043

(F)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	239351563	232070133
SC	239351580	232070371
-2 Log L	239351561	232070105

(G)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	240896631	240621023
SC	240896648	240621058
-2 Log L	240896629	240621019

(H)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	226288670	213985326
SC	226288687	213985598
-2 Log L	226288668	213985294

(I)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	226288670	216148635
SC	226288687	216148872
-2 Log L	226288668	216148607

(J)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	247089240	246794036
SC	247089257	246794070
-2 Log L	247089238	246794032

(K)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	231824722	215444664
SC	231824739	215444935
-2 Log L	231824720	215444632

(L)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	231824722	219785992
SC	231824739	219786230
-2 Log L	231824720	219785964

Table S3: Model Fit for: overall well-being in unadjusted model (A) and adjusted model for all variables (B), adjusted model for only covariates (C), and psychological distress in unadjusted model (D), adjusted model for all variables (E), and adjusted model for only covariates (F).

(A)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	254392453	253635178
SC	254392470	253635212
-2 Log L	254392451	253635174

(B)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	238027453	218785719
SC	238027470	218785991
-2 Log L	238027451	218785687

(C)

Model Fit		
Criterion	**Intercept Only**	**Intercept and Covariates**
AIC	238027453	224061688
SC	238027470	224061926
-2 Log L	238027451	224061660

(D)

Model Fit		
Criterion	**Intercept Only**	**Intercept and Covariates**
AIC	241280211	240737147
SC	241280228	240737181
-2 Log L	241280209	240737143

(E)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	226335052	209959500
SC	226335069	209959772
-2 Log L	226335050	209959468

(F)

Model Fit		
Criterion	**Intercept**	**Intercept and Covariates**
Akaike information criterion	226335052	212860313
SC	226335069	212860550
-2 Log L	226335050	212860285

Appendix C

Declining mental health and overall health of informal caregivers after the COVID-19 pandemic

ABSTRACT

Caregiving can be stressful, with unfavorable health outcomes. The COVID-19 pandemic has also reportedly exacerbated health issues, particularly mental health. This study aimed to nationally investigate whether the pandemic influenced behavioral health (physical activity and smoking), mental health (worrying, nervous, hopeless, little interest, and psychological distress score), and overall health perception among informal caregivers in the USA. Whether certain sociodemographic characteristics and behaviors could predict mental and overall health was also investigated. The Health Information and National Trends Survey (HINTS), spanning the pre-pandemic (2017–2019) and post-pandemic periods (2020, 2022), was the data source.

A weighted multivariable survey logistic regression was employed for all outcomes. Predictors for mental health and overall health were sociodemographic characteristics and behaviors (physical activity and smoking).

Post-pandemic, informal caregivers exhibited significantly higher odds of reporting "worrying" (OR=1.43, 95% CI: 1.10, 1.87, p=0.0081) and overall unwell-being (OR=1.33, 95% CI: 1.05-1.69, p=0.0159). Smoking and insufficient physical activity were predictors of both mental health and overall health. Different sociodemographic characteristics were predictors of

mental health and overall health. Bing males, older adults, marriage/living with a partner, college graduation, and health insurance were protective against mental health issues, while college graduation and census regions predicted overall health.

This research revealed a decline in the mental and overall health of informal caregivers following the pandemic. Sociodemographic characteristics, smoking, and insufficient physical activity predicted mental and overall health.

Appendix D

Sociodemographic Factors Predicting the Use of Electronic Health Technologies among Informal Caregivers

ABSTRACT

Background: Informal caregivers can be invaluable resources for promoting the utilization of electronic health technology among patients, particularly those who might be mentally or physically challenged. This study investigated sociodemographic factors associated with the use of electronic health technology among informal caregivers.

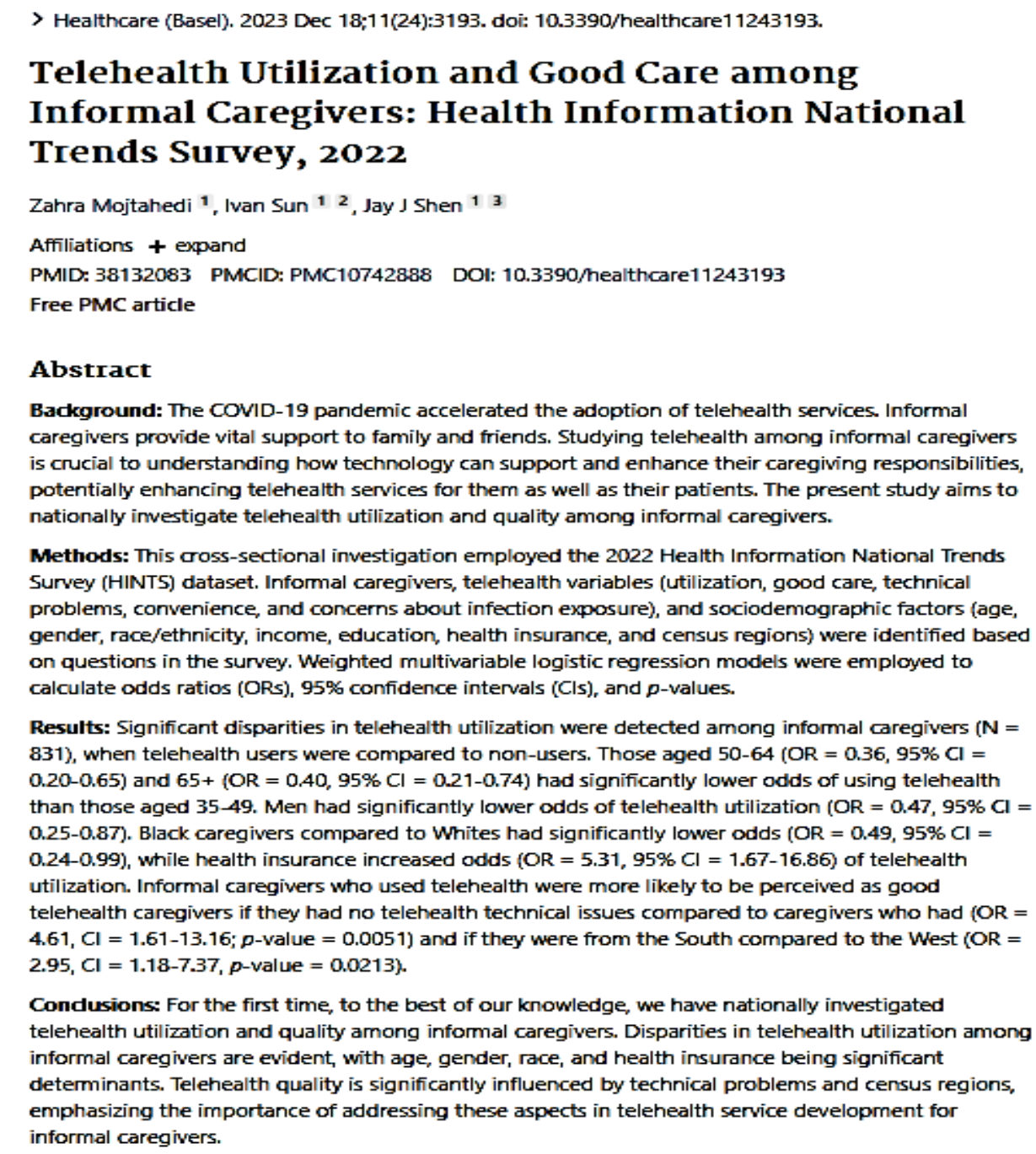
Methods: Data from the 2022 Health Information National Trends Survey (HINTS) were examined for this cross-sectional study. Informal caregivers, online medical record/patient portal outcomes, health app/wearable device use, and electronic sharing of health information (with a health professional, on social media, or with others with similar health issues), and sociodemographic factors (age, gender, race/ethnicity, income feeling, education, and census division) were identified based on questions in the survey.

Results: Caregivers with high school education or less showed higher odds of not using health apps, not using electronic wearable health devices, and not sharing personal health information on social media.

Conclusions: The findings underscore disparities in the utilization of caregivers' electronic health technology, particularly in wearable health devices.

Appendix E

Figure 1S: A screenshot of published article on telehealth of informal caregivers.



> Healthcare (Basel). 2023 Dec 18;11(24):3193. doi: 10.3390/healthcare11243193.

Telehealth Utilization and Good Care among Informal Caregivers: Health Information National Trends Survey, 2022

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PMID: 38132083 PMCID: PMC10742888 DOI: 10.3390/healthcare11243193

Free PMC article

Abstract

Background: The COVID-19 pandemic accelerated the adoption of telehealth services. Informal caregivers provide vital support to family and friends. Studying telehealth among informal caregivers is crucial to understanding how technology can support and enhance their caregiving responsibilities, potentially enhancing telehealth services for them as well as their patients. The present study aims to nationally investigate telehealth utilization and quality among informal caregivers.

Methods: This cross-sectional investigation employed the 2022 Health Information National Trends Survey (HINTS) dataset. Informal caregivers, telehealth variables (utilization, good care, technical problems, convenience, and concerns about infection exposure), and sociodemographic factors (age, gender, race/ethnicity, income, education, health insurance, and census regions) were identified based on questions in the survey. Weighted multivariable logistic regression models were employed to calculate odds ratios (ORs), 95% confidence intervals (CIs), and *p*-values.

Results: Significant disparities in telehealth utilization were detected among informal caregivers (N = 831), when telehealth users were compared to non-users. Those aged 50-64 (OR = 0.36, 95% CI = 0.20-0.65) and 65+ (OR = 0.40, 95% CI = 0.21-0.74) had significantly lower odds of using telehealth than those aged 35-49. Men had significantly lower odds of telehealth utilization (OR = 0.47, 95% CI = 0.25-0.87). Black caregivers compared to Whites had significantly lower odds (OR = 0.49, 95% CI = 0.24-0.99), while health insurance increased odds (OR = 5.31, 95% CI = 1.67-16.86) of telehealth utilization. Informal caregivers who used telehealth were more likely to be perceived as good telehealth caregivers if they had no telehealth technical issues compared to caregivers who had (OR = 4.61, CI = 1.61-13.16; *p*-value = 0.0051) and if they were from the South compared to the West (OR = 2.95, CI = 1.18-7.37, *p*-value = 0.0213).

Conclusions: For the first time, to the best of our knowledge, we have nationally investigated telehealth utilization and quality among informal caregivers. Disparities in telehealth utilization among informal caregivers are evident, with age, gender, race, and health insurance being significant determinants. Telehealth quality is significantly influenced by technical problems and census regions, emphasizing the importance of addressing these aspects in telehealth service development for informal caregivers.

The full text of the published article is available in PubMed though this link (Telehealth Utilization and Good Care among Informal Caregivers: Health Information National Trends Survey, 2022 – PubMed)

SAS Codes of the Telehealth Study

```
libname longdata"/home/u60708413/EPY 747";
Data zz1;
Set longdata.hints6_public;
run;
/*
 Proc contents data=zz1;
  run;*/
 /*missing values*/
  data zz2;
    set work.zz1;
    if Caregiving_no < 0   then delete;
        if ReceiveTelehealthCare < 0   then ReceiveTelehealthCare=.;
        if THYes_AvoidExposure < 0   then THYes_AvoidExposure=.;
        if THYes_Convenient < 0   then THYes_Convenient=.;
        if THYes_IncludeOthers < 0   then THYes_IncludeOthers=.;
        if Telehealth_TechProbs < 0   then Telehealth_TechProbs=.;
```

```
        if Telehealth_GoodCare < 0   then Telehealth_GoodCare=.;
        if BirthGender < 0   then BirthGender=.;
        if  AgeGrpB < 0   then  AgeGrpB=.;
        if  EducA < 0   then  EducA=.;
        if  RaceEthn5 < 0   then  RaceEthn5=.;
        if  HHInc < 0   then  HHInc=.;
      if HealthInsurance2 < 0  then HealthInsurance2=.;
   if Caregiving_Professional <0  then Caregiving_professional=.;
   if generalhealth <0  then generalhealth=.;
   run;

data WORK.ZZ3;
            set WORK.ZZ2;
            run;

/*recoding  varibles */

data WORK.ZZ3;
            set WORK.ZZ3;
            select (agegrpb);
                        when (1) _agegrpb=1;
                        when (2) _agegrpb=2;
                        when (3) _agegrpb=3;
```

```
                when (4) _agegrpb=4;
                when (5) _agegrpb=4;
                otherwise _agegrpb=agegrpb;
        end;
run;

data WORK.ZZ3;
        set WORK.ZZ3;
        select (Telehealth_TechProbs);
                when (1) _recodeprob_=1;
                when (2) _recodeprob_=1;
                when (3) _recodeprob_=1;
                when (4) _recodeprob_=2;
                otherwise _recodeprob_=Telehealth_TechProbs;
        end;
run;
data WORK.ZZ3;
        set WORK.ZZ3;
           select (Telehealth_GoodCare);
                when (1) _recodegood_=1;
                when (2) _recodegood_=2;
                when (3) _recodegood_=2;
                when (4) _recodegood_=2;
```

```
                otherwise _recodegood_=Telehealth_GoodCare;
        end;
run;
data WORK.ZZ3;
        set WORK.ZZ3;
                select (ReceiveTelehealthCare);
                when (1) _recodetel_=1;
                when (2) _recodetel_=1;
                when (3) _recodetel_=1;
                when (4) _recodetel_=2;
                otherwise _recodetel_=ReceiveTelehealthCare;
        end;
run;

data WORK.ZZ3;
        set WORK.ZZ3;
                select (RaceEthn5);
                when (1) _RaceEthn5_=1;
                when (2) _RaceEthn5_=2;
                when (3) _RaceEthn5_=2;
                when (5) _RaceEthn5_=2;
                when (4) _RaceEthn5_=2;
                otherwise _RaceEthn5_=RaceEthn5;
```

```
            end;
run;

 /*removing non-caregivers*/
 data zz4;
    set work.zz3;
    if Caregiving_No =1  then delete;
      run;
  data zz8;
    set work.zz3;

    if Caregiving_No =2  then delete;
      run;
    data zz9;
    set work.zz8;

    if  _recodetel_=2  then delete;
      run;
 /*removing professional caregivers*/
data zz5;
    set work.zz4;
    if Caregiving_Professional =1  then delete;
  run;
```

```
/*removing  non-telehealth users*/
data zz6;
   set work.zz5;
   if _recodetel_=2  then delete;

   run;
    data zz7;
   set work.zz5;
   if _recodetel_=1  then delete;
   run;
/*frequency*/
proc freq data=WORK.ZZ4;
            tables Caregiving_No Caregiving_Professional;
run;
proc freq data=WORK.ZZ5;
            tables BirthGender   Agegrpb _AgeGrpB   educa  RaceEthn5
              HealthInsurance2 HHinc  CENSREG
 ReceiveTelehealthCare _recodetel_  generalhealth  ;
run;
proc freq data=WORK.ZZ6;
            tables BirthGender   Agegrpb _AgeGrpB   educa  RaceEthn5
              HealthInsurance2 HHinc  CENSREG
```

```
 ReceiveTelehealthCare _recodetel_
  _recodeprob_  _recodegood_ generalhealth;
run;


proc freq data=WORK.ZZ7;
             tables BirthGender   Agegrpb _AgeGrpB   educa  RaceEthn5
               HealthInsurance2 HHinc  CENSREG
 ReceiveTelehealthCare _recodetel_
  _recodeprob_  _recodegood_ generalhealth;
run;
/*logostic*/
/*Sociodemographic differences by telehealth among caregivers*/


proc surveylogistic data= WORK.ZZ5 varmethod=jackknife;
weight person_FINWT0;
repweights person_FINWT1-person_FINWT50 / df=49 jkcoefs=0.98;
class
  BirthGender  _AgeGrpB  (ref='2')   RaceEthn5 (ref='1')
 HHinc (ref='5')  educa   CENSREG HealthInsurance2
 /param=REF;
model _recodetel_ (event='1') =BirthGender  _AgeGrpB  RaceEthn5
 HHinc  educa HealthInsurance2 CENSREG     /tech=newton
xconv=1e-8 CLPARM EXPB;
```

```
run;

/*goodcare among informal caregivers who used telehealth */
proc surveylogistic data= WORK.ZZ6 varmethod=jackknife;
weight person_FINWT0;
repweights person_FINWT1-person_FINWT50 / df=49 jkcoefs=0.98;
class
  BirthGender  _AgeGrpB  (ref='2')   RaceEthn5 (ref='1')
    HHinc (ref='2')  THYes_Convenient educa _recodeprob_ (ref='1') HealthInsurance2
CENSREG
 THYes_AvoidExposure/param=REF;
model _recodegood_ (event='1') =BirthGender  _AgeGrpB    RaceEthn5
 HHinc    educa _recodeprob_ HealthInsurance2   CENSREG THYes_AvoidExposure
THYes_Convenient
     /tech=newton
xconv=1e-8 CLPARM EXPB;
run;
```

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Curriculum Vitae

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Education

PhD candidate, Department of Healthcare Administration and Policy, School of Public Health, University of Nevada, Las Vegas, NV 89154, USA. 2020-present

Medical Doctor. Mashhad University of Medical Sciences, Mashhad, Iran,1991- 1998

Employment

Graduate Research Assistant, School of Public Health, University of Nevada, Las Vegas, NV 89154 (2020-2024).

Biostatistics consultant, Northern Arizona University, Flagstaff, AZ (2024-present).

Part-time instructor, School of Public Health, University of Nevada, Las Vegas (2021-2023)

Research Associate – Mayo Clinic, Rochester, MN. October 2013-May 2015

Licensed Teacher for Clark County School District since 2016

University Teaching Experience

Course Title	Terms	Modalities	Class size
PBH 205 Introduction to Public Health	F2023	In-person	25
HCA 175 USA Healthcare System	Spring 2023	remote, online	30
PBH 205 Introduction to Public Health	F2022	remote, online	25
PBH 205 Introduction to Public Health	F2021	remote, online	25

Recent Publications

1. **Mojtahedi Z**, Sun I, Shen JJ. Telehealth Utilization and Good Care among Informal Caregivers: Health Information National Trends Survey, 2022. Healthcare (Basel). 2023 Dec 18;11(24):3193. doi: 10.3390/healthcare11243193. PMID: 38132083.

2. **Mojtahedi Z,** et al. Changes in Characteristics of Inpatient Respiratory Conditions from 2019 to 2021 (before and during the COVID-19 Pandemic). *Frontiers in Public Health*, accepted for publication.

3. **Mojtahedi Z,** et al. Mental Health Conditions- and Substance Use-Associated Emergency Department Visits during the COVID-19 Pandemic in Nevada, USA. *Int J Environ Res Public Health*. 2023;20:4389. PMID: 36901398.

4. **Mojtahedi Z**, Shen JJ. Home Palliative Care during the COVID-19 Pandemic: A Scoping Review. *Am J Hosp Palliat Care*. 2023;40(2):216-224. PMID: 35503513.

5. Shen JJ, **Mojtahedi Z**, et al. Disparities in Adverse Maternal Outcomes Among Five Race and Ethnicity Groups. *J Womens Health (Larchmt)*. 2022 Oct;31(10):1432-1439. PMID: 35675682.

6. **Mojtahedi Z**, et al. Awareness of Obesity-Related Cancers: A Complex Issue. *Int J Environ*

Res Public Health. 2022;19(11):6617. PMID: 3568220.

7. Joo MK, Yoo JW, **Mojtahedi Z**, et al. Ten-year trends of utilizing palliative care and palliative procedures in patients with gastric Cancer in the United States from 2009 to 2018 - a nationwide database study. *BMC Health Serv Res*. 2022;22(1):20. PMID: 34980097.

8. **Mojtahedi Z**, et al. Inpatient palliative care utilisation among patients with gallbladder cancer in the United States: A 10-year perspective. *Eur J Cancer Care (Engl)*. 2022;31(6):e13520. PMID: 34633118.

9. **Mojtahedi Z**, et al. Inpatient Palliative Care Is Less Utilized in Rare, Fatal Extrahepatic Cholangiocarcinoma: A Ten-Year National Perspective. *Int J Environ Res Public Health*. 2021;18(19):10004. PMID: 34639305.

10. **Mojtahedi Z**, et al. Palliative Care and Life-Sustaining/Local Procedures in Colorectal Cancer in the United States Hospitals: A Ten-Year Perspective. *Cancer Manag Res*. 2021;13:7569-7577. PMID: 34629903.

11. Min K, Ouh Y, Kang H, Fadhel, E Yoo J**, Mojtahedi Z,** et al. Trends in palliative care and life-sustaining procedure provision for patients with cervical cancer in the United States. European Journal of Gynaecological Oncology. 2021. 42(6);1105-1111.

12. Bolourian A, **Mojtahedi Z**. Obesity and COVID-19: The mTOR pathway as a possible culprit. *Obes Rev*. 2020;21(9):e13084. PMID: 32578354.

Recent presentations

1. **Mojtahedi Z,** et al**.** Mental and behavior health of informal caregivers. HINTS data user conference, NIH, MD, September, 2023.

2. **Mojtahedi Z**, et al. Palliative Care and Life-Sustaining/Local Procedures in Colorectal Cancer in the United States Hospitals: A Ten-Year Perspective. 2021 UNLV graduate forum. Las Vegas, NV. 2021.
3. Awan A, Raich S, **Mojtahedi Z,** et al (2023, October 12). Planning A Quality Improvement Community Based Participatory Evaluation of Public Health Disparity Reduction Efforts in Nevada. University of Nevada Las Vegas Community Engagement Expo, 2023, Las Vegas, NV.

Contribution to annual and quarterly reports for grants

1. Sharma M, Awan A, Raich S, Alcala M, Klenczar B, **Mojtahedi Z**, & Arora A. (2022). Annual report of the process evaluation for the CDC public health disparity grant: Annual July 2021-June 2022. Division of Public and Behavioral Health/Nevada Office of Minority Health and Equity/UNLV School of Public Health
2. Sharma M, Awan A, Raich S, Alcala M, Klenczar B, **Mojtahedi Z**, & Arora A (2022). Quarterly report of the process evaluation for the CDC public health disparity grant: Quarter 4 April-June 2022. Division of Public and Behavioral Health/Nevada Office of Minority and Health and Equity/UNLV School of Public Health

Community work

- Interviewing community members as well as organization members (related to the CDC Public Health Disparity Grant)
- Participating in the Process Evaluation for the CDC Public Health Disparity Grant
- Participating in community events related to the CDC Public Health Disparity Grant

Editorial work

- Editorial board of International Journal of Environmental Research and Public Health (2020 to 2022)

Professional Trainings

- Mentorship certificate. Graduate & Professional Student Association (GPSA), University of Nevada Las Vegas; May, 2023.
- Research certificate. GPSA, University of Nevada Las Vegas; May, 2022.
- Teaching certificate. GPSA, University of Nevada Las Vegas; May, 2022.
- CITI Biomedical Responsible Conduct of Research, IRB, Social/Behavioral March 2020

Award/Scholarship

- American College of Healthcare Executives Endowed Scholarship, April 2022
- Travel scholarship for HINTS data users conference at NIH, MD, Sep
- Delta Omega Honorary Society in Public Health, 2022

Professional Affiliations

- American College of Healthcare Executives, Active Member

Technical Skills

- Proficiency in SAS, Excel, SPSS, STATA, and Photoshop

Interests/Hobbies

Public Health, data analyses, writing, teaching, Travel, music, reading