PREVALENCE, PREDICTORS, AND IMPACT OF HEALTH-RELATED SOCIAL NEEDS ON CAREGIVER BURDEN AMONG INFORMAL CARE PARTNERS OF STROKE SURVIVORS

by

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To those resilient survivors, whose strength empowers my passion

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ABSTRACT

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BACKGROUND: Stroke imposes profound challenges not only for survivors but also for the informal care partners (ICPs) who provide day-to-day support. While health-related social needs (HRSNs) have been increasingly recognized as relevant to positive patient outcomes, little is known about the prevalence, predictors, and impact of HRSNs among ICPs of stroke survivors. Guided by the Roy Adaptation Model, this dissertation examined HRSNs and their association with caregiver burden among ICPs of stroke survivors. **METHODS:** A cross-sectional survey (n = 81) design was used to collect demographic data, assess HRSNs across 12 domains, and measure caregiver burden using the Caregiver Burden Inventory (CBI). Analyses included descriptive statistics, chi-square tests, *t*-tests, ANOVA, and stepwise multiple regression models. **RESULTS:** Results demonstrated that ICPs experienced an average of moderate burden, with diverse results across both cumulative and domain levels of burden. Unmet HRSNs were prevalent, particularly in domains such as mental health, physical activity, and family and community support. Regression analyses identified specific HRSNs as significant predictors of overall caregiver burden and distinct CBI subdomains. Demographic

factors, including age and marital status, further predicted the likelihood of experiencing multiple unmet needs. **CONCLUSIONS:** Findings underscore that ICPs' burden is not only shaped by stroke-related care demands but also by HRSNs. By applying the Roy Adaptation Model, this dissertation conceptualizes HRSNs as stimuli influencing adaptive responses, offering a theoretical and empirical foundation for targeted interventions. Addressing HRSNs among ICPs represents a critical strategy to reduce burden, improve adaptation, and promote equity in the stroke care partnership experience.

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CHAPTER ONE

INTRODUCTION

In the United States (US), nearly 800,000 people experience a stroke each year (Tsao et al., 2022). Stroke remains a leading cause of death and long-term functional dependence as a prominent national health concern (Tsao et al., 2022). Many stroke survivors are discharged home, where they rely on unpaid family members and friends, often referred to as informal care partners (ICPs), for ongoing care. In this dissertation, the term ICP refers to the individual providing unpaid support, whereas "care partnership" denotes the shared relationship and experience between the ICP and the stroke survivor. For the purposes of this study, a person is designated as a stroke survivor beginning the moment they experience a stroke, with the hope that this language demonstrates appreciation for the life altering experience of stroke while showing respect for the agency of individuals as they go through the lifelong process of experiencing stroke.

The economic impact of all informal care partnerships exceeds $500 billion annually, factoring in lost income from caregiving hours, employment disruptions for both ICPs and survivors, and direct care partnership costs (Hickey & Strayer, 2020). Stroke imposes a significant financial burden on families and the healthcare system, with the annual stroke-related costs in the US estimated at $56.2 billion (Martin et al., 2024).The economic cost of informal caregiving for survivors of cardiovascular disease as a whole is projected to be $128 billion in 2035, with stroke survivors expected to

constitute greater than 50% of the total cost of all cardiovascular disease informal care partnerships (Dunbar et al., 2018). The increasing prevalence of stroke, and therefore stroke care partnership costs, will require an in-depth understanding of all facets of the stroke care partnership experience. This is especially true as it relates to the negative aspects of care partnership, such as caregiver burden (CB).

CB affects approximately 83% of ICPs of stroke survivors (Achilike et al., 2020), making it a critical public health issue, with CB being defined as "the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time" (Liu et al., 2020, p.442). The appreciation of CB as multidimensional is essential to understand the experiences of ICPs, as domains of CB (such as time-dependence, developmental, physical, social, or emotional burden) may impact total CB in different ways for individual ICPs of stroke survivors. Recognizing the relevance of CB to public health outcomes, national initiatives have increasingly focused on alleviating CB. Healthy People 2030, for example, emphasizes reducing stroke-related mortality and morbidity while improving outcomes for care partners (Office of Disease Prevention and Health Promotion, 2020). This study is particularly inspired by the 2022 National Strategy to Support Family Caregivers (Administration for Community Living, 2022), which outlines five key goals: (1) increasing awareness and outreach, (2) advancing partnerships and engagement, (3) strengthening services and support, (4) ensuring financial and workplace security, and (5) expanding data, research, and evidence-based practice. These national priorities underscore the urgent need for research that addresses the challenges faced by ICPs and informs policies aimed at improving their well-being.

Background

Despite stroke being a widely researched topic, there is a marked lack of research that explores health-related social needs (HRSNs) in all stroke care partnership populations. HRSNs are the conditions in which individuals are born, grow, work, live, and age that directly impact their ability to maintain health and well-being (Centers for Medicaid and Medicare Services [CMS], 2024). While related to social determinants of health (SDOH), HRSNs are more immediate and actionable needs that arise due to the influence of broader SDOH factors. SDOH encompass systemic factors such as education access, economic stability, and healthcare quality (Office of Disease Prevention and Health Promotion, 2020), whereas HRSNs include specific concerns such as food insecurity, lack of transportation, and exposure to interpersonal violence (for the purpose of this study, these specific social needs will be referred to as "domains" of HRSNs to facilitate their operationalization as measurable variables). The CMS and the Accountable Health Communities (AHC) Model (CMS, 2017) outlines 5 core domains of HRSNs, including housing instability, food insecurity, transportation problems, utility help needs, and interpersonal safety. Also included in their model are eight supplemental domains: financial strain, employment, family and community support, education, physical activity, substance use, mental health, and disability.

Few studies addressing stroke care partnerships include any assessment of HRSNs (Magin et al., 2013; Yadav et al., 2022), leaving a significant gap in the understanding of how each of these domains may impact the care partnership experience. Despite growing recognition of these domains in general healthcare policy, stroke care partnership research has yet to systematically examine how HRSNs relate to ICP outcomes.

Furthermore, contextual characteristics of ICPs of stroke survivors may impact the prevalence of HRSNs, potentially influencing the prevalence and occurrences of HRSNs. The occurrence of a stroke has the potential to create sudden needs for both the stroke survivor and ICP. These needs may include financial adjustments, need for stroke safe housing, altered food needs, and much more, with many of these variables not being assessed in any way in current literature. This information is especially lacking regarding diverse stroke ICP populations.

In the US, stroke disproportionately affects individuals from lower socioeconomic backgrounds and communities of color (Tsao et al., 2022). Although the focus of this study includes all ICPs of stroke survivors, the unique challenges faced by racial and ethnic minority (REM) ICPs remains an important consideration. For the purposes of this study, the term REM refers to individuals from historically marginalized racial and ethnic groups who have experienced systemic disparities in healthcare access, outcomes, and SDOH. In this study, REMs include, but are not limited to, Black and/or African American (BAA) individuals, Hispanic individuals, Indigenous peoples, Asian Americans, Arab Americans, and Chaldean Americans. REM populations are more likely to experience stroke and poorer functional outcomes compared to their white counterparts (Tsao et al., 2022). Despite this, current literature provides limited demographic and contextual data about REM ICPs, including their relationship to the stroke survivor, age, gender, and other relevant variables (Shamoun & Harris, 2022). This study will present novel and essential data regarding contextual variables that are often entirely missing or at the very least underreported in stroke care partnership research. Collecting and analyzing this information is critical for identifying disparities, informing targeted

interventions, and ensuring that support strategies are responsive to the diverse needs of ICPs of stroke survivors across populations.

Existing care partner support interventions often fall short of achieving positive patient outcomes (Bakas et al., 2022; Elsheikh et al., 2022; Rhudy et al., 2023; Bakhtiari-Dovvombaygi et al., 2025), perhaps because they rarely account for ICPs' underlying social needs or the diverse contexts in which they provide care. While many programs focus on education or stress management, few interventions address critical challenges such as housing instability, food insecurity, or lack of transportation. Reviews of stroke ICP interventions have shown little success in promoting positive ICP outcomes (Bakas et al., 2022; Bakhtiari-Dovvombaygi et al., 2025). Moreover, most interventions are designed with a "one-size-fits-all" approach (Elsheikh et al., 2022), limiting their effectiveness for ICPs from different cultural, linguistic, or socioeconomic backgrounds. Few programs are tailored to the needs of REM ICPs, and none identified are integrated with systems that screen for or address HRSNs (Young et al., 2020). This gap highlights the need for studies that aim to better understand how HRSNs relate to CB and provide adequate descriptive context to support future strategies to support ICPs of stroke survivors.

Although national attention to social needs has increased in recent years, stroke research has yet to comprehensively evaluate their impact on ICPs. To date, no known studies have simultaneously examined the prevalence of 12 HRSN domains, their demographic predictors, and their association with multidimensional CB among stroke ICPs. By exploring these relationships in a broad and inclusive sample using both exploratory and confirmatory analyses, this study provides preliminary insights for use in

future research. The primary aim of this study is to examine the relationship between HRSN domains and CB. Additionally, the study explores the prevalence and demographic predictors of HRSNs among stroke ICPs, with attention to disparities affecting REM groups. Findings are intended to support future equity-oriented research, policy developments, and practice regarding stroke care partnerships.

Problem Statement

Despite widespread recognition of the challenges faced by ICPs of stroke survivors, such as CB (Achilike et al., 2020), prolonged caregiving hours (Skolarus et al., 2017), and financial hardship (Hickey & Strayer, 2020), research has largely overlooked the role of HRSNs in shaping these outcomes. Most existing studies focus on clinical or psychological predictors of CB, with little attention given to the broader social context in which care occurs (Shamoun & Harris, 2022). At the same time, intervention efforts aimed at supporting stroke ICPs have shown limited effectiveness (Bakas et al., 2022; Bakhtiari-Dovvombaygi et al., 2025), likely in part because they fail to assess or address ICPs' foundational social needs or account for demographic and contextual diversity. Few studies have captured comprehensive data on multiple HRSN domains among ICPs, and even fewer have examined how these needs intersect with demographic characteristics to shape CB. This lack of inclusion hampers the development of tailored, equity-informed interventions and policy efforts. This study addresses these gaps by analyzing the prevalence, demographic predictors, and burden-related impact of 12 distinct HRSN domains among a diverse sample of stroke ICPs, offering an essential, exploratory foundation for more targeted and effective ICP support strategies.

Section Summary

While CB among ICPs of stroke survivors is well documented, the role of HRSNs in shaping this burden remains underexplored. Existing research rarely includes a comprehensive assessment of HRSNs or examines how these needs intersect with demographic characteristics (such as race, age, income, and education) to predict CB. As a result, many interventions designed to support stroke ICPs likely lack the contextual specificity needed to be truly effective, particularly for REMs.

This dissertation responds to these gaps by examining the prevalence, predictors, and impact of 12 HRSN domains among a diverse sample of ICPs of stroke survivors. In doing so, it aims to provide a deeper, more nuanced understanding of the care partnership experience, one that accounts for the interplay between social context and ICP well-being. Although the study includes confirmatory analyses to assess statistical relationships between HRSNs and CB, it is primarily exploratory in nature, offering foundational data that can inform future research, policy, and intervention design.

By addressing these critical gaps in the literature, the findings support national calls (such as those in the National Strategy to Support Family Caregivers and Healthy People 2030) to develop equity-informed, data-driven solutions that meet the needs of ICPs. Ultimately, this research contributes both empirical insight and practical direction for advancing ICP support strategies throughout the dyadic stroke care partnership experience.

Review of the Literature

Introduction

Using the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed databases, peer-reviewed articles published in English were reviewed. Key search terms are detailed in Table 2.1.

Table 2.1
Key Search Terms

Group	Search Terms
Condition	stroke or CVA or cerebrovascular accident or ICH or intracerebral hemorrhage or SAH or subarachnoid hemorrhage
Population	caregiver burden or caregiver role strain or caregiver strain or caregiver or care partner or informal care partner
HRSN	health-related social needs or HRSN or social determinants of health or SDOH or transportation needs or food insecurity or housing instability or employment or utilities or safety
REM	Black or African American or Arab American or Arab or Chaldean American or Chaldean or racial minority or ethnic minority or racial and ethnic minority or minority or Asian American or Indigenous or Native American or Indian American.

These terms were combined, mixed, and matched in various combinations to ensure a comprehensive and thorough search. Article titles and abstracts were initially screened for relevance, with priority given to literature published within the past five years. However, due to the limited availability of information specifically addressing variables such as REM ICPs of stroke survivors and HRSN, articles published beyond this timeframe were also included when appropriate. Older studies were retained if they were peer-reviewed and either (1) provided foundational or seminal insights into caregiver burden or HRSN measurement; (2) addressed underrepresented populations or

variables otherwise absent in recent research; or (3) contained rigorous empirical data or conceptual frameworks that remained methodologically or theoretically relevant to current practice and research.

This literature review begins with an overview of stroke and care partnership within the stroke survivor population, providing context and highlighting key findings relevant to the study's focus. Subsequently, the impact of stroke on ICP outcomes is discussed, encompassing functional dependence, psychosocial impact, economic impact, physical impact, and dyadic relationships. The review then examines literature addressing the influence of HRSNs on ICP outcomes, followed by evidence related to feelings of neglect reported by ICPs. Additionally, literature concerning role transitions, and coping strategies are presented, followed by a discussion regarding the underrepresentation of REM throughout the literature. The section concludes by highlighting existing gaps in the literature and emphasizing the significance of the current study. Please see Table 2.2 for a summary of key findings and their relevance to this dissertation study.

Table 2.2
Summary of the Review of the Literature

Section	Relevance to Study	Key Findings
An Overview of Stroke: Prevalence and Disparities	Provides epidemiologic and contextual foundation for understanding why stroke remains a leading health concern and how disparities shape outcomes for survivors and ICPs	Stroke affects over 7.6 million Americans, with racial and socioeconomic disparities driving higher incidence and worse outcomes among REM populations. These inequities extend to recovery, rehabilitation access, and survivor–ICP experiences.

Table 2.2 – Continued
Summary of the Review of the Literature

Section	Relevance to Study	Key Findings
An Overview of Care Partnership in the Stroke Population	Describes the demographic and relational landscape of ICPs, emphasizing variability across gender, relationship type, and cultural background.	Most ICPs are women and spouses; however, BAA ICPs are often adult children, reflecting cultural norms. Gender and relational differences influence burden, and contextual diversity remains underreported across REM groups.
Impact of Stroke on Informal Care Partner Outcomes: Functional Dependence	Identifies functional status of survivors as a key driver of ICP burden while providing further context to disparities in the stroke care partnership experience.	Functional dependence is the most consistent predictor of CB. Higher dependence increases time spent caregiving, stress, and physical strain for ICPs, particularly among those caring for survivors with severe deficits.
Impact of Stroke on Informal Care Partner Outcomes: Psychosocial Impact	Highlights psychological and emotional dimensions of ICP outcomes to illustrate the self-concept and interdependence modes of adaptation.	ICPs frequently experience depression, anxiety, guilt, and isolation. Burden correlates with poor mental health, but coping and social support can buffer distress. Cultural beliefs influence emotional responses and resilience.
Impact of Stroke on Informal Care Partner Outcomes: Economic Impact	Connects HRSN domains such as financial strain and employment instability to ICP burden and adaptation.	Financial hardship is a leading cause of CB. Costs of stroke care partnership are high and expected to rise; however, economic effects on REM ICPs are almost entirely unexplored.

Table 2.2 – Continued
Summary of the Review of the Literature

Section	Relevance to Study	Key Findings
Impact of Stroke on Informal Care Partner Outcomes: Physical Impact	Describes physiological impact of care partnership, aligning with components of adaptation and CB.	ICPs report fatigue, pain, hypertension, and reduced self-care. Female ICPs and those providing longer hours are most affected. Few studies include REM ICPs despite likely higher risk.
Impact of Stroke on Informal Care Partner Outcomes: Dyadic Impact	Emphasizes the bidirectional nature of the stroke survivor–ICP relationship and mutual influence on outcomes.	Role transition is often sudden and overwhelming. Preparedness improves mental health and reduces strain, but many ICPs report inadequate discharge training. REM ICPs may view care partnership more positively yet face greater task difficulty.
Impact of Health-Related Social Needs on Informal Care Partners of Stroke Survivors	Directly aligns with study aims by linking specific social needs to burden and adaptation within the care partnership.	HRSNs such as transportation, food, housing, and digital access significantly affect recovery and ICP outcomes. Yet, no studies have comprehensively examined their prevalence, predictors or effect among ICPs of stroke survivors.
Feelings of Neglected Needs among Informal Care Partners of Stroke Survivors	Frames how unmet informational and emotional needs contribute to ICP burden, providing context for results of this study and future research.	ICPs feel unsupported by healthcare systems and lack education about post-discharge care. Neglect leads to confusion, isolation, and risky improvisation in care practices, with REM perspectives missing entirely.

Table 2.2 – Continued
Summary of the Review of the Literature

Section	Relevance to Study	Key Findings
Transition to Care Partner Role	Explains how ICPs adapt to new roles and responsibilities and emotional adjustments following the occurrence of stroke.	Role transition is often sudden and overwhelming. Preparedness improves mental health and reduces strain, but many ICPs report inadequate discharge training. REM ICPs may view care partnership more positively yet face greater task difficulty.
Methods of Coping	Describe strategies of ICPs used to manage strain, providing context to adaptive modes.	ICPs use emotion-focused coping, spirituality, and optimism to manage burden. Social support and positive reframing improve outcomes, though coping data for REM ICPs remain sparse.
Underrepresentation of Racial and Ethnic Minority Informal Care Partners in Current Literature	Justifies the study's equity focus by documenting systemic exclusion of REM groups from prior research.	REM ICPs are severely underrepresented across all domains of stroke research. This gap limits understanding of culturally specific experiences and perpetuates inequities in care and outcomes.

An Overview of Stroke: Prevalence and Disparities

Understanding the impact of stroke across all populations is essential for contextualizing the complex, dyadic nature of stroke care partnership and will therefore serve as the starting point for this review of literature. Stroke remains a prevalent and serious health issue: in the US alone, over 7.6 million people are stroke survivors, and approximately 795,000 people experience a new or recurrent stroke each year (Tsao et

al., 2022). Notably, nearly 1 in 4 strokes occur in individuals with a previous stroke (Centers for Disease Control and Prevention, 2023). Approximately 75% of strokes occur in individuals aged 65 or older, making older adults the most affected demographic (Benjamin et al., 2019). There has, however, been a significant increase in the quantity of younger people experiencing stroke, likely tied to a higher incidence of stroke risk factors, such as obesity, hypertension, and hyperlipidemia, among young people (Yahya et al., 2020). Stroke is also a leading cause of serious long-term disability, significantly reducing mobility and independence for more than half of survivors aged 65 and older (Tsao et al., 2022). As the US population continues to age, the absolute number of strokes is expected to rise substantially, placing increased pressure on healthcare systems, long-term care facilities, and other points of care (Joynt Maddox et al., 2024; Renedo et al., 2024).

Racial and ethnic disparities in stroke incidence and outcomes are well-documented, indicating that stroke does not affect all people equally. For example, BAA individuals experience significantly higher stroke rates than White individuals. A community-based study found that BAA adults under 65 had a 200% higher incidence of stroke compared to White young adults (Gardener et al., 2020). Similarly, national data indicate the risk of a first stroke is nearly twice as high for non-Hispanic Black adults as for White adults (Tsao et al., 2022). BAAs also suffer greater stroke recurrence, with a 15.4% three-year stroke recurrence rate, higher than that of White stroke survivors (Robinson et al., 2022). This elevated burden extends to stroke outcomes as well, with five-year survival after an ischemic stroke being lowest in BAA men compared to any

other REM groups (Tong et al., 2021). BAA stroke survivors also generally experience poorer functional recovery than their White counterparts (Lau et al., 2023).

Many of these disparities are attributed to stroke risk factors and healthcare access issues that disproportionately affect minority communities. Notable stroke risk factors with higher prevalence among REM populations include hypertension, diabetes mellitus, hyperlipidemia, peripheral vascular disease, elevated inflammatory markers, left ventricular hypertrophy, heavy alcohol use, cigarette smoking, and physical inactivity (Ashley & Berry, 2020). BAAs, for instance, have higher rates of hypertension and diabetes than White Americans, yet are less likely to have these conditions adequately managed (Abrahamowicz et al., 2023). Research has noted lower adherence to hypertension treatment regimens among BAA patients, with adherence rates being less than half that of White patients (Sheehan et al., 2022). This contributes to stroke mortality in BAA communities being significantly higher than in White populations, with disparities worsening following the COVID-19 pandemic (Yang, 2023). Disparities in acute stroke care further exacerbate outcomes. BAAs are more often subject to delays in emergency treatment, including less frequent use of ambulance services (Mochari-Greenberger et al., 2015), later arrivals to the emergency department (Royan et al., 2024), and longer wait times (Qiao et al., 2016). These delays can reduce access to time-sensitive treatments like thrombolytic therapy, leading to worsened stroke outcomes. BAA patients are also more likely to discontinue or not receive recommended medications for secondary prevention (Sheehan et al., 2022). Even young people and children experience these disparities. For example, BAA children have a higher incidence

of stroke than White children, even when accounting for those with sickle cell disease (Tsao et al., 2022).

While the differences between BAA and White peoples are the most extensively reported, other REM groups also experience stroke disparities. Hispanic Americans have higher rates of stroke recurrence and certain stroke subtypes. Both BAA and Hispanic patients who survive a hemorrhagic stroke have a significantly greater risk of subsequent ischemic stroke compared to White patients (Simonetto et al., 2023). REM groups have lower treatment rates for unruptured intracranial aneurysms, with treatment odds for BAA patients slightly improving over time, but not for Hispanic or other REM patients (Kandregula et al., 2023). Indigenous peoples have shown a disproportionate burden of stroke, with incidence rates markedly higher than their non-Indigenous counterparts in several countries (Balabanski et al., 2023). Arab Americans also demonstrate elevated cardiovascular risk profiles, with higher-than-average rates of diabetes, smoking, and psychosocial stressors such as discrimination and low health literacy (Lababidi et al., 2024).

Stroke risk and outcomes are also influenced by geographic and environmental factors, including rural residence (Kapral et al., 2019), neighborhood deprivation (Rivier et al., 2023), and air pollution exposure (Gabet & Puy, 2025; Kabangu et al., 2024). Rural residents often have reduced access to stroke specialists and are less likely to receive guideline-concordant care, including thrombolysis and thrombectomy, which can worsen outcomes (Man et al., 2024). Exposure to air pollutants, including fine particulate matter (PM2.5) and nitrogen dioxide (NO_2), has been associated with increased stroke incidence

and stroke-related mortality, particularly in socioeconomically disadvantaged areas (Kabangu et al., 2024).

Several broader factors contribute to these disparities. HRSNs like income, education, housing, transportation, and healthcare access play a critical role in stroke outcomes. Lower socioeconomic status is associated with higher stroke incidence and worse survival; with poverty linked to a shorter life expectancy and higher stroke mortality (Dhanasekara et al., 2024; Voura et al., 2024). BAAs are disproportionately affected by poverty and are less likely to have insurance adequate for primary prevention or post-stroke care (Bosch et al., 2022). Mistrust in the healthcare system is also more pronounced among BAAs (Powell et al., 2019) and can impede timely care. Cultural and language barriers also reduce effective stroke education and early intervention in immigrant and minority groups (Clark et al., 2022). While research on SDOH in stroke is growing (Reshetnyak et al., 2020), most studies continue to underreport socioeconomic data and specific REM backgrounds (Magin et al., 2013; Yadav et al., 2022). REMs are also underrepresented in stroke clinical trials (Young et al., 2020), and virtually no studies have examined how these disparities affect ICPs.

Following acute hospitalization for stroke, most survivors require ongoing care and support, with only a minority regaining full independence. In the US, 19% of stroke patients are discharged to inpatient rehabilitation, 25% to skilled nursing facilities, and 12% to home with health services (Tsao et al., 2022). Despite these services, approximately 13% are readmitted within 30 days (Le et al., 2019), with many survivors remaining functionally dependent, requiring help with basic tasks and medical care.

Disparities persist in the rehabilitation phase. Studies show REM stroke survivors often experience longer stays and worse outcomes (Ahmed et al., 2024; Freburger et al., 2025; Somani et al., 2022). BAA stroke survivors, for example, are less likely to achieve optimal functional improvement, and some evidence shows they underutilize outpatient rehab services (Odonkor et al., 2021). One analysis found 94% of studies on racial differences in stroke rehabilitation examined only BAA and White patients (Ellis et al., 2014). A more recent study found that stroke recovery studies continue to underreport on REMs and women, with only 35% of studies reporting race of participants (Hassani et al., 2025). This lack of inclusive data leaves gaps in understanding how recovery and care partnership differ across groups.

In summary, stroke is a prevalent condition with long-term effects on survivors and their families across all populations. Stroke burden, however, is not equally distributed. REM populations face disproportionate risks, poorer outcomes, and systemic barriers that can worsen both survivor recovery and the care partnership experience. This context provides a foundation for examining ICP outcomes, HRSNs, and the role of systemic inequities in the care partnership experience.

An Overview of Care Partnership in the Stroke Population

Studies from various regions indicate that ICPs of stroke survivors have diverse demographic profiles. The average age of stroke ICPs can range widely, from 36.9 years (Chuluunbaatar et al., 2017) to 62.5 years (Kruithof et al., 2016). Across most studies, the majority of stroke ICPs are female (Chuluunbaatar et al., 2017; Han et al., 2017; Kruithof et al., 2016; Menon et al., 2017; Oni et al., 2019; Pucciarelli et al., 2017; Zhu & Jiang, 2019). This female predominance is reflected in subpopulations as well: both BAA and

Mexican American stroke ICPs are predominantly women (Jessup et al., 2015; Mehdipanah et al., 2024), although one study reported a more balanced gender split among Mexican American ICPs (Morgenstern et al., 2021). However, detailed gender breakdowns for other REM ICP groups, such as Asian American, Native American, and Middle Eastern populations, are generally lacking.

Whether ICP sex influences the care partnership experience remains an open question. Some research indicates that female ICPs are more likely to experience CB than males (Achilike et al., 2020; Lutz et al., 2023; Menon et al., 2017; Oni et al., 2019). Other studies, however, show no significant correlation between sex and CB (Kruithof et al., 2016), or even the opposite, with male ICPs reporting more burden (Kalemikerakis et al., 2021). Male ICPs have been reported to focus more on the positive aspects of care partnership, while female ICPs are more likely to report emotional strain (Liu & McDaniel, 2015). These conflicting results suggest that contextual and cultural variables may influence the gendered experience of care partnership (Achilike et al., 2020; Govina, et al., 2021; Kalemikerakis, et al., 2021). To date, however, no studies have thoroughly explored the long-term outcomes of stroke ICPs by gender, highlighting a key gap in the literature.

The relationship of the ICP to the stroke survivor varies significantly, but best estimates show that 75% of ICPs are the stroke survivor's spouse, 24% are the survivor's adult child, and 1% are categorized as "other" (Zhang et al., 2023). Unfortunately, data specific to REM ICPs are severely limited, and most studies do not identify whether the ICP shares the same racial or ethnic background as the stroke survivor. There remains a pronounced lack of data on ICPs from other REM groups, including Hispanic, Asian

American, Native American, and Middle Eastern populations. This absence hinders a nuanced understanding of how intersecting identities shape the care partnership experience.

Relationship status and family structure also influence ICP experiences, although findings are mixed. Relationship satisfaction has been shown to improve ICP outcomes (Kruithof et al., 2016), but unmarried ICPs may report better physical health and quality of life than married or divorced ICPs (Efi et al., 2017). Similarly, ICPs without children often report less burden than those caring for both a stroke survivor and their children (Efi et al., 2017). This is especially relevant for BAA ICPs, who are more likely to have children at home and less likely to be married compared to White ICPs (Skolarus et al., 2017). Mexican Americans also differ from non-Hispanic Whites in this domain, with older Mexican Americans more likely to be widowed or divorced, potentially altering the pool of available spousal care partners (Morgenstern et al., 2021).

The "sandwich generation," individuals caring for both aging parents and dependent children, often faces compounded emotional and logistical stress. These ICPs have described feeling "like a prisoner" and report guilt about not being able to fully support either the stroke survivor or their children (Wang et al., 2023). BAA ICPs are particularly likely to fall into this category, as they are more likely than their White counterparts to care for both children and older adults (National Alliance for Caregiving, 2024). Jessup et al. (2015) found that BAA stroke survivors are more often cared for by their children (53%) than by spouses (47%). This care partnership arrangement may have clinical implications: Tyagi et al. (2019) reported that stroke survivors cared for by their children were nearly three times more likely to be hospitalized again within 3 to 12

months post-stroke. Given that BAA stroke survivors are more likely to be cared for by their adult children, these findings raise concern about long-term health outcomes and burden for both the survivor and the ICP.

Impact of Stroke on Informal Care Partner Outcomes

The impact of stroke on ICP outcomes has been examined across several domains that reflect distinct dimensions of the care partnership experience. These outcomes demonstrate how changes in survivor function, health, and circumstances extend to influence the ICP's own adaptation, well-being, and daily life. The following subsections address five major domains commonly described in the literature (functional status, psychosocial impact, economic impact, physical impact, and dyadic impact) to highlight how each contributes uniquely to the overall burden and experience of ICPs following stroke.

Functional Dependence

As the functional dependence of stroke survivors increases, CB also increases, with nearly all ICPs reporting some degree of CB (Han et al., 2017; Kruithof et al., 2016; Menon et al., 2017; Oni et al., 2019; Pucciarelli et al., 2017; Zhu & Jiang, 2019). In fact, functional dependence is the most significant predictive variable of CB (Achilike et al., 2020). Even when measured over time, functional dependence remains a significant predictor of CB (Han et al., 2017; Jaracz et al., 2014; Oni et al., 2019; Pucciarelli et al., 2017), with one study reporting that it is the only statistically significant variable impacting CB after six months (Han et al., 2017). The presence of burden is not only relevant for ICPs, but also for stroke survivors, with higher levels of burden correlating

with higher rates of stroke survivor hospitalization (Tyagi et al., 2019), further emphasizing the importance of the relationship between functional dependence and CB.

Functional dependence is also significantly positively correlated with quality of life among ICPs (Ogunlana et al., 2014; Pucciarelli et al., 2017; Villa-García et al., 2024; Vincent-Onabajo et al., 2013). Much of this burden can be attributed to the amount of time spent caregiving, with stroke survivors requiring approximately 64 hours of caregiving per week three months post-stroke, and 77 hours per week 12 months post-stroke (Wang et al., 2021). Research shows that BAA stroke survivors tend to receive 11 more hours of care per week from ICPs than White stroke survivors (Cohen et al., 2019; Skolarus et al., 2017). Research also shows that caregiving for more than eight hours per day is associated with adverse ICP outcomes (Han et al., 2017). These results are in line with qualitative research, where ICPs state that they wake up in the morning only to immediately think of caregiving tasks that need to be completed (Wagachchige Muthucumarana et al., 2018). There is also a significant correlation between CB scores and time spent caregiving on tools such as the Zarit Burden Interview (Zarit et al., 1980), in which a single point increase on the scale is associated with a 400% increase in time spent caregiving (Oni et al., 2019). Of note, these results would seem to contradict findings from another study that shows BAA ICPs are more positive about their caregiving experience while providing more hours of care per week (Skolarus et al., 2017), potentially due to BAAs viewing the act of caregiving as an important expectation rather than as an innately burdensome activity (Dilworth-Anderson et al., 2005; Irani et al., 2024), although this finding is not consistent throughout the literature. Other studies, for example, suggest that BAAs have worse (Martin, 2000) or even better psychological

well-being when compared to White ICPs (Liu et al., 2021). However, because these studies were not specific to stroke ICPs, their generalizability is limited.

Specific facets of functional dependence that impact CB include generalized disability (Oni et al., 2019), incontinence (Oni et al., 2019), dysarthria (Oni et al., 2019), aphasia (Oni et al., 2019), shoulder pain (Menon et al., 2017), and dysphagia (Menon et al., 2017; Oni et al., 2019; Robinson et al., 2022), although the associations were weak, and both studies suggest further research on this topic. Many ICPs state that they struggle with maintaining the survivor's hygiene (Menon et al., 2017) and administering medication (Menon et al., 2017; Robinson et al., 2022). It is also the case that the extent of functional dependence, which can be clinically correlated to the severity of stroke, influences ICP outcomes such as sleep disturbances, ICP physical health deterioration, and distress (Labberton et al., 2020; Menon et al., 2017), although neither study specifies the inclusion of REM participants. One study that analyzes the difference between Mexican Americans and non-Hispanic Whites found that the Mexican American ICPs struggled with ambulation, bathing, general hygiene, eating, dressing, and toileting (Morgenstern et al., 2021).

Access to rehabilitation to manage the stroke survivor's functional dependence is also a predictor of CB (Zhu & Jiang, 2019). ICPs of stroke survivors who are discharged home are also more likely to have better outcomes than those who are discharged to inpatient rehabilitation facilities (Kruithof et al., 2016), likely due to those who experienced a more severe stroke being more likely to be discharged to a rehabilitation facility. Accordingly, research shows that ICPs of hemorrhagic stroke survivors tend to experience more adverse outcomes (Zhu & Jiang, 2019), as hemorrhagic stroke is known

to cause greater degrees of functional dependence than ischemic stroke (Woo et al., 2022). Notably, BAAs have an increased risk of hemorrhagic stroke when compared to White stroke survivors (Kittner et al., 2021). Racially disproportionate risk factors for the occurrence of intracranial hemorrhage include treated or untreated hypertension and lack of health insurance, while hyperlipidemia and sleep apnea are not associated with race (Kittner et al., 2021). BAA stroke survivors are less likely to access rehabilitation services (Odonkor et al., 2021), although the reasons for this have yet to be adequately explored.

Psychosocial Impact

Stroke has profound psychosocial effects on both survivors and their ICPs. ICPs frequently report significant levels of depression, which in turn contributes to greater CB (Han et al., 2017). Notably, these mental health challenges can be long-lasting; one longitudinal study found that stroke ICPs' depression and poor mental health-related quality of life persisted for nearly three years post-stroke (Haley et al., 2015). Research indicates approximately 40% of all ICPs assisting stroke survivors experience depressive symptoms, which often persist or worsen over time if not adequately managed (Alemayehu et al., 2025). Moreover, the emotional well-being of the ICP and the survivor are closely intertwined. For example, ICPs' psychosocial well-being is positively correlated with the stroke survivor's own well-being, and ICP depression levels are significantly higher when the stroke survivor has seriously contemplated suicide (Pompili et al., 2015). Importantly, depression and even suicidal thoughts are observed in both ICPs and stroke survivors themselves. In a Nigerian study, about one in six stroke survivors suffered recurrent serious suicidal thoughts, a prevalence notably

higher than the 7–8% reported in higher-income countries (Ojagbemi et al., 2019). Ojagbemi et al. (2019) also found comparable rates of suicidal ideation between stroke survivors' ICPs (15.4%) and the control group (14.6%), even though 70% of the "control" ICPs were the survivors' own care partners. This suggests a significant dyadic psychosocial effect, wherein both members of the stroke survivor–ICP dyad share elevated risks for depression and suicidal ideation.

CB is closely linked with psychological distress. Higher burden is associated with greater depression and anxiety in ICPs, and many studies confirm that as CB increases, ICPs are more likely to experience symptoms of anxiety and depression (Hu et al., 2018; Okeke et al., 2020). One study, however, reported that lower perceived burden was linked to higher anxiety and depression in ICPs (Efi et al., 2017), suggesting that ICPs who do not recognize the strains of care partnership might still suffer significant hidden emotional distress. Overall, anxiety itself is a significant contributor to CB, as ICPs with higher anxiety levels tend to feel more burdened over the long term (Jaracz et al., 2014). In addition to anxiety, ICPs often experience profound guilt. Many ICPs express feelings of guilt, wondering if their own actions (such as the food they provided or not encouraging an active lifestyle) contributed to their loved one's stroke (Robinson et al., 2022).

Racial and cultural differences play a notable role in ICP psychosocial outcomes. For example, BAA stroke ICPs have been observed to show a form of resilience, reporting lower levels of burden and depression compared to White ICPs (Clay et al., 2013). In fact, BAA ICPs often report better psychological well-being and fewer depressive symptoms on standardized measures than their White counterparts, although

this is not clearly found in stroke ICPs (Irani et al., 2024). Nonetheless, some evidence suggests that BAA ICPs may exhibit more somatic or subtle depressive symptoms even when their overall depression scores are lower (McCallum et al., 2008). In contrast, Hispanic and Asian-American ICPs tend to report higher levels of depression than White ICPs (Pinquart & Sörensen, 2005). All REM care partnership groups also report worse physical health than White ICPs, reflecting the compounded stress and potential disparities they face (Pinquart & Sörensen, 2005). These differences suggest that cultural factors and coping styles influence how ICPs experience and report burden. For instance, some studies note that BAA ICPs often use more positive coping and have strong informal support networks, which may buffer psychological distress (Kenigsberg et al., 2016; Pickard et al., 2011). On the other hand, Hispanic and Asian ICPs may feel intense cultural pressure (i.e., familism or filial piety) to provide care, which can increase emotional strain (Mehdipanah et al., 2024; Xiao et al., 2024).

Social isolation and loss of personal time are significant psychosocial issues for many stroke ICPs. The severity of the stroke and resultant functional dependence are linked to a more impaired social life for ICPs. More severe strokes often require constant supervision and assistance, which means ICPs struggle to leave the house or engage in social activities (Jaracz et al., 2014; Kruithof et al., 2016). For example, ICPs commonly report that they “cannot go out for any reason” because no one else is available to look after the survivor (Wagachchige Muthucumarana et al., 2018, p.399). Such social restrictions likely contribute to adverse outcomes like higher burden and loneliness. Consistent with this, social support is a key predictor of ICP burden across many populations (Kavga, Kalemikerakis, et al., 2021). ICPs with robust social support

networks generally experience less burden and better mental health, whereas those with little support feel more overwhelmed. Notably, this predictive effect of social support on burden persists even when measured over time, as ICPs with more support tend to handle long-term care partnership demands with less stress (Chung et al., 2021). Among BAA ICPs specifically, social support is negatively correlated with depression (i.e., higher perceived support is associated with lower caregiver depression) (Koh et al., 2022). More broadly, adequate social support has been linked not only to lower depression but also to reduced anxiety and irritability among ICPs (Cumming et al., 2008; Priego-Cubero et al., 2023), although once again, not specifically measured in the stroke care partnership population.

Stroke's impact extends deeply into family and intimate relationships. The majority of ICPs of stroke survivors are spouses or long-term partners (Zhang et al., 2023), and a stroke often transforms these relationships in fundamental ways. Many couples report being unable to cope with the sudden role changes brought on by stroke; spouses who once were equals may now find themselves in care partner and patient roles, leading to role conflicts and strains in the marriage (Ramazanu et al., 2019). In a review of couples' experiences post-stroke, over half (64.3%) of ICPs said the stroke caused a major upheaval in their family life, and about 40% reported new upheaval specifically within their spousal relationship (Ramazanu et al., 2019). ICPs often avoid social engagements with extended family as well. For instance, many report not leaving home much or visiting relatives anymore due to the survivor's condition and care needs (Wabula & Suharyono, 2021).

Communication difficulties after stroke (such as aphasia or dysarthria) further strain the relationship between survivor and spouse. ICPs can struggle to understand the survivor's emotional needs when speech is limited. One study found that ICPs were often unable to detect stroke survivors' feelings of shame or feelings of being demeaned a difficulty largely due to communication barriers (Bucki et al., 2019). ICPs do report feeling more empathy for their loved ones after witnessing the challenges of stroke, but they also admit that these communication difficulties make it harder to maintain their previous relationship dynamic (A. Robinson et al., 2022). This issue may be especially pronounced in BAA stroke survivors and their partners, as aphasia has been found to be more common or severe among BAA stroke survivors than White survivors (Gadson et al., 2022). Thus, BAA ICPs are disproportionately likely to face the challenge of aphasia in their loved ones, potentially compounding psychosocial stress.

Another sensitive area of change is sexual and intimate life. For most spousal ICPs of stroke survivors, sexuality and sexual activity essentially cease to exist during the care partnership period (Kitzmüller & Ervik, 2015). Spouses often feel that they should not bring up intimacy or sexual needs, either out of fear of overburdening the survivor or because communication and physical limitations make the topic difficult to address. Some ICPs feel it is not worth the effort to potentially frustrate a survivor with aphasia by discussing intimacy, so they simply set that aspect of the relationship aside (Kitzmüller & Ervik, 2015). This can potentially lead to unspoken resentment or sadness, as an important dimension of the couple's relationship goes unaddressed. Additionally, partners commonly express that healthcare providers did not adequately prepare them for the realities of sexuality after stroke, as the topic is often glossed over in discharge

planning or rehabilitation (Kitzmüller & Ervik, 2015). Yet, resources do exist, for example educational materials like "Intimacy After Stroke" (American Stroke Association, 2024), indicating a missed opportunity in care. The lack of guidance leaves many couples to figure out on their own how to navigate affection, intimacy, and changing roles as partners. It's also worth noting the link between relationship disruptions and the mental health of survivors: stroke survivors who are divorced or separated are more likely to develop major depressive disorder and have suicidal thoughts (Ojagbemi et al., 2019). Marital separation, in fact, was associated with a fourfold increase in odds of serious suicidal thoughts among stroke survivors (Ojagbemi et al., 2019).

Finally, cultural norms and expectations significantly shape ICPs' psychosocial experiences. In many cultures, caregiving for an ill or disabled family member is seen as a normal duty and often as a moral obligation that one gladly undertakes for their loved ones. For instance, some ICPs describe their role by saying, "It is my moral duty to do so. I am glad to be able to help them" (Blinka et al., 2022, p.3). Spousal ICPs frequently frame their care partnership as an expression of love rather than a burden; they may even reject the label "caregiver" for themselves, because from their perspective they are "just" being a devoted spouse (Blinka et al., 2022). Such attitudes may be protective in that they have the potential to imbue care partnership with personal meaning and positivity. However, cultural expectations can also add pressure. One study of BAA ICPs found that those with either very weak or very strong culturally-driven care partnership values actually had worse psychosocial outcomes (Falzarano et al., 2022). This suggests that if an ICP has weak cultural support for care partnership, they might feel isolated or

conflicted; whereas if they have very strong traditional views, they might be less likely to seek help and more likely to tolerate extreme stress, potentially leading to burden. Being BAA was also associated with endorsing more cultural reasons for care partnership (Falzarano et al., 2022), which potentially leads to viewing care partnership as a natural and expected part of life in that community. Similar strong familism values are observed in Hispanic and Asian cultures, where ICPs often feel an intense duty to elder family members. These cultural beliefs, especially among Hispanic and East Asian populations, emphasize interdependence and filial piety, which provide meaning and identity but can also create internal pressure and role strain (Cheng et al., 2014; Knight & Sayegh, 2010; Xiao et al., 2024). For example, Hispanic ICPs may delay seeking formal services out of fear that doing so implies familial failure, contributing to increased emotional distress and depression (Pinquart & Sörensen, 2005). Among Asian American ICPs, reluctance to seek outside help is often compounded by stigma and concerns about family reputation, especially in multigenerational households or recent immigrant families (Jang et al., 2018; Li Verdugo et al., 2023). Furthermore, language barriers, culturally insensitive services, and systemic bias may intensify psychosocial stress for ICPs from these communities (Gallagher-Thompson et al., 2006).

Conversely, cultural and spiritual beliefs can also be protective. Religious faith and strong community ties have been shown to buffer stress among BAA, Hispanic, and Asian American ICPs, helping them find meaning in the care partnership role (Toth-Cohen, 2004). ICPs who maintain cultural values while also accepting help and practicing self-care report more favorable psychosocial outcomes. Therefore,

interventions aimed at supporting diverse ICPs should be culturally tailored, involving extended families, churches, or community groups where relevant (Napoles et al., 2010).

Economic Impact

Poststroke functional dependence severe enough to render a survivor incapable of employment is a significant predictor of CB (Chuluunbaatar et al., 2017). The overwhelming majority of ICP-survivor dyads experience deteriorating financial status, with financial strain being a significant cause of CB (Chuluunbaatar et al., 2017; Kruithof et al., 2016; Oni et al., 2019). ICPs also express generalized concern over their economic future, citing not just costs for primary treatment of the stroke, but also recurrent expenses for care and the family's everyday needs, which are now harder to address (Wabula & Suharyono, 2021). Some ICPs express inability to engage in treatment for their loved one, even stopping physical therapy due to financial concerns (See Toh et al., 2022; Wagachchige Muthucumarana et al., 2018). Notably, none of these studies included REM participants.

In the US, caregiving of stroke survivors over the age of 65 was estimated to cost $8,211 per year, with a national economic burden of $14.2 billion in 2008 (Joo et al., 2014). More recent estimates suggest that total care partnership costs for this population are closer to $11,300 annually per person, with a national burden of approximately $40 billion, of which approximately $18.2 billion remains attributed specifically to stroke (Skolarus et al., 2016). A systematic review conducted in Europe showed extensive variability in costs associated with stroke care partnership, ranging from $663–$240,250 (Lucas-Noll et al., 2023), indicating a need to better understand the impact of care partnership costs. As adverse effects post-stroke occur, care partnership becomes even

more economically taxing. Falls among stroke survivors that result in injury, for example, result in nearly 3 billion dollars of economic loss due to increased care partnership hours (Joo et al., 2017). By 2035, the people of the US alone are expected to pay $130 billion per year in stroke care partnership costs (Hickey & Strayer, 2020). Although it is known that BAAs are more likely to be in worse socioeconomic condition (Tsao et al., 2022), the economic impact of care partnership on BAA and other REM ICPs is a concept that has not been explored. Moreover, the overwhelming majority of research which examines the economic impact of stroke is concentrated in Europe and North America, demonstrating further work is needed to advance global health outcomes (Strilciuc et al., 2021). With REM status being associated with worse SDOH outcomes (Reshetnyak et al., 2020), it is reasonable to conclude that REMs are more susceptible to adverse economic outcomes. This is evidenced by BAA male ICPs being the most likely group to report financial problems when compared to other racial groups (Liu et al., 2022). In contrast, White male ICPs were more likely to report emotional challenges related to care partnership (Liu et al., 2022). Once again, however, these differences are assessed in dementia care partnership rather than stroke. Among Asian American and Hispanic ICPs of individuals with dementia, financial burden is also prominent, with Hispanic ICPs reporting difficulty balancing care partnership and work (Mage et al., 2023) and Asian American ICPs experiencing high levels of role strain related to multigenerational household expectations (Xiao et al., 2024).

Physical Impact

ICPs of stroke survivors report the emergence of physical health issues they attribute to care partnership, such as back, neck, and leg pain; hypertension; and fatigue

(Wagachchige Muthucumarana et al., 2018). Exhaustion in particular is common in more than half of all care-partners of stroke survivors (Kazemi et al., 2021). Low back pain is common among ICPs, especially females, those who are overweight, and those who spend more time caregiving (Abba et al., 2022; Yilmaz Yalcinkaya et al., 2010). With BAA ICPs being known to spend more time caregiving (Skolarus et al., 2017), it is likely that they also experience more caregiving-related pain. Pain among ICPs is associated with ICP depression, and those ICPs with pain are more likely to underestimate the pain experienced by the stroke survivor (Hung et al., 2007).

Interestingly, paid care partnership assistance is associated with physical and emotional burden among ICPs of stroke survivors (Fabius & Parker, 2023). ICPs have also been found to not engage in personal health measures when engaging in intensive care partnership roles (Kalemikerakis, et al., 2021). ICPs report worrying about both their own physical health and the health of their loved one but feel as if they could not focus on themselves due to the sheer amount of support required from their loved one (Wang et al., 2023). BAA ICPs in particular are less likely to exercise, more likely to be obese, and more likely to have a diabetes diagnosis (Baik et al., 2023). Importantly, very few of the previously mentioned studies regarding caregiving for stroke survivors included any REM participants, although one study found that BAA male ICPs have the highest risk of stroke occurrence when compared to other race-sex groups (Haley et al., 2010).

Additional studies support similar findings in White and REM ICPs. Hispanic ICPs report higher rates of sleep disturbances and physical fatigue compared to non-Hispanic White ICPs (Pinquart & Sörensen, 2005). Indigenous ICPs often experience compounding health burdens due to systemic underfunding of tribal health systems and

chronic illness prevalence in their communities (Racine et al., 2022). Asian American ICPs, particularly those born outside the U.S., may experience somatic symptoms such as tension headaches and fatigue but underreport due to cultural norms around endurance and silence (Xiao et al., 2024). Among White ICPs, physical burden is still significant and correlated with duration and intensity of care, though White ICPs are more likely to access respite or external health services when available (Roth et al., 2001).

Dyadic Impact

Variables present in one member of the ICP- stroke survivor dyad influence the other member in several instances. Depressive symptoms among the stroke survivor, for example, are known to affect both the stroke survivor and the ICP's overall quality of life (Yuliana et al., 2023). Higher levels of anxiety among either the ICP or stroke survivor impact the survivor/ICP's quality of life (Yuliana et al., 2023). Inversely, higher quality of life among the stroke survivors and/or their ICPs is associated with lower levels of CB (Bergström et al., 2011).

When stroke survivors and ICPs disagree in the management of stroke care, feelings of helplessness can ensue (Wang et al., 2023). When compromise in care is reached, it is essential to strike a balance, as too much dependence on ICPs not only hinders stroke recovery but also overwhelms ICPs (Wang et al., 2023). Interventional studies are also aimed at improving the relationship between ICPs and stroke survivors. One such intervention is called Hand in Hand, which is a novel and promising approach to improve the quality of the ICP relationship in the ICP-stroke survivor dyad, even if in a feasibility study (McCarthy et al., 2021).

Research on dyadic dynamics across REM groups is limited but growing. BAA ICPs often report a strong sense of familial and religious obligation, which can strengthen emotional bonds in the dyad but may also create unspoken expectations and strain (Haley et al., 2015). Hispanic ICPs are more likely to live with the care recipient and report both high burden and high relationship satisfaction due to cultural emphasis on familism (Falzarano et al., 2022), although this information is not stroke care partnership specific. Asian American ICPs often report higher burden in relation to expectations of deference and caretaking hierarchy, with less communication between survivor and ICP (Jang et al., 2018). Meanwhile, dyads involving White ICPs may show more proactive care coordination but also more overt strain when communication fails (Roth et al., 2001). These variations highlight the importance of culturally tailored dyadic interventions that foster mutual understanding and respect within the ICP-stroke survivor relationship.

Impact of Health-Related Social Needs on Informal Care Partners of Stroke Survivors

Recent literature increasingly recognizes that HRSNs play a critical role in stroke recovery outcomes (Billioux et al., 2017; Hill & Livesay, 2024). As discussed previously, HRSNs are distinct from broader SDOH: while SDOH refer to systemic factors such as education or income, HRSNs are specific, actionable barriers like transportation, housing instability, or food insecurity (Billioux et al., 2017; Hill & Livesay, 2024). These often-overlooked needs are essential to post-stroke recovery, influencing readmission rates (Rodriquez et al., 2023), rehabilitation adherence (Lin et al., 2022a; Reshetnyak et al., 2020), and long-term well-being (Hill & Livesay, 2024; Naqvi et al., 2021), but are

entirely unexplored as they relate to the stroke care partnership experience (Young et al., 2020).

CMS, through its Accountable Health Communities (AHC) model, classifies HRSNs into five core domains: housing instability, food insecurity, transportation difficulties, utility assistance needs, and interpersonal safety (Billioux et al., 2017). Supplemental domains often include family and community support, education, financial strain, disability, mental health, employment, and substance use. These domains are highly relevant for stroke survivors, who often rely heavily on ICPs to manage these needs. For example, housing instability may prevent home modification for post-stroke functional dependence; food insecurity may complicate stroke recovery due to poor nutrition; and transportation is repeatedly cited by ICPs as a barrier to accessing therapy and follow-up care (Garnett et al., 2022; Lin et al., 2022a). Digital access and health literacy also affect ICPs' ability to navigate healthcare systems and utilize telehealth services (Naqvi et al., 2021; Sherifali et al., 2018).

HRSNs are known to shape stroke incidence and severity. Reshetnyak et al. (2020) found that BAA race, low education, low household income, lack of insurance, and residence in underserved regions correlate with higher stroke incidence. Similarly, individuals with three or more SDOH disadvantages were nearly two and a half times more likely to suffer a stroke before age 75 (Reshetnyak et al., 2020). Though these studies focus on survivors, they imply that ICPs, especially in underserved communities, are also exposed to intensified stress and logistical challenges due to the dyadic nature of stroke and stroke severity. However, the literature rarely addresses how HRSNs affect ICP outcomes directly (Young et al., 2020). Domains such as housing accessibility, post-

discharge education, adaptive equipment, and ICP-specific financial strain remain underexplored in terms of their impact on CB. Despite growing recognition of HRSNs, few studies have quantified their impact on ICP outcomes. Research remains focused on survivors rather than the care dyad. Yet CMS's AHC model and other emerging strategies are beginning to incorporate ICP needs into broader care planning (Billioux et al., 2017; Hill & Livesay, 2024). These include social needs screenings, resource referrals, and navigation support that benefit both the survivor and the ICP.

Qualitative data reveal that ICPs of stroke survivors frequently struggle with transportation, financial strain, and lack of social support (Garnett et al., 2022). One ICP, for example, reported depleting their retirement funds to afford therapy and transportation (Garnett et al., 2022). Even low-cost services become inaccessible when transit is unavailable or disjointed (Garnett et al., 2022). These barriers are more pronounced in rural or economically disadvantaged communities, affecting both survivor and ICP outcomes (Garnett et al., 2022; Kayola et al., 2023).

Disparities also exist in digital access. Naqvi et al. (2021) reported that non-Hispanic White ICPs had more internet access than BAA and Hispanic ICPs, influencing their ability to manage appointments or engage in online health interventions. This digital divide limits access to telehealth and web-based ICP support tools, interventions that have demonstrated effectiveness in reducing stress and improving ICP mental health (Sherifali et al., 2018). Social support is another critical supplemental HRSN. While White ICPs more often access formal respite care, BAA ICPs are less likely to utilize these services due to cultural expectations, systemic distrust, and resource scarcity

(Garnett et al., 2022). This disparity may compound burden, isolation, and health risks among REM ICPs.

In conclusion, HRSNs such as transportation, housing, financial stability, and digital access remain largely unexplored in relation to their impact on the stroke care partnership experience. While prior research has examined the role of HRSNs in stroke occurrence and severity, significant gaps persist in understanding which specific needs must be addressed to promote positive outcomes within the ICP–stroke survivor dyad. Additionally, limited research has examined how demographic characteristics of ICPs influence the prevalence and nature of HRSNs, hindering a nuanced understanding of this phenomenon across diverse care partnership populations.

Feelings of Neglected Needs among Informal Care Partners of Stroke Survivors

ICPs of stroke survivors frequently report having unmet needs within the healthcare system. Specifically, many ICPs feel that their emotional needs are not adequately addressed by healthcare professionals (Cameron & Gignac, 2008). They experience intense stress and anxiety related to their loved one's stroke yet receive little emotional support from providers (Wabula & Suharyono, 2021). These feelings of neglect often persist throughout the care continuum, from the initial hospital admission and diagnostic procedures through to discharge, leaving ICPs feeling unsupported during every phase of the survivor's treatment (Wabula & Suharyono, 2021). ICPs commonly feel alone in managing their loved one's care, especially during the transition from hospital to home. This handover period is often perceived as difficult and marked by poor communication from health professionals, contributing to a sense of isolation and

overwhelming responsibility (Robinson et al., 2022). The new and sudden care partnership responsibilities that fall on family members are not always fully appreciated or understood by clinical staff, adding to ICPs' feelings of stress and being underprepared (Robinson et al., 2022).

ICPs also report that their educational needs are neglected, resulting in considerable confusion about how to care for their loved one after stroke (Wabula & Suharyono, 2021). Many lack essential information on practical matters such as proper nutrition for the survivor, medication management, and rehabilitation exercises at home. In particular, ICPs are often unsure whom to contact for guidance or how to make informed decisions regarding the survivor's ongoing care (Wabula & Suharyono, 2021). This lack of clear information frequently leads well-intentioned ICPs to "bend the rules" (Robinson et al., 2022, p. 931) that healthcare providers have established. For example, family members may improvise or deviate from prescribed guidelines for feeding and administering medication to meet what they perceive as the immediate needs or preferences of the stroke survivor (Robinson et al., 2022). Any such deviation from recommended care practices (particularly around diet consistency for dysphagia or medication timing) can create unnecessary risks, such as aspiration or other complications, making stroke survivors more susceptible to adverse, potentially fatal outcomes. This illustrates how the ICPs' unmet informational needs can inadvertently compromise patient safety when they are left to manage complex care tasks without sufficient guidance.

Notably, feelings of neglect are not confined to interactions with healthcare professionals. ICPs also crave greater support from family and peers, yet often find this

lacking. ICPs commonly state that they need urgent social support to help reduce their psychological overload and to prevent deterioration of their own physical health (Wang et al., 2023). Unfortunately, friends and family members may not understand how to support the ICPs or grasp the emotional toll of the care partner role. Some ICPs report that even close family members fail to comprehend the depth of their distress, with comments such as “I do not know why you are crying” illustrating a lack of understanding about the ICPs’ depression or anxiety (Wang et al., 2023, p. 3). This lack of empathy and assistance from one’s social network leaves many ICPs feeling further isolated and overwhelmed. Importantly, these observations likely apply to diverse groups of ICPs, yet there is a gap in understanding how they manifest among REM ICPs. None of the studies reviewed in this context included REM participants, so it remains crucial to assess whether REM ICPs experience similar unmet needs or if their experiences differ in significant ways. Addressing the impact of neglect and unmet needs among REM ICPs specifically is necessary to ensure that support interventions are equitable and culturally appropriate.

Transition to Care Partner Role

After a loved one’s stroke, ICPs undergo a significant role transition, often suddenly becoming the primary source of care. Whenever possible, ICPs attempt to maintain aspects of their family’s routine and the survivor’s former lifestyle, even as they adapt to new limitations. For example, in cases of post-stroke dysphagia, ICPs report striving to honor their loved one’s personal food preferences despite the dietary restrictions, finding creative ways to incorporate favorite flavors or textures safely (Robinson et al., 2022). ICPs frequently take on an “I do all of it” mentality, aiming to

preserve a sense of normalcy in daily life. However, this can involve considerable improvisation. As discussed previously, one qualitative study of spouses managing post-stroke swallowing difficulties found that family ICPs became adept at problem-solving and even bending certain rules to help their spouse eat and drink, all while trying to balance safety with nutrition and the enjoyment of meals (Robinson et al., 2022). These efforts to sustain pre-stroke routines underscore the emotional importance of normalcy for both survivor and ICP, even as the ICP's role has fundamentally changed.

The preparedness of an ICP for this new care partnership role has a dyadic impact on both the ICP and the stroke survivor. Research shows that when ICPs feel more prepared and knowledgeable, it correlates with better outcomes for survivors, including fewer depressive symptoms and improved communication within the survivor–ICP dyad (Petrizzo et al., 2023). Conversely, when ICPs feel uncertain or unready, both parties can suffer. In fact, spouses of stroke survivors have often expressed profound uncertainty as they transition into the care partner role, unsure how to navigate the responsibilities that were previously handled by an entire team of healthcare professionals (See Toh et al., 2022). This uncertainty leaves ICPs questioning their own abilities to provide proper care and worrying about how to plan for the future, which may hinder their confidence in taking on the new role.

In the early post-acute period, many ICPs experience a brief window of optimism about the stroke survivor's recovery, especially once the survivor's condition has stabilized (Lin et al., 2022). Initially, ICPs are hopeful and encouraged by any signs of improvement. However, this optimism often fades within days as discussions of discharge and returning home begin (Lin et al., 2022). The impending end of professional

support triggers growing worry and discomfort. ICPs commonly report a surge of anxiety when faced with the reality that they will soon assume full responsibility for the survivor's daily care at home (Lin et al., 2022). They recognize that tasks previously managed by nurses, therapists, or doctors will now fall entirely to them, and many do not feel fully prepared for this responsibility.

There may also be important cultural or demographic differences in how ICPs adapt to the role transition. For example, some evidence suggests that REM ICPs of stroke survivors tend to have a more positive overall view of caregiving than their peers from other racial groups. In one study, ICPs of BAA stroke survivors reported finding more positive aspects of caregiving (such as personal growth or strengthened relationships) compared to ICPs of White stroke survivors (Louie et al., 2022). At the same time, however, REM ICPs have also reported the highest perception of task difficulty, meaning they often find the day-to-day tasks of caregiving exceptionally challenging (Jessup et al., 2015). High task difficulty has been associated with increased depressive symptoms and more negative perceptions of life changes among ICPs (Jessup et al., 2015). This paradox in available data, relatively positive attitudes about being an ICP, yet greater burden from the tasks, suggests that REM ICPs might experience the role transition differently, possibly due to strong cultural or familial expectations of ICPs that coexist with limited resources or support. It highlights the need for tailored support that can bolster the positive outlook while alleviating the tangible difficulties of care tasks.

One potential key to smoothing this role transition is enhancing ICP preparedness before the survivor returns home. Recent studies using care partner preparedness scales reinforce that feeling prepared is not just beneficial, but rather essential for preventing

negative outcomes. Higher preparedness scores among ICPs are strongly linked with lower rates of ICP depression, better health-related quality of life, and less care partner strain over time (Camicia et al., 2023). In fact, a validated preparedness assessment for stroke ICPs, the Preparedness Assessment for the Transition Home after Stroke (PATH-s) tool (Camicia et al., 2023), has demonstrated that well-prepared ICPs tend to experience fewer depressive symptoms, less stress, and lower strain, and they report better overall health in the months following the survivor's discharge (Camicia et al., 2023). This implies that interventions focusing on training and educating ICPs (and assessing their understanding) before discharge can directly improve well-being and capacity to care, ultimately benefiting the stroke survivor as well.

By contrast, a lack of knowledge and guidance during the transition creates significant anxiety for ICPs. Many ICPs describe not knowing the proper course of action when new or sudden situations arise at home. For instance, if a stroke survivor shows unusual symptoms or if there is a potential emergency, ICPs are often unsure whether it's serious and what steps to take (See Toh et al., 2022; Wagachchige Muthucumarana et al., 2018). Ideally, hospital staff should equip family ICPs with decision-making tools and clear instructions for common scenarios. However, in practice, ICPs frequently report that such discharge education is insufficient or not clearly understood. Despite healthcare providers' attempts to provide instructional sessions, many ICPs recall the teaching as if the staff were speaking "an alien language," indicating that the information was delivered in medical jargon or abstract terms that they could not grasp (Lin et al., 2022, p. 5). Consequently, ICPs leave the hospital not fully knowing what to expect or how to perform certain care tasks. Compounding this issue, very few ICPs can later recall the

details of information provided by healthcare professionals during those discharge briefings (Heiberger et al., 2020). Importantly, it has been noted that health professionals rarely assess the family ICP's health literacy or understanding during discharge education (Roy et al., 2015). This gap means critical knowledge can be lost, leaving ICPs underprepared.

Methods of Coping

ICPs of stroke survivors have both the highest levels of burden and lowest levels of resourcefulness with regard to coping mechanisms when compared with ICPs of other survivor populations (such as dementia, traumatic brain injury, etc.) (Zauszniewski et al., 2021). In order to cope with the experience of caregiving for a stroke survivor, however, ICPs employ several notable coping mechanisms (Zauszniewski et al., 2021). In order to address feelings of burden, ICPs encourage and oversee fatigue management in the stroke survivor and engage in pacing, or spreading out daily tasks, to attempt to reduce fatigue in both the stroke survivor and themselves (Ablewhite et al., 2022). Emotion-focused coping also mediates stress and anxiety among ICPs of stroke survivors (Lee & Song, 2022). Similarly, hope, and maintaining an optimistic view of the future is a coping mechanism used by ICPs of stroke survivors (Lin et al., 2022). Positive coping measures, such as learning to find balance and learning new skills, such as completing household chores are also associated with confidence in the care partnership role and increase the compassion in their caregiving tasks (Wang et al., 2023). ICPs use spirituality and religion as a method of coping with the burden of care partnership (Gibbs et al., 2020; Misawa et al., 2014). Specific to BAAs, the role of religiosity is ambiguous. Specifically, in a study conducted by Louie et al. (2022), religion was an important method of positive

coping. In a study conducted by Fider et al., (2019) however, male BAA ICPs viewed God as being less loving and more controlling, and had more negative church interactions than White male ICPs. Additionally, BAAs also rely on social support and high self-esteem to cope with stressors (Louie et al., 2022). Other REMs are not as well represented in the literature related to this topic, revealing a gap for future studies to address.

Underrepresentation of Racial and Ethnic Minority Informal Care Partners in Current Literature

The literature consistently shows that ICPs of stroke survivors from REM backgrounds are markedly underrepresented in stroke care partnership research. This lack of inclusion has significant consequences for both science and practice. When study samples are overwhelmingly non-Hispanic White, findings may not generalize to diverse communities, potentially overlooking unique stressors and resources in REM groups (Pardhan et al., 2025). As Pardhan et al. (2025) observe, insufficient REM participation in health research undermines the development of interventions that meet the needs of those communities and can perpetuate health inequalities. In the context of stroke care partnership, the omission of REM ICPs means that the full picture of the care partnership experience is not captured, and culturally specific challenges or protective factors may go unrecognized. Researchers and policymakers increasingly acknowledge the ethical and scientific imperative to improve REM representation in care partner studies (Pardhan et al., 2025), yet meaningful progress remains slow.

A growing body of work has examined why REM ICPs remain hard to recruit and retain in studies. Systemic barriers rooted in historical and ongoing injustices play a

major role. A major factor is mistrust, many REM individuals have deep-seated skepticism toward healthcare systems and research, often stemming from experiences of discrimination and exploitation in medical settings (Bazargan et al., 2021). Socioeconomic hurdles also discourage engagement: REMs are disproportionately of lower socioeconomic status, often managing multiple jobs or financial strains while caregiving (Administration for Community Living, 2022). These practical constraints can potentially make attending research sessions or interventions untenable. An umbrella review by Pardhan et al. (2025) found that socioeconomic and logistical challenges are among the most common barriers limiting REM participation in research. Additionally, language and cultural inaccessibility in research design can alienate REM ICPs. Studies not offered in participants' native language, or those that ignore cultural communication styles and values, fail to earn the trust of these communities (Ejiogu et al., 2011; Yancey et al., 2006). Many REM ICPs also lack awareness of research opportunities or perceive bias in how studies are conducted (Assfaw et al., 2025; George et al., 2014). Together, these factors create an unfortunate cycle: researchers struggle to recruit diverse samples due to mistrust and structural obstacles, yet the persistence of homogenous research further erodes trust by yielding recommendations that may not be culturally relevant. Experts emphasize that overcoming this cycle will require sustained, community-engaged efforts such as partnering with trusted community leaders, providing linguistically appropriate materials, and offering practical supports (i.e., travel stipends, flexible scheduling) to facilitate REM participation (George et al., 2014).

Beyond issues of research recruitment, the care partnership experience itself can differ markedly across cultural groups, shaped by distinct norms, values, and coping

mechanisms. BAA ICPs, for instance, often draw on strong informal networks and spiritual coping in managing stress. Multiple studies have noted that BAA ICPs tend to report greater reliance on faith, prayer, and church-based support as a source of resilience (Chatters et al., 2020). A meta-analysis by Liu et al. (2017) found that BAA ICPs had better psychological well-being but worse physical health outcomes relative to White ICPs. This suggests that strong community and spiritual supports might buffer emotional distress among BAA ICPs, even as chronic stress still takes a toll on their physical health.

By contrast, Hispanic ICPs often center their care partnership on the cultural value of familism, a profound sense of duty and loyalty to family. In Mexican American and other Hispanic families, it is a culturally reinforced norm that family members will personally care for ill or elderly relatives, sometimes to the exclusion of outside help (Mehdipanah et al., 2024; Savage et al., 2016). Familism fosters close-knit support, but it also means Hispanic ICPs may underutilize formal services and hesitate to admit burden (Savage et al., 2016). Research indicates that Hispanic ICPs tend to rely heavily on immediate family networks and have smaller, less active support from non-family sources compared to non-Hispanic Whites (Crist et al., 2009; Gelman, 2014). They are also often reluctant to seek help even from their own relatives, trying not to burden others with care partnership responsibilities (Mehdipanah et al., 2024). Consequently, Hispanic ICPs can experience high levels of stress and depression. In fact, prior studies have noted higher depressive symptoms in Hispanic and Asian American ICPs than in White ICPs (Pinquart & Sörensen, 2005).

Asian American ICPs likewise operate under cultural expectations of family care partnership. Values such as filial piety in many Asian cultures dictate that caring for an

elder parent or disabled family member is a moral obligation, not to be delegated (Lai, 2010; Sun et al., 2012). They too tend to underutilize external respite or mental health services, due in part to stigma around seeking help outside the family and in part to linguistic or cultural barriers in access (American Psychological Association, 2017). Some studies have found Asian American ICPs report elevated distress. For example, one analysis noted Asian American and Hispanic ICPs had higher rates of depressive symptoms than their White counterparts, potentially reflecting these unaddressed stresses (American Psychological Association, 2017). However, Asian families may also benefit from strong family cohesion and culturally embedded respect for care partnership roles, which can provide ICPs with a sense of honor and purpose. Importantly, these values and characteristics have only been inadequately explored among ICPs of other populations and have been nearly completely undiscovered in the stroke care partnership population.

Indigenous American and Pacific Islander ICPs are the least represented in the stroke care partnership literature, but available evidence suggests similarly distinctive patterns. Indigenous American/Alaska Native communities have strong traditions of intergenerational care; over 46% of Indigenous ICPs live with their older relatives and explicitly link their care partnership to cultural beliefs about respecting and repaying elders (National Alliance for Caregiving, 2021). At the same time, Indigenous ICPs often end up as sole providers with minimal support with nearly 50% serving as the only care partner for their loved one (National Alliance for Caregiving, 2021). Combined with geographic isolation in some tribal areas and historical distrust of government health services (Jervis, 2010), Indigenous ICPs are less likely to use formal assistance and more likely to experience high CB and financial strain (Strachan & Buchwald, 2023). Pacific

Islander ICPs, though seldom studied in stroke contexts, are believed to share many of these family-centric and culture-bound care partnership norms, such as collective decision-making and deference to elders, which may both enrich and challenge their caregiving experience (Browne et al., 2014). In summary, each REM subgroup brings its own cultural context to care partnership, from the faith and community solidarity prevalent in BAA care partnership experiences to the familism shaping Hispanic care, the filial obligations in Asian traditions, and the communal/tribal ethos in Indigenous communities. These cultural norms influence how ICPs cope, where they seek support (if at all), and how they perceive their role. Unfortunately, because of the scant inclusion of these groups in research, many of these nuances have only been superficially explored in care partnership literature and have been left nearly entirely unexplored in stroke specific care partnership research.

The underrepresentation of REM ICPs is especially stark in interventional studies, such as randomized controlled trials (RCTs) of ICP support programs, psychosocial therapies, or technology-based interventions. A review of stroke ICP interventions by White et al. (2015) noted that the majority of studies had samples lacking in REM ICPs, which limited the generalizability of trial results. Unfortunately, this trend appears to persist. Even recent meta-analyses continue to highlight that many stroke ICP RCTs have small sample sizes and homogenous cohorts, making it difficult to draw conclusions for diverse populations (Rhudy et al., 2023). In practice, this means that evidence-based interventions may have unknown or different effects in REM communities because so few participants in those trials belonged to minority groups.

For example, a recent nurse-led telehealth intervention (the TASK III program) reported positive outcomes in reducing ICP strain, but BAAs were underrepresented among the participants, despite BAA individuals having the highest stroke risk nationally (Saban et al., 2022). The authors explicitly acknowledged this as a limitation and urged future studies to recruit larger, more diverse samples to ensure findings apply to high-risk groups. Similarly, in developing a mobile health program for stroke families, researchers found it essential to include both English- and Spanish-speaking ICPs and tailor content to cultural needs; yet they still struggled to enroll participants from some REM groups, highlighting the recruitment challenges discussed earlier (Chin et al., 2022). The lack of REM inclusion extends to psychosocial trials, where minority ICPs' uptake may be low due to factors like mistrust or scheduling conflicts. As a consequence, few intervention studies have performed subgroup analyses by race or ethnicity, and even fewer have tested culturally adapted interventions for specific REM ICPs (Gallagher-Thompson et al., 2006; Shin et al., 2022).

Research underscores that economic hardship and social deprivation exacerbate ICP stress and may worsen mental and physical health outcomes for REM ICPs (Gardiner et al., 2020; Moon et al., 2020). Caring for a stroke survivor can impose heavy financial strain, from medical costs to lost income, and this burden tends to be higher in REM families with less wealth to draw upon (Mehdipanah et al., 2024; Skolarus et al., 2017). Additionally, many REM ICPs lack formal respite care. In a national survey, nearly half of Indigenous American ICPs reported being the sole care partner with little to no outside help (National Alliance for Caregiving, 2021). This isolation, combined with distrust of formal services, likely results in unmet HRSNs such as respite, care partner

training, and mental health support in REM communities. The cumulative effect of unmet social needs is reflected in outcomes such as higher reported stress, burnout, and even possible adverse health effects among REM caregivers (Pinquart & Sörensen, 2005).

These findings align with the broader literature on SDOH. ICPs who are socially disadvantaged face both the direct strain of care partnership and the indirect, potentially compounding, stress imposed by unmet social needs (Pinquart & Sörensen, 2005; Schulz & Eden, 2016). Addressing HRSNs is increasingly recognized as essential to improving caregiver outcomes, particularly in communities with limited access to resources (Gardiner et al., 2020; Schulz & Eden, 2016). Experts advocate for interventions that connect ICPs to social services, financial assistance programs, and local resources, alongside policy reforms aimed at easing the economic burdens placed on ICPs, especially those in underserved communities (Gallagher-Thompson et al., 2006; Napoles et al., 2010). In REM populations, specifically, targeted approaches such as case management or community health worker interventions may help mitigate disparities in CB and health outcomes (Saban et al., 2022; Sun et al., 2012). Notably, when ICPs' basic social and financial needs are unmet, interventions may have limited impact (Camicia et al., 2023; Chin et al., 2022). The literature thus underscores that any strategy aimed at improving ICP well-being in REM populations must be holistic, combining culturally tailored programming with systemic efforts to reduce socioeconomic and healthcare access barriers (Gallagher-Thompson et al., 2008; Napoles et al., 2010), and the first step in accomplishing this will be to understand what HRSN exist in the unique and diverse population of ICPs of stroke survivors.

In summary, the underrepresentation of REM groups in stroke care partnership research is a multifaceted problem with roots in historical inequities, cultural differences, and structural challenges. Recent studies reaffirm that REM ICPs remain underserved and understudied. Systemic barriers, from mistrust in research to economic hardships, continue to limit participation by REM ICPs, resulting in their perspectives being insufficiently reflected in the evidence base. Meanwhile, cultural norms shape distinct ICP experiences across many REM communities, underscoring that a one-size-fits-all approach to care partnership research and support is inadequate. The lack of inclusion of these groups in clinical trials and intervention research further hampers progress toward equitable support, as effective programs for one population may not translate to others. Crucially, HRSNs emerged as powerful, yet poorly understood influences on ICP outcomes in REM communities, exacerbating burdens and health risks. The literature review highlights an urgent need for more inclusive and culturally informed research: studies that not only enroll diverse ICPs but also explicitly examine how factors like culture, trust, and social needs interact to affect well-being.

Gaps in Literature and Significance of Study

Despite stroke being a widely researched topic, there are several gaps in interdisciplinary knowledge related to the experiences of ICPs of the stroke survivor. These gaps are especially prevalent among REM ICPs of stroke survivors, as the majority of the reviewed studies either did not report on race, did not include any REM participants, or recruited an inadequate number of REM participants to draw statistically meaningful conclusions. As barriers and facilitators of stroke recovery begin to gain the attention of researchers (Magwood et al., 2019), there remains a limited amount of

information related to the facilitation of positive ICP outcomes such as reduced burden, fatigue, and physical health issues. Furthermore, the relationship between variables such as gender, race, HRSNs, and care partner outcomes are also not well defined. This issue is once again exacerbated among REM ICPs of stroke survivors, as few articles related to the experience of caregiving for the stroke survivor reported adequate demographic information. Therefore, basic demographic information regarding ICPs of stroke survivors has been underreported thus far. In addition to basic demographic information, data related to the relationship of the stroke survivor to the ICP; the race of the care receiver; and availability of adaptive equipment and stroke safe housing are also unknown.

The overwhelming majority of research dedicated to ICPs of the stroke survivor pertains to descriptive studies of the ICP's psychological distress (Shamoun & Harris, 2022). Despite this, negative outcomes such as burden remain prominent in the majority of ICPs (Shamoun & Harris, 2022), and interventions aimed at addressing this psychological distress produced mixed-results at best (Chin et al., 2022; Hu et al., 2015; White et al., 2015). Information related to HRSNs barriers and facilitators of the ICP experience, such as safe housing, transportation, quality food, pollution, and others has not been adequately explored in current research.

Accordingly, this study addressed the following gaps in knowledge:

1.) **Lack of information regarding ICP experiences related to HRSNs and how these factors are associated with CB.**
2.) **Lack of information regarding the prevalence and predictors of HRSNs among ICPs of stroke survivors.**

Summary

Stroke is a leading cause of death and disability worldwide, which is expected to impact nearly 25% of American adults during their lifetime (Tsao et al., 2022). Stroke is known to disproportionately impact people of color and other vulnerable populations (Hickey & Strayer, 2020; Tsao et al., 2022). Most ICPs of stroke survivors are female, although information related to the impact of demographic factors such as gender and race are limited (Achilike et al., 2020). Stroke impacts the experiences of ICPs in many ways, with functional dependence being one of the most common and significant causes of adverse ICP outcomes (Shamoun & Harris, 2022). The overwhelming majority of ICPs of stroke survivors experience negative health outcomes, including CB, anxiety, depression, and reduced quality of life (Shamoun & Harris, 2022). Furthermore, most ICPs are not prepared to face the challenges associated with transitioning into the care-partner role (See Toh et al., 2022), and have not developed adequate coping skills to manage the stressors of full time caregiving (Zauszniewski et al., 2021). HRSNs are an important component of stroke and stroke risk factors but remain nearly entirely unexplored in the stroke care partnership domain. Interventions targeted at alleviating negative ICP experiences have shown promise, but the quantity of unsuccessful interventions (Chin et al., 2022; White et al., 2015). Additionally, the presence of burden in the majority of ICPs (Achilike et al., 2020) suggests that interventions are not targeting the needs of ICPs or are not capitalizing on the supports/facilitators of the ICP experience.

REM are vastly underrepresented throughout the literature review. Articles identified that covered the phenomenon of interest were often published more than five

years ago, indicating a need for more current research on this essential topic. As stated by Perrin et al., “viewing stroke rehabilitation through a color-blind lens may mask important components of rehabilitation, because race and culture likely influence the social structures in which individuals with stroke receive care and function” (Perrin et al., 2010, p. 380).

Research Questions/Hypotheses

The review of the literature revealed that CB among ICPs of stroke survivors remains a critical and under-addressed issue. Despite the well-documented impact of CB on both ICP and stroke survivor outcomes, research exploring the influence of HRSNs remains limited. For example, very few studies report on race and income, key components of social context, let alone the broader range of HRSNs (Magin et al., 2013; Young et al., 2020). This gap is especially concerning given that REM ICPs experience significantly greater CB compared to their White counterparts, due in part to increased caregiving hours and the disproportionate burden of stroke among REM populations (Skolarus et al., 2017; Tsao et al., 2022). However, all ICPs, regardless of race or ethnicity, may face challenges related to HRSN that exacerbate the stress of care partnership. More research is needed to identify and address these unmet social needs. Accordingly, this study explored the prevalence and impact of HRSNs among ICPs of stroke survivors in order to address the following research questions:

1.) <u>Is there a relationship between 12 domains of HRSNs and CB among ICPs of stroke survivors?</u>
    a.) Specific Aim #1 (Primary Aim): Examine the relationship between 12 domains of HRSNs and CB among ICPs of stroke survivors.

b.) Null hypothesis: There is no statistically significant relationship between any domain of HRSNs and CB among ICPs of stroke survivors.

2.) What are the most prevalent HRSNs among ICPs of stroke survivors?

a.) Specific Aim #2 (Primary Aim): Identify the most prevalent HRSNs among ICPs of stroke survivors.

3.) Is there a relationship between demographic variables and total HRSNs among ICPs of stroke survivors?

a.) Specific Aim #3 (Primary Aim): Examine the relationship between demographic characteristics and total HRSNs among ICPs of stroke survivors.

b.) Null Hypothesis: There is no statistically significant relationship between any demographic characteristic and total HRSNs among ICPs of stroke survivors.

4.) Are there significant differences in the prevalence of HRSN domains and demographic variables between REMs and non-REMs?

a.) Specific Aim #4 (Secondary Aim): Examine group differences in the prevalence of HRSN and demographic variables by REM group.

b.) Null Hypothesis: There are no statistically significant differences in HRSN prevalence and demographic variables between REMs and non-REMs.

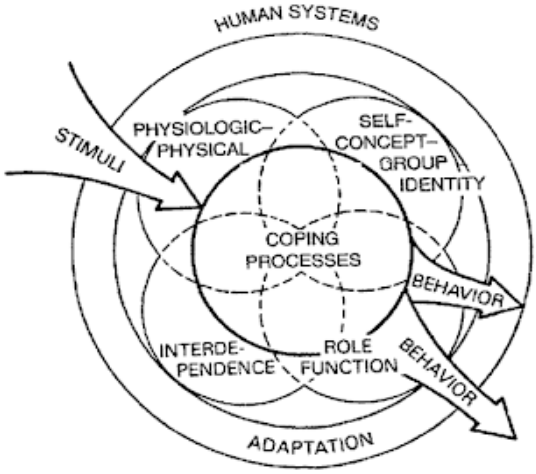
Theoretical Foundations

Overview

The Roy Adaptation Model (RAM), as described by Roy and Andrews (2009), serves as the theoretical underpinning guiding this study. This section outlines the fundamental assumptions of the model, defines the model's key terms, and explains their relevance and application to this research. Subsequently, a theoretical substruction of the RAM is presented. This substruction, a conceptual-theoretical-empirical diagram, visually links the theoretical constructs of the RAM with the study's specific aims, variables, and measurement instruments.

Roy and Andrews (2009) posit that nursing is a specialized knowledge-based healthcare discipline with the primary objective of promoting the holistic health of individuals and communities (University of Tulsa, 2023). Nursing, therefore, demands unique knowledge tailored toward understanding the complex and multifaceted nature of human health. In this study, the RAM provides a structured framework by which essential elements of the study are validated within the model. The principal investigator (PI) further adapted RAM to produce a detailed substruction, visually representing the operationalization and measurement of each variable within each adaptive mode. By embedding the research within the context of the RAM, the study aims to strengthen its theoretical rigor and clearly articulate the relationships between the key variables under investigation.

Figure 1.1
Theoretical Diagram Depicting the Roy Adaptation Model



Note. From Roy & Andrews (2009).

RAM rests upon philosophical, scientific, and cultural assumptions that directly inform this research. From a philosophical standpoint, RAM is grounded in humanism, a worldview emphasizing human experiences as central to understanding reality. Humanism views human beings as purpose-driven individuals who derive meaning through their interactions and relationships with environments and others (Britannica, 2023). Roy and Andrews (2009) highlight the universal human pursuit of purposeful existence and interconnectedness as foundational to this viewpoint. This is particularly relevant to the present study, which seeks to understand how ICPs of stroke survivors adapt to the physical, emotional, and social demands of care partnership. Humanism, as embedded in RAM, views health not merely as the absence of illness, but as a dynamic process through which individuals strive for wholeness and purpose despite challenges. By situating ICPs as purposeful, adaptive human beings, the model provides a holistic, human-centered lens through which to examine CB.

Scientifically, RAM assumes that human beings function as adaptive systems composed of interdependent parts operating in dynamic unity. Roy conceptualizes human experience as a continual and dynamic process of interacting with stimuli in the environment, generating adaptive responses. Individuals actively engage in these adaptive processes to maintain equilibrium and achieve meaningful existence and purposeful interaction with their surroundings. Importantly, this adaptive process is nonlinear, complex, and interactive, underscoring the multifaceted nature of human adaptation. This assumption is particularly relevant to the current study, which explores how ICPs of stroke survivors navigate multiple, possibly often co-occurring HRSNs, such as housing instability, food insecurity, or social isolation, which function as multifactorial stimuli. The model's emphasis on complexity and interdependence supports a research design that does not isolate a single predictor of CB, but instead considers the collective impact of multiple social stressors. By viewing the ICP as an adaptive system, the study recognizes that CB emerges not from a single source, but from the interactive and cumulative burden of environmental pressures, resource limitations, role demands, and others.

Culturally, RAM acknowledges that human adaptation is deeply influenced by cultural experiences and societal contexts. It recognizes that cultural backgrounds significantly shape how individuals interpret, respond to, and manage environmental stimuli. Roy and Andrews (2009) emphasize that cultural variability impacts adaptive expressions and responses, which has direct implications for nursing practice, education, and research. Thus, culturally responsive nursing care must consider how different cultural contexts shape adaptive behaviors and experiences. This view of cultural

perspectives is well-aligned with this study design, as acknowledging various cultural perspectives forms an essential component of the purposes of this study.

RAM, as outlined by Roy and Andrews (2008), conceptualizes individuals as holistic adaptive systems in constant interaction with a changing environment. As defined by Roy, adaptation is the continuous process through which a person strives to maintain integrity and health amid environmental stimuli. Key elements of RAM include inputs (stimuli), throughput (coping processes), and outputs (adaptive responses). Stimuli are classified as focal, contextual, or residual. The focal stimulus is the immediate challenge requiring the person's attention; it is directly confronting the individual. Contextual stimuli are the myriad of other factors, internal or external, that influence the situation. Residual stimuli refer to environmental or personal factors whose effect is not immediately clear, such as deeply held beliefs or past experiences, and are not explored in this study.

Within RAM, individuals employ coping mechanisms (the regulator and cognator subsystems) to deal with these stimuli. The regulator subsystem encompasses physiological coping (such as neural, chemical, and endocrine responses to stress), whereas the cognator subsystem involves cognitive-emotive coping processes like perception, information processing, judgment, and emotion. These coping subsystems are the pathways through which stimuli are transformed into observable behaviors. When an individual's coping is effective, the outcome is adaptive responses manifesting in one or more of four adaptive modes: physiological, self-concept, role function, and interdependence. These four adaptive modes represent the categories of behavior through which we can assess how well a person is adapting to their environment. When coping is

effective, the individual achieves an integrated or healthy adaptation in all modes; when coping is overwhelmed, compromised or maladaptive responses may occur. The goal of nursing in RAM is to assess these behaviors and stimuli and intervene to promote more effective adaptation in each mode.

For this dissertation, RAM provides a guiding theoretical framework to examine how HRSNs function as contextual stimuli as well as components of adaptive modes and how care partners' responses (in terms of burden) can be understood as outcomes in the four adaptive modes. By using RAM, the study situates CB not just as a singular outcome, but as a reflection of the ICP's adaptive status across multiple domains of life. This holistic lens is especially pertinent for research on CB, which is known to be a multidimensional construct.

Theoretical Substruction of the Roy Adaptation Model

Overview of Substruction and Discussion on Conceptual-Theoretical-Empirical Applications of Stimuli

Roy describes individuals and groups as holistic adaptive systems continuously interacting with their environments. For this study, the adaptive system specifically represents ICPs of stroke survivors. Adaptation within RAM begins with a stimulus, broadly defined as any factor that elicits a response within the adaptive system. RAM categorizes stimuli into focal and contextual types, each playing distinct roles in shaping adaptive responses. The stimulus and the adaptive levels make up the input, which then activates the human coping process and cognator and regulator subsystems, which leads to the use of adaptive modes. How the individual responds at each of these levels will then lead to a behavioral output.

The focal stimulus represents the most immediate and impactful factor directly influencing the individual's adaptive response, which in this study is the assumption of the care partner role by ICPs. This role assumption directly challenges ICPs, prompting significant adaptations to meet new responsibilities and cope with emerging stressors. Importantly, for this study, an ICP can be designated an ICP regardless of the duration of the assumption of the role or the type of stroke their care receiver survived.

Contextual stimuli are additional factors, both internal and external, influencing the ICP's experience and perception of care partnership. In this study, contextual stimuli include demographic characteristics such as age, sex, marital status, employment status, transportation access, and HRSNs specific to stroke care partnership, such as financial strain and access to adaptive equipment. The greater the number or severity of unmet needs, the theoretically heavier the contextual load on the ICPs adaptive system. These factors provide critical context, shaping the ICP's ability to adapt effectively. Contextual stimuli will be measured using demographic questionnaires and the Accountable Health Communities Health-Related Social Needs Screening Tool (Centers for Medicare and Medicaid Services, 2017).

It is important to note that the study is actively looking to include REM ICPs of stroke survivors. REMs often face distinctive contextual stimuli related to their minority status. These can include socioeconomic disparities (Garnett et al., 2022), cultural norms and expectations around care partners (Gelman, 2014), and even experiences of systemic bias or discrimination within healthcare and social service systems (Clark et al., 2010; Garnett et al., 2022). For instance, cultural values like familism in Latino communities can lead to ICPs feeling obligated to handle everything themselves and guilt about

seeking help (Gelman, 2014). Such a value is a contextual stimulus rooted in culture, it can provide a sense of purpose but may also add pressure to the ICP's role (Crist et al., 2009; Morgenstern et al., 2021). Similarly, BAA care partners of stroke survivors often provide more hours of care on average and may have less access to external support (Skolarus et al., 2017), which may influence the adaptive processes of the human system.

While residual stimuli are recognized as a likely influence of every adaptive process, they are not measured in this study. Residual stimuli could include the care partner's personality traits, prior experience with care partnership, or deep-seated beliefs (for example, faith or spirituality) that are harder to quantify. These factors might subtly influence how a care partner perceives their burden or copes with stress, even though the impact of residual factors is not measured in this study. By acknowledging their possible presence, this study remains aligned with RAM's comprehensive view that many factors shape the adaptation process.

In summary, RAM guides us to consider that an ICP's experience is not solely a result of the assumption of the role of care partner (focal stimulus), but also heavily shaped by context. The demographic questionnaire administered in the study captures some of these contextual details (i.e., care partner age, gender, race/ethnicity, employment status, relationship to the survivor, etc.), which situate the care partnership experience. The HRSN assessment directly measures key contextual stimuli, revealing which HRSNs are unmet and to what extent. Together, these inputs lay foundations for understanding the ICP's adaptive process. The theory posits that these stimuli will influence the care partner's responses in each adaptive mode, ultimately affecting the level of CB observed.

Discussion on Conceptual-Theoretical-Empirical Applications of Adaptive Modes

RAM's four adaptive modes, physiological-physical (labeled as physiological in the provided substruction), self-concept, role function, and interdependence, provide a structured way to discuss the various dimensions of CB and how HRSNs impact each. The following is a discussion on the conceptual-theoretical-empirical application of the RAM to this study.

Physiological Mode

The physiological mode in RAM focuses on the basic physical and biochemical processes needed for survival and overall health. In the context of care partnership, this mode reflects the ICP's physiological health and physical well-being as they adapt to the experience of care partnership. Caregiving for a stroke survivor can take a significant physical toll on the ICP. Many ICPs experience fatigue, poor sleep, aches and pains from assisting with transfers or mobility, and neglect of their own health needs (Abba et al., 2022; Hung et al., 2007). The Caregiver Burden Inventory (CBI) (Novak & Guest, 1989) captures this domain through items that assess physical burden. For example, feeling tired all the time or feeling one's health is suffering due to care partnership responsibilities. A high score on the physical burden subscale of the CBI would indicate a potential maladaptive response in the physiological mode.

HRSNs directly tie into the physiological mode as contextual stimuli. For instance, if an ICP has unmet needs in the domains of food insecurity or interpersonal safety, their own physical health may be at risk. An ICP who cannot afford their medications or who skips medical appointments (perhaps due to lack of transportation or

time) is facing HRSNs that can worsen their physical well-being. Similarly, food insecurity or inadequate housing (living in a damp, unsafe environment, for example) or lack of physical activity could compromise the ICP's health. These HRSNs create additional stress on the physiological mode by jeopardizing the ICP's ability to maintain their health while caregiving. In REM populations, such needs are often prevalent. ICPs from under-resourced communities, for example, might have higher rates of chronic conditions like diabetes or hypertension (Campbell & Egede, 2020) yet face barriers to managing these conditions. Under RAM, these unmet needs are contextual stimuli influencing the physiological adaptive mode. If they accumulate, the ICP's regulator subsystem (physical coping) may be overwhelmed, leading to signs of poor adaptation like constant fatigue, illnesses, or somatic symptoms. Thus, one theoretical expectation is that ICP with more HRSNs will report greater physical burden and potentially poorer health, indicating difficulty adapting physically to the care partnership role.

Self-Concept Mode

The self-concept mode centers on the psychological and spiritual aspects of the individual, such as one's perception of self, including concepts like self-esteem, emotional well-being, and sense of purpose. It encompasses what Roy also describes as the personal self (including self-consistency, self-ideal) and the moral-ethical-spiritual self. In ICPs, the self-concept mode is reflected in their emotional state, mental health, and sense of identity in the care partnership role. Care partnership can deeply affect how individuals see themselves (Cejalvo et al., 2021). Some may derive positive self-worth and meaning from being able to care for their loved one (Autio et al., 2025), but many also experience negative feelings like guilt, anxiety, depression, or a sense of inadequacy

(Mohamed Hussin & Mohd Sabri, 2023). The CBI (Novak & Guest, 1989) addresses this mode primarily through its emotional burden subscale (and partly through items in the developmental or time-dependence subscales that affect one's personal life). High emotional burden scores indicate the care partner frequently feels sadness, anger, or resentment, or perceives major emotional strain from the care partnership, signs that the self-concept mode is under duress.

In the RAM framework, HRSNs can significantly impact the self-concept mode. Mental health support needs are a clear example, as if an ICP has an unmet need for mental health, their self-concept adaptation may suffer, leading to higher emotional distress. Additionally, financial strain can potentially weigh heavily on one's mental wellbeing. Constant worry about finances due to medical bills or reduced work hours can cause anxiety and feelings of helplessness, undermining emotional stability. Many REMs are in financially vulnerable positions due to systemic inequalities and juggling care partnership with jobs that have little flexibility or no paid leave (Quiros & Biswas, 2025) which can create chronic stress. This financial contextual stimulus feeds into the ICP's emotional state. For example, an ICP who cannot make ends meet may feel despair or failure, potentially harming their self-concept.

Role Function Mode

The role function mode addresses the roles an individual occupies in society and the behaviors associated with those roles. Every person holds multiple roles (such as parent, spouse, employee, friend, etc.), and adaptation in this mode means effectively meeting the obligations of those roles. In the context of this conceptual-theoretical-empirical adaptation, the ICP has taken on the role of an ICP to a stroke survivor. This

care partner role might be new or an extension of a previous family role (such as a spouse now becoming an ICP, or an adult child becoming an ICP to a parent). The introduction of intensive care partnership responsibilities may disrupt the ICP's ability to fulfill other roles. They might reduce work hours (affecting their employee role) (Gordon et al., 2012), have less time for their children (parental role), or lose time for personal hobbies and social life (individual roles) (Rokicka & Zajkowska, 2020). Role strain and role conflict are thus central issues for ICPs. The CBI's subscales, like time-dependence burden (which reflects how much the care partner role infringes on the ICP's time and other activities) and developmental burden (which reflects how care partnership interrupts the ICP's life-course plans or achievements), align with this mode. For example, an ICP might endorse items about having to give up personal ambitions or feeling that their schedule is dictated entirely by the survivor's needs, clear indicators of role function challenges. A high burden in these areas signals that the ICP is struggling to integrate the care partner role with their other life roles.

HRSNs are connected to the role function mode because many social needs relate to role performance. An ICP who cannot find affordable day care for the survivor or lacks workplace flexibility may have to abandon or cut back on their job, which in turn causes financial strain. The inability to perform the worker role due to care partnership is both a result of an unmet need and a potential cause of further burden.

Interdependence Mode

The interdependence mode involves the balance of giving and receiving love, respect, and support in significant relationships. It addresses the social support system and relational integrity of the individual. For ICPs, this mode reflects how well they are

supported by others and how their relationships are maintained. A healthy interdependence mode means the ICP has adequate social support, communication, and reciprocal nurturance in their life. On the other hand, if they feel isolated, abandoned, or strained in their relationships, the interdependence mode is in jeopardy. CB often includes a social dimension: many ICPs experience social isolation and strained family relationships (Kavga, Kalemikerakis, et al., 2021; Kruithof et al., 2016). The CBI's (Novak & Guest, 1989) social burden subscale directly measures some of these issues, such as feelings of isolation or that caregiving has limited one's social life. Additionally, items in other subscales, like time-dependence, can indirectly reflect social constraints (no time for friends or recreation). A high social burden suggests the ICP is not receiving sufficient social support or that their normal social ties have been weakened, indicating a potential failure in interdependence adaptation.

HRSNs related to social connections and support are also theoretically relevant. If the REM ICP has an unmet need for social support, that is a critical variable undermining the interdependence mode. Many ICPs rely on extended family networks or communities for support (Britt et al., 2023). However, those same ICPs might also face barriers to accessing formal support services due to language barriers, lack of culturally tailored services, or mistrust of formal systems. Furthermore, there is limited data available regarding the use of social networks within the stroke care partnership community, even if it is present for other care partnership communities (such as dementia). If one of the 12 HRSN domains assessed involves social isolation or lack of care partner support, it is theoretically expected to correlate with higher social burden.

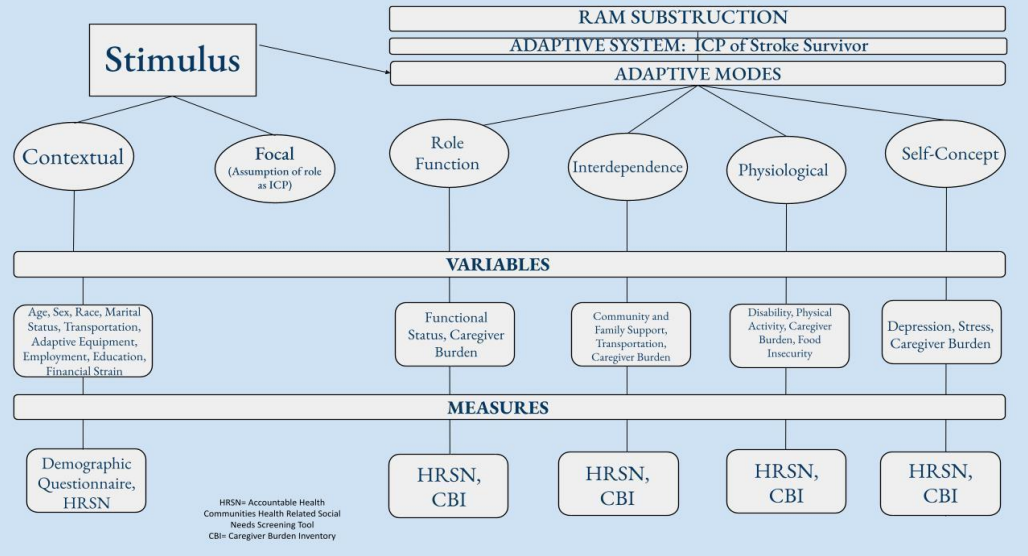
Another aspect of interdependence for ICPs of stroke survivors is the relationship with the stroke survivor themselves. Cultural norms may influence communication and expectations in this dyad. For instance, in some cultures, elders are respected authority figures, and an adult child caring for a parent might struggle to assert needs or set boundaries, potentially leading to burnout (Blinka et al., 2022; Falzarano et al., 2022; Subramaniam & Mehta, 2024), although this has not been demonstrated in the REM ICP of stroke survivor community in the US.

Summary of Conceptual-Theoretical-Empirical Integration

Each adaptive mode discussed corresponds to certain variables and measures in the study's substruction. The stimulus inputs (focal and contextual) feed into the ICPs coping processes and manifest as outputs that are measured via our empirical indicators. To summarize these linkages, please see figure 1.2.

Figure 1.2

Theoretical Substruction of the Roy Adaptation Model



Concluding Thoughts on the Application of a Theoretical Substruction of the Roy Adaptation Model

Employing the Roy Adaptation Model in this dissertation provides a theoretical foundation that connects individual ICP outcomes to broader HRSNs contexts. This is particularly significant for REM ICP research for several reasons. First, RAM's holistic view ensures that we examine CB not just as an endpoint, but as part of a dynamic process of coping and adjusting. ICPs of stroke survivors might have different coping resources and stressors than majority populations. By structuring around the adaptive modes, CB is inherently treated as multidimensional, which is congruent with how ICPs actually experience burden (Novak & Guest, 1989).

Second, RAM explicitly integrates the concept of environment in understanding health outcomes. This is a natural bridge to incorporate HRSNs and health disparities into the framework. In health research that emphasizes REM populations, it is crucial to acknowledge that disparities are often driven by environmental and social inequities

(Yearby, 2022). Scholarly work using RAM in ICP research has similarly highlighted that CB needs to be understood in context, noting that a holistic model is useful to reconceptualize burden (Newman, 1997).

Third, using RAM helps to frame interventions and future research. Although this dissertation is a cross-sectional correlational study, the ultimate goal of such research is to inform interventions and health policy to reduce CB. RAM, as a nursing theory, is action-oriented; it implies that if we assess maladaptive responses in certain modes, we can target stimuli to improve adaptation. The model provides a rationale for why such multi-pronged interventions are necessary: because human adaptation is multifaceted, addressing only one aspect may not be sufficient to bring the system into balance, which has been evident in the lack of successful interventions targeting negative outcomes among ICPs of stroke survivors.

Finally, using RAM pays respect to the fact that this dissertation is grounded in nursing science. Roy's model is one of the grand theories of nursing that has been widely used over the past decades in research concerning chronic illness, rehabilitation, and care partner well-being (Roy, 2011). Its application to this study reinforces the idea that ICP health is an integral part of nursing's domain, and that theoretical guidance is essential for rigor. This claim is reinforced by literature that is theoretically adjacent to this dissertation. For instance, work reframing CB through RAM (Newman, 1997) provides precedent, and more recent studies continue to apply RAM to understand care partnership in chronic illness contexts (Khiewchaum et al., 2025). This study adds to this literature by focusing on the unique population of ICPs of stroke survivors and explicitly incorporates

social needs into the RAM paradigm, thus extending the model's application to the realm of HRSNs.

In conclusion, RAM offers a comprehensive theoretical framework that enriches the understanding of CB among ICPs of stroke survivors. It prompts the consideration of the full range of stimuli affecting ICPs and allows for a conceptual-theoretical-empirical framework to connect those influences with outcomes in key adaptive domains. This framework underscores why there is an expectation that certain HRSNs correlate with CB and why it matters: any observed correlation is not just a statistical finding, but a reflection of an adaptive challenge faced by the ICP. Recognizing these challenges in theoretical terms enhances the scholarly significance of the work and lays a conceptual groundwork for future interventions aimed at promoting better adaptation in this vulnerable population.

Methods

Introduction

This section outlines the study's exploratory, descriptive, correlational, cross-sectional methodology using multiple regression analysis. It details the research design, sample characteristics, recruitment setting, data collection, and analytic strategy. Additional information is provided regarding quality assurance, ethical considerations, and accessibility.

Design

Overview

This study employed an exploratory, descriptive, correlational, cross-sectional design to examine the relationship between the independent variables (12 domains of

HRSNs) and the dependent variable, CB, among ICPs of stroke survivors for the primary analysis. Given the limited existing literature on HRSNs among stroke ICPs, this study was designed as an exploratory analysis intended to identify preliminary patterns and relationships rather than establish causal inferences.

Sample

Recruitment Setting

Participants were largely recruited through two primary sources: 1.) social media and 2.) stroke support groups. Social media recruitment methods included posts on stroke and care partner specific stroke support pages. Participants recruited online were screened over the phone to prevent potential scam responses. Stroke support groups included in-person visits from the PI to stroke support groups in southeastern Michigan, as well as additional outreach via email and phone calls to stroke support groups in mid and northern Michigan, New York, Los Angeles, North Carolina, Tennessee, and Ohio with requests to distribute recruitment material. Other settings of recruitment included flyer placement at neurology focused outpatient rehabilitation facilities, southeastern Michigan senior and community centers, and snowball sampling. Additionally, attempts were made by the PI to recruit at local churches and other religious institutions. A recruitment flyer (see Appendix A) was shared online and in-person. Participants received a $20 Amazon gift card upon completion of all three surveys.

Inclusion Criteria

Participants were eligible if they met the following criteria:

- Self-identification as an informal care partner of a stroke (ischemic or hemorrhagic) survivor aged 18 or older

- English literacy
- Access to the internet via a smartphone or computer

Exclusion Criteria

- Inability to provide informed consent

Convenience Sampling and Estimated Sample Size

Convenience sampling was used across all recruitment sites. While all ICPs of stroke survivors who met the previously discussed criteria were eligible to participate, special attention was paid to recruiting REMs. The principal investigator (PI) consulted with community members and a REM nursing expert to identify culturally sensitive and effective recruitment strategies. These strategies were modeled after those used in similar research efforts in REM populations through community centers (Burns et al., 2022; Ratnapradipa et al., 2024) and local rehabilitation facilities (Clark et al., 2010; de Leon Arabit, 2008).

Using G*Power (Faul et al., 2007), a minimum sample size of 124 was determined for a multiple regression analysis for the primary regression based on the following parameters: effect size $f^2 = 0.15$ (medium), power = 0.80, $\alpha = 0.05$, and 12 predictor variables. To accommodate the potential impact of dichotomous predictors and incomplete data, a target sample size of 150 was set. Separate power analyses are presented for additional regression analyses and are presented in the corresponding methods sections.

An effect size of $f^2 = 0.15$ was selected based on limited but compelling precedent in the current literature. A study using the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989) to evaluate the impact of a supportive home care program on CB among

ICPs of stroke survivors reported a large effect size ($\eta^2 = 0.305$), indicating that the intervention accounted for over 30% of the variance in CB scores (Ashghali Farahani et al., 2021). While this study supports the CBI's sensitivity to external factors influencing burden, it was conducted outside the US and did not report key contextual variables such as race or income. Additional evidence of the CBI's utility and responsiveness is seen in psychometric validation work by Shafiezadeh et al. (2020), who reported strong internal consistency (Cronbach's $\alpha = 0.91$) and a factor structure explaining 45.2% of the variance in CB among Alzheimer's ICPs. Similarly, Chen et al. (2017) found large group differences in CBI scores (Cohen's $d = 0.99$ to 1.80) when comparing ICPs of stroke survivors with and without spatial neglect. A broader meta-analysis of 74 studies by del-Pino-Casado et al. (2021) reported a large overall correlation ($r = 0.51$) between CB and anxiety across ICP populations, further illustrating the scale's ability to capture meaningful differences in psychosocial outcomes. Taken together, these findings suggest that CB, when measured using the CBI, is highly responsive to both contextual and clinical predictors. Thus, the use of a conservative, small-to-medium effect size ($f^2 = 0.15$) in the current study's power analysis is justified given the novelty of this study's inclusion of REMs in the US.

Ethics

Study approval was obtained from the Oakland University and Henry Ford Health System Institutional Review Boards (IRB). The PI completed IRB research modules and was certified through Collaborative Institutional Training Initiative. Consent was implied via participants choosing to move forward in the survey following reading the information sheet. Data were kept confidential, with the emails of participants collected

to send out the surveys and incentives. All data were deidentified. IRB timelines will be followed regarding storage/destruction of data (see Appendix C for a copy of the IRB exemption letter).

There were minimal risks for participants. Discussing the experience of care partnership may result in emotional distress, and while every attempt at secure data storage will be made, as discussed previously, potential breaches of data remain possible. The $20 incentive serves as the only direct personal benefit to participants.

Study Accessibility

To ensure the accessibility of study materials such as recruitment flyers and email communications, material was created using recommendations from the Oakland University Web Accessibility Guidelines (Oakland University, n.d.). Once the material was finalized, a meeting was scheduled between the PI and the University accessibility team. Though stroke survivors were not included in the study sample, recruitment materials were publicly distributed and therefore designed to be accessible to a wide range of potential viewers, including those with physical, sensory, or cognitive impairments. In alignment with principles of equity and inclusion, efforts were made to ensure that materials could be understood and engaged with by individuals regardless of disability status, educational background, literacy level, age, or device type.

Data Collection

Introduction

Data collection involved three questionnaires completed by each participant: a PI-developed demographic questionnaire, the Accountable Health Communities Health-Related Social Needs Screening Tool (AHC-HRSN) (Centers for Medicare and Medicaid

Services, 2017), and the CBI (Novak & Guest, 1989). All instruments were administered electronically via Qualtrics. Participants were provided with detailed instructions for completing the surveys (see Appendix B). Although all data were de-identified, IP addresses were collected to confirm participants' geographic location within the US. To ensure cultural sensitivity in survey language and administration, the PI collaborated with a REM nursing expert throughout the study design process. Following expert review, the substance use domain of the AHC-HRSN tool was identified as potentially culturally insensitive and was subsequently excluded from analysis.

Measures

Demographic Questionnaire

Description. The demographic questionnaire consisted of 15-items designed to capture participant characteristics. This data was not included in the primary multiple regression analysis (but was used as the independent variable and group comparisons in some analyses) but was summarized using descriptive statistics. The questionnaire assessed the following variables: care partner race, age, gender, marital status, education level, employment status, household income, race/ethnicity of the stroke survivor, relationship to the stroke survivor, use of adaptive equipment, hours spent caregiving per week, duration in the care partner role, amount of skilled nursing care provided, cohabitation status with the stroke survivor, and zip code.

The Accountable Health Communities Health-Related Social Needs Screening Tool (AHC-HRSN)

Description. The AHC-HRSN is a 26-item screening instrument that assesses 13 domains of HRSNs, including: housing instability, food insecurity, transportation

problems, utility assistance needs, interpersonal safety, financial strain, employment, family and community support, education, physical activity, substance use, mental health, and disabilities. Items on the instrument include a variety of response types (e.g., Likert scale, categorical, ordinal). For the physical activity domain, responses were evaluated against U.S. physical activity guidelines (i.e., at least 30 minutes of exercise five days per week). Any report of less than this standard was coded as (1) (Mayo Clinic, 2023).

For the purposes of this study, the substance use domain was excluded prior to data collection due to concerns about cultural sensitivity, as determined in consultation with a REM nursing expert. This decision aligns with best practices in cross-cultural instrumentation, which recommend altering or omitting items that may not have equivalent meaning or may be interpreted differently across cultures, to reduce measurement bias (Lei & Lee, 2021). Research has demonstrated that culturally adapting questionnaires, through item modification or removal, is essential to maintain validity, avoid stigmatization, and improve respondent comfort and data quality, particularly among marginalized populations (Lei & Lee, 2021). Each of the remaining 12 domains were recoded into dichotomous variables: (0) indicating no social need, and (1) indicating presence of a social need. In domains with multiple items, the domain was still scored as a binary outcome, with any positive response resulting in a score of 1. This dichotomization approach was chosen to account for inconsistent scaling within the original tool and to facilitate clearer comparison across participants, reduce measurement error, and enhance statistical simplicity for regression modeling. The 12 dichotomized HRSN domain scores were entered as predictor variables in the primary multiple regression analysis.

Although the original AHC-HRSN includes a mix of binary and ordinal response items, the current study dichotomized each of the 12 included domains to reflect the presence (1) or absence (0) of need. This approach aligns with the intent of the tool, which was developed by the Centers for Medicare & Medicaid Services (CMS) to efficiently flag actionable social needs for follow-up, rather than to grade severity (Centers for Medicare and Medicaid Services, 2022). This scoring method improves consistency across domains with varying response formats, reduces noise from item-level variability, and enhances the interpretability of regression models. Prior research supports dichotomization of HRSN measures in studies where the goal is to identify correlates of need presence and associated outcomes (Billioux et al., 2017). Thus, this analytic decision preserves the tool's clinical utility while supporting statistically sound and theoretically coherent variable construction, while also presenting several limitations. Furthermore, dichotomization of these variables is present in current literature, emphasizing how this methodology allows for clearer interpretation of need presence across heterogenous domains and reducing scaling inconsistencies across item types (Adepoju et al., 2022; Dart, 2025)

Psychometrics. A systematic review of 21 instruments assessing social risk, among them the AHC-HRSN, found that none adhered fully to best practices in measurement development (Lewis & Dorsey, 2020). A separate evaluation of the psychometric quality of these tools placed all in the third lowest quartile of potential psychometric scores, with data especially lacking with regard to known groups validity and responsiveness (Henrikson et al., 2019), indicating limited psychometric rigor in this measurement field overall. *Content Validity.* Content validity refers to the extent to which

the instrument is relevant to the concept it wishes to measure (Rusticus, 2014). Measuring content validity involves asking content experts whether included items actually target the phenomenon the item intends on targeting. The AHC-HRSN tool was developed with input from a diverse panel of stakeholders including public health experts, clinicians, health system executives, community organization leaders, and federal partners. This collaborative development process supports its content validity by ensuring that items reflect the lived realities of the populations served (Billioux et al., 2017). *Concurrent Validity*. Concurrent validity assesses agreement between two different instruments designed to assess the same or similar concept (Jane & Tatano, 2025). When comparing the HRSNs assessment to the Your Current Life Situation (YCLS) (Kaiser Permanente, 2016), the HRSNs had 7%-29% reporting social risks, the YCLS had 4% to 23% (Lewis et al., 2020). Throughout similar domains of the instruments, one was found to have moderate agreement, three were found to have substantial agreement, and three were found to have almost perfect agreement (Lewis et al., 2020; McHugh, 2012). *Predictive Validity.* The AHC-HRSN has demonstrated evidence of predictive validity through its associations with key health outcomes. In particular, individuals reporting one or more social needs on the AHC-HRSN tool were significantly more likely to report poor or fair self-rated health, a widely accepted proxy for overall physical and mental well-being (Lewis et al., 2020). This finding suggests that the presence of unmet social needs identified by the tool is meaningfully related to downstream health effects.

Furthermore, social risks captured by the AHC-HRSN (although not research involving the AHC-HRSN directly), particularly those related to housing instability, food

insecurity, and financial strain, have been associated in prior research with increased rates of hospital utilization, emergency department visits, and difficulty managing chronic illness (Gottlieb et al., 2016; Holcomb et al., 2022). These relationships highlight the tool's utility in identifying patients who may be at heightened risk for adverse health outcomes, even when clinical indicators alone may not reveal such vulnerability.

Justification for Use in the Current Study. The AHC-HRSN was selected for this study because it provides a structured and comprehensive method for identifying HRSNs that influence health and care partnership outcomes. While the tool has recognized psychometric limitations, its domains capture tangible, real-world conditions that shape individual adaptation and well-being. This aligns with the aims of the current study, which sought to explore how contextual and environmental factors contribute to the experience of CB among ICPs of stroke survivors. Although originally developed for clinical screening rather than research measurement, the AHC-HRSN's emphasis on actionable and person-centered needs supports its relevance in generating early, exploratory evidence about the social context of care partnership.

The use of the AHC-HRSN in this exploratory context provides valuable preliminary insights into which domains of need may be most salient for ICPs and how they may interact with multidimensional burden processes. Findings from this study can therefore inform refinement of measurement strategies and guide the development of targeted, testable hypotheses in future research. Furthermore, the AHC-HRSN's multidimensional structure parallels the adaptive processes described in the RAM. Each domain represents potential external stimuli that may challenge one or more adaptive modes, linking social environments to adaptation processes. Used alongside the CBI,

which captures internal manifestations of strain across corresponding adaptive modes, the AHC-HRSN enables a complementary, theory-driven assessment of both environmental and personal influences on caregiver burden. Together, these instruments provide a multidimensional framework for understanding how HRSNs contribute to the broader adaptive experience of ICPs and inform future hypothesis development.

Caregiver Burden Inventory

Description. The Caregiver Burden Inventory (CBI) is a 24-item questionnaire designed to assess the multidimensional burden experienced by informal caregivers. Each item is scored on a 5-point Likert scale ranging from 0 ("not at all descriptive") to 4 ("very descriptive"), yielding a total score range of 0 to 96. Higher scores indicate a greater level of CB. The CBI measures five distinct domains of burden:

- Time-Dependent Burden (5 items): Reflects the extent to which caregiving restricts the ICP's time and interferes with personal schedules, leisure activities, and other responsibilities. Higher scores indicate significant interference with personal and professional time commitments.
- Developmental Burden (5 items): Assesses perceived disruption of personal growth and life plans due to care partnership responsibilities, including feelings of stagnation and missed opportunities. Elevated scores reflect a sense of lost potential or altered life trajectories.
- Physical Burden (4 items): Evaluates the physical toll of care partnership, including fatigue, physical strain, and declines in overall physical health. High scores denote greater physical stress attributed to caregiving duties.

- Social Burden (5 items): Captures the impact of care partnerships on social relationships and community engagement. It includes feelings of isolation, restricted social interaction, and strained interpersonal relationships. Higher scores indicate increased social disruption.
- Emotional Burden (5 items): Measures emotional and psychological strain, such as anxiety, frustration, sadness, and resentment. High scores suggest a greater degree of emotional distress related to care partnership.

This instrument was used with proper licensing for the current study (License Number: 5746050909332).

Justification for Use in the Current Study. The CBI was selected for this study due to its comprehensive, multidimensional approach to CB, which aligns closely with the complex and multifaceted experiences of ICPs of stroke survivors. Stroke care partnership frequently involves not only physical and time-related demands but also major emotional, social, and developmental disruptions. These impacts are especially salient in the stroke recovery trajectory, which often requires long-term adaptation to sudden, life-altering impairments. Unlike unidimensional burden scales, the CBI allows for a more nuanced assessment that reflects the holistic strain experienced by ICPs.

Furthermore, the domains of the CBI map well onto the RAM, the guiding theoretical framework of this study. RAM posits that individuals respond to external stressors through four adaptive modes: physiological, self-concept, role function, and interdependence. The CBI's physical, emotional, and social burden domains directly parallel these adaptive modes, offering insight into areas where maladaptation may occur. For example, high developmental and emotional burden scores may signal challenges in

role function and self-concept, while social and physical burden scores may reflect breakdowns in interdependence and physiological integrity. Thus, the CBI supports a theory-driven assessment of how HRSNs and CB interact in this population.

Psychometrics. A systematic review of CB using the CBI among caregivers of stroke survivors found the range of Cronbach's α to be 0.73-0.85, indicating acceptable reliability (Rigby et al., 2009).A study conducted more recently, although not involving REM ICPs of stroke survivors, found that the CBI had acceptable construct validity (with all items having a communality value greater than 0.4 and 70.8% of variance within the five factors explained), reliability (Cronbach α for the CBI was 0.946), and concurrent validity (CBI total score showed Pearson's *r* of 0.811) (Kyeong Eun Uhm et al., 2021). Other studies with similar samples demonstrated strong internal consistency, with Cronbach's alpha ranging from .84 to .92 across domains.

Data Analysis

Introduction

This section outlines the analytic procedures used to examine the relationships between HRSNs and CB. Analyses were conducted using IBM SPSS Statistics for Windows, Version 29.0 (IBM Corp., 2023). Techniques for analysis were based on Pallant (2020) and supplemented by other statistical texts and outputs from related literature. Steps included data cleaning, reliability testing, descriptive statistics, assumption testing, bivariate analyses (correlations, chi-square tests, t-tests, and ANOVA), and multiple linear regression. Both primary and secondary models were tested: (1) HRSNs as predictors of CB (Chapter 3) and (2) demographic characteristics as

predictors of total HRSN burden (Chapter 4). Additional analyses such as outlier detection were conducted as needed. Statistical significance was set at $p < .05$.

Steps of Data Analysis

Data Set Cleansing and Descriptive Analysis

Data cleaning began with an examination of missing values and outliers (Pallant, 2020). Due to no presence of nonrandom missing data, Little's MCAR test was not required, and no further imputation was necessary (Mertler & Vannatta, 2017). Due to the limited number of missing values and their random distribution, listwise deletion was used for analyses involving those variables.

Univariate outliers were identified using standardized *z*-scores, with values exceeding ±3.0 flagged for review (Mertler & Vannatta, 2017). Any flagged cases were retained unless clearly erroneous or influential; sensitivity analyses were conducted to assess their impact on regression results (Pallant, 2020). Cases that failed embedded attention check questions were also flagged and compared to the full dataset in sensitivity analyses.

Descriptive analyses were conducted to characterize the sample. Frequencies and percentages were calculated for categorical demographic variables, and means, medians, and standard deviations were calculated for continuous variables. Each HRSN domain was summarized by frequency and proportion endorsed, both overall and by key demographic subgroups. Crosstabulations were used to examine demographic distributions across HRSN domains.

Reliability Testing

Internal consistency was evaluated using Cronbach's alpha for the total CBI and each CBI domain. Cronbach's alpha values greater than or equal to 0.70 were considered acceptable (Cohen, 2013).

Assumption Testing

Linearity: Linearity was evaluated by generating scatterplots of each independent variable (HRSN domains) against the dependent variable (CBI score) (Kim & Mallory, 2016).

Independence: The independence of observations assumption was satisfied through the study design, as each participant completed the survey independently. The Durbin–Watson statistic was not required due to the cross-sectional (not time-series) nature of the study design (Kim & Mallory, 2016).

Normality: Normality was assessed by examining Q-Q plots and histograms of the residuals, along with skewness and kurtosis values, with +/- 2 being established as acceptable (Kim & Mallory, 2016).

Homoscedastity: Homoscedasticity was assessed by plotting residuals against predicted values to determine if error variance was consistent across the range of predictors. No patterns such as funnels or bowtie shapes were observed, supporting equal variance of residuals (Kim & Mallory, 2016).

No Multicollinearity: Multicollinearity refers to high correlation among independent variables. This was assessed via variance inflation factor (VIF) scores, where a score of 10 were deemed problematic and tolerance, where a score of <.10 were considered problematic (Kim & Mallory, 2016).

Multivariate Outliers: Mahalanobis distance values not calculated due to cross-sectional nature of the study used in combination with dichotomous HRSN variables, rendering this statistical test inappropriate (Mertler & Vannatta, 2017).

Multiple Linear Regression

Two separate regression models were run in Chapters 3 and 4 (Kim & Mallory, 2016; Mertler & Vannatta, 2017; Pallant, 2020). Chapter 3: Scores of each domain of the HRSNs tool were used as the independent variables (12 total domains/predictors), while overall CBI scores were used as the dependent variable. Individual items were also be assessed for inclusion in the final regression model. Importantly, scores for each domain of the HRSNs tool were reported dichotomously as either (0) for no issue present or (1) for issue present. If a participant marked any responses consistent with an issue present, a score of (1) was recorded, even if the domain has multiple items. Results presented included the unstandardized coefficients, standard error of unstandardized coefficients, significance, standardized coefficients, and R^2. Additionally, Cronbach α was reported for the CBI. An alpha error of 0.05 was set for statistical significance. Sensitivity analyses compared results with and without flagged outliers and attention-check failures. Moderation analyses tested whether race moderated the relationship between significant HRSN predictors and total CBI scores, using interaction terms. Chapter 4: A separate regression analysis was run for analysis of the relationship between binary coded demographic variables and total HRSN scores. Outputs remained the same as for the primary regression with some adaptation based on the target journal of each chapter as suggested by dissertation committee. Sensitivity analyses excluded outliers and attention-check failures, confirming robustness.

Domain-Level Regression Models

In addition to the primary regression model predicting total CB, five secondary linear regression models were conducted using each CBI domain score as a dependent variable. Dependent variables included the five domains of the CBI, being: Time dependence burden, developmental burden, physical burden, social burden, and emotional burden. Independent variables were the same 12 HRSN domains, coded dichotomously. Model outputs included R and R^2 to assess model fit, p-value for overall significance, unstandardized coefficients (B), standard error (SE B), standardized coefficients (β) with 95% confidence intervals established for coefficients (Mertler & Vannatta, 2017). These models allowed for the identification of specific HRSNs that most strongly predicted each domain of CB. The standardized coefficients (β) were interpreted to assess the relative strength of each predictor, while R^2 values indicated how much variance in the burden domain was explained by the model.

Expanded Bivariate Analysis

To further explore relationships between variables, additional bivariate analyses were conducted (Mertler & Vannatta, 2017; Pallant, 2020):

Group differences in CBI: Independent samples *t*-tests (for binary variables such as gender and race) were used to compare mean CBI scores across demographic groups. Where ANOVA results were significant, post hoc tests (Tukey HSD) were used to identify specific group differences. Outputs included group means, standard deviations, *t*-values or F-values, degrees of freedom, *p*-values, and effect sizes (Cohen's *d* or partial eta squared). These tests helped identify whether certain demographic groups experienced significantly higher or lower CB, allowing for a richer contextual

understanding of regression findings.

Associations between HRSNs and Demographics: Chi-square tests of independence were conducted to assess whether the prevalence of each HRSN domain varied by demographic group (e.g., gender, race, income, age group). Outputs included Pearson Chi-square values, degrees of freedom, *p*-values, and standardized residuals. Statistically significant results indicated that the likelihood of having an unmet social need was not equally distributed across demographic groups. For instance, a significant chi-square result for transportation need × income would suggest that lower-income participants are more likely to report this HRSN.

Summary

The research design of this study was a descriptive, cross-sectional design that used multiple regression to assess the relationships between the independent variables (health-related social need composite domain scores) and the dependent variable (CB). Sampling occurred via a variety of convenience sampling techniques. A demographic questionnaire was used in addition to the AHC-HRSN (Centers for Medicare and Medicaid Services, 2017) and the CBI (Novak & Guest, 1989). A desired sample of 150 was established, however the study proceeded with less than desired sample size following committee approval. Data was collected via Qualtrics and analyzed using SPSS. Data analysis employed a variety of statistical techniques, including multiple regression, moderation analysis, and group comparisons.

Manuscripts Introductions and Purpose Statements

Impact of Stroke Survivors' Physical Disability on the Presence of CB: A Systematic Review

The first of three manuscripts included in this dissertation is titled *Impact of Stroke Survivors' Physical Disability on the Presence of Caregiver Burden: A Systematic Review* (Shamoun and Harris, 2022). This peer-reviewed publication emerged from the initial literature review phase and served as both a conceptual and methodological foundation for the broader dissertation. The review systematically examined evidence from nursing and allied health disciplines to evaluate the relationship between stroke survivors' physical disability, later reframed in this dissertation as functional dependence, and CB.

Findings from this review identified physical disability as one of the most consistent predictors of CB across various care settings. However, the manuscript also revealed critical gaps in the literature, including the underrepresentation of REM ICPs and individuals from lower socioeconomic backgrounds. In addition, it noted a lack of studies addressing broader social determinants of health such as housing instability, transportation barriers, and access to healthcare.

These limitations provided the rationale for expanding the dissertation's focus beyond individual clinical factors to include contextual and structural contributors, specifically HRSN. The review established the need for a multidimensional and theory-informed investigation of CB, which guided the development of the present study using the Roy Adaptation Model.

The Impact of Health-Related Social Needs on CB Among Informal Care Partners of Stroke Survivors: An Exploratory Cross-Sectional Study

The second manuscript included in this dissertation is titled *The Impact of Health-Related Social Needs on Caregiver Burden Among Informal Care Partners of Stroke Survivors: An Exploratory Cross-Sectional Study*. This article addresses the primary aim of the dissertation: to investigate how HRSNs influence CB among ICPs of stroke survivors.

This manuscript offers several novel contributions to nursing science. It provides detailed demographic characteristics of ICPs, a population often underrepresented in stroke care partnership literature. It also presents internal consistency metrics for the CBI among ICPs, including total and domain-level reliability estimates, which have not been previously reported.

Analyses include group comparisons of CBI total scores based on HRSN presence and a series of multiple linear regression models examining which of the 12 HRSN domains significantly predict total and domain-specific CB. In addition to reporting these findings, the manuscript discusses their implications for practice, policy, and future research, highlighting how addressing HRSNs may reduce CB and inform the development of more equitable, targeted interventions for stroke ICPs.

Demographic Disparities in Health-Related Social Needs Among Informal Care Partners of Stroke Survivors: An Exploratory Cross-Sectional Study

The third and final manuscript included in this dissertation is titled *Demographic Disparities in Health-Related Social Needs Among Informal Care Partners of Stroke Survivors: An Exploratory Cross-Sectional Study*. The purpose of this study is to examine

the prevalence and demographic predictors of HRSNs among ICPs of stroke survivors. ICPs are central to stroke recovery, yet their ability to provide sustained care is shaped not only by clinical factors but also likely by HRSNs. These needs, ranging from food insecurity and transportation challenges to financial strain and lack of social support, have been linked to poorer outcomes for both patients and families, yet their prevalence among ICPs of stroke survivors remains insufficiently studied. Understanding the scope and distribution of HRSNs in this population is an essential step toward addressing disparities in CB and long-term recovery.

First, descriptive statistics are provided to outline the distribution of individual HRSN domains. Next, chi-square analyses are used to assess group differences in HRSN prevalence by race and ethnicity, while independent-samples *t*-tests compare total HRSN counts across binary demographic groups. One-way ANOVAs further test variation by multi-level categorical characteristics such as age and income. Finally, a stepwise multiple linear regression is employed to identify which demographic factors most strongly predict the total number of reported HRSNs. Together, these analyses offer both a granular and holistic view of how social needs cluster among ICPs, providing insight into which subgroups may be most at risk and where targeted interventions may be most impactful.

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CHAPTER TWO

FIRST MANUSCRIPT

Impact of Stroke Survivors' Physical Disability on the Presence of Caregiver Burden: A Systematic Review

Abstract

BACKGROUND: Caregiver burden (CB) associated with caring for stroke survivors remains a prominent issue in nursing. With stroke being a leading cause of disability world-wide, it is essential that the impact of the stroke survivor's physical disability be analyzed so interventions can be developed to relieve related CB. The purpose of this systematic review is to review the existing nursing and allied-health literature aimed at the impact of stroke survivors' physical disability on the presence of CB. **METHODS:** A systematic review of the CINAHL and PubMed databases was conducted using PRISMA guidelines (searched 06/16/2021). Study inclusion criteria for this review were: 1. Publication in the last five years; 2. Examine the impact of stroke survivors' physical disability on CB; 3. Caregiver-survivor dyads aged 18 or older; 4. Published in English; and 5. Longitudinal study designs (an exception for reports that present findings not demonstrated in longitudinal studies). Data extracted from articles included sample characteristics, study design, instruments, analyses, and results. **RESULTS:** A total of seven studies met the inclusion criteria and were synthesized for use in this systematic review. These studies implemented a variety of instruments to assess for both physical disability in the stroke patient and CB. A positive correlation between physical disability and CB was universally reported. **CONCLUSION:** Further nursing research is warranted in order to explore the aspects of physical disability that contribute to CB, to develop interventions to both improve the physical functioning of stroke survivors, include social determinants of health, and specifically address the greatest contributors to CB.

Introduction

It is currently estimated, in the United States, nearly 800,000 people suffer a stroke annually (Benjamin et al., 2019). With strokes being more prominent in older adults (Benjamin et al., 2019), it is likely stroke will remain a prominent issue as life-expectancy continues to increase world-wide (Hickey & Strayer, 2020). Stroke care is estimated to cost the United States nearly $46 billion annually and is a leading cause of death and long-term disability (Hickey & Strayer, 2020). Furthermore, stroke is known to disproportionately impact people of color and those in lower socioeconomic statuses (SES) in the U.S., making stroke research a priority for improving the health of vulnerable populations (Benjamin et al., 2019; Hickey & Strayer, 2020). Many stroke patients are discharged home and cared for by unpaid family and friends who are often referred to as informal caregivers (IFCs) (Hickey & Strayer, 2020). Informal caregiving is estimated to have an economic value of over $500 billion annually (Hickey & Strayer, 2020) as IFCs are expected to care for every aspect of the patient's needs, often leading to caregiver burden (CB). Given the prevalence and severity of post-stroke disability requiring care by an IFC, nursing research is warranted to address relieving and preventing burden.

Background

Caring for stroke patients presents unique challenges for IFCs. Following management of acute neurologic and physical events associated with stroke, many patients suffer chronic deficits and residual disability (Hickey & Strayer, 2020). The majority of current literature related to caregiving for stroke patients focuses on the management of psychosocial aspects (i.e., depression, anxiety, etc.) of CB. It is essential

to have the stroke survivor's physical disability analyzed so interventions can be developed to relieve associated CB (psychological and physical). The purpose of this systematic review is to review the existing nursing and allied-health literature to analyze the impact of stroke survivors' physical disability on the presence of CB.

Methods

A systematic review was conducted to answer the research question, "What is the relationship between stroke survivors' physical disability and IFCs' CB?" The following concepts were defined before the review. The term "stroke survivor" was chosen because of its recurring presence in the reviewed literature. For the purpose of this review, any person can be designated a stroke survivor, beginning the moment they experience a stroke. The term "caregiver" is defined in this review as any non professional individual providing care to a stroke survivor. All caregivers in the reviewed studies for this systematic review are IFCs, meaning that the individuals providing care to the stroke survivor did not receive any financial compensation for their care (Hickey & Strayer, 2020). Most IFCs in the reviewed studies are related to the stroke survivor. The term "caregiver-survivor dyad" was chosen because this term, and the term "dyad," was frequently used in the reviewed studies. This phrase emphasizes the dynamic between the stroke survivor and the IFC as one unit where each member is equal.

This systematic review was conducted using Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines (Moher et al., 2009). The CINAHL and PubMed databases were searched for relevant literature (most recent search conducted on June 16, 2021). Filters were applied that limited the search to articles published within the last 5 years and that had full texts available for access. One author

screened each record for inclusion and extracted data from reports, whereas the second author reviewed all decisions made to verify consistency. The following search terms were used: group 1 (targeting stroke survivors): Stroke OR CVA OR cerebrovascular accident OR ICH OR intracerebral hemorrhage AND group 2 (targeting CB): CB OR caregiver role strain OR caregiver strain.

The study inclusion criteria for this review were as follows: (1) publication in the last 5 years, (2) discusses stroke survivors' physical disability on the presence of CB, (3) both IFC and survivor 18 years or older, (4) published in English, and (5) longitudinal study design. The decision to exclude non longitudinal studies was made because of saturation; other cross sectional studies did not present any new findings. Data were extracted in accord with Preferred Reporting Items for Systematic Reviews and Meta-analyses (Moher et al., 2009) guidelines. Components included author, purpose, sample, design, instruments, analyses, and significant findings (see Appendix D). Both authors assessed each study report for its fit with the review criteria in accord with the tenants of the ROBIS, a tool to assess for risk of bias in systematic reviews (Whiting et al., 2016). One study was included in the review that did not meet the criterion of longitudinal design (Oni et al., 2019) because it examined specific aspects of the survivors' disability (i.e., dysphagia, hemiplegia, aphasia) related to CB. Overall, no individual study represented a high risk for bias.

The ROBIS tool was implemented by each author to assess the risk for bias in the studies currently reviewed and determined a risk for bias of this review.4 The 4 domains of this tool include study eligibility criteria (domain 1), identification and selection of studies (domain 2), data collection and study appraisal (domain 3), and synthesis and

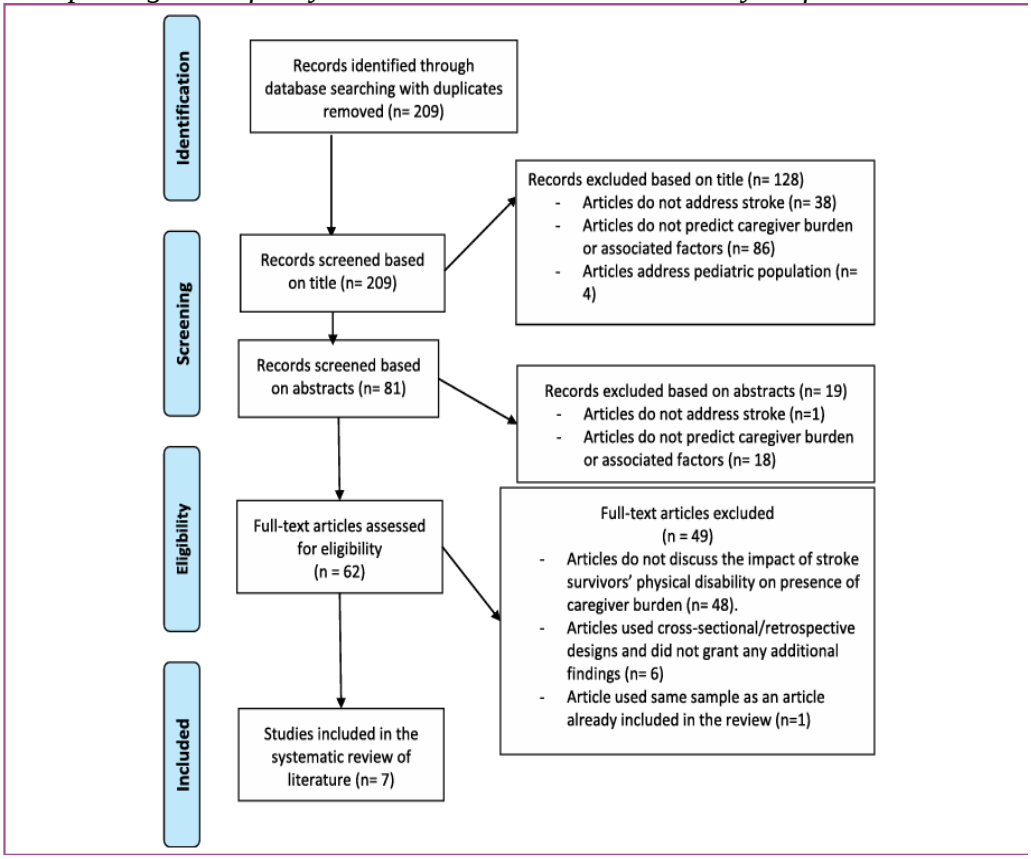
findings (domain 4). Each domain is assessed by a variety of items that result in a score that ranges from “low risk” to “unclear” to “high risk (Whiting et al., 2016).” Results of the assessment yielded the risk for bias as low for domains 1 to 3 and ranging from low to somewhat unclear for domain (Whiting et al., 2016). Overall, the risk for bias in the current review was low.

Results

The comprehensive search of literature revealed 7 articles that fit the inclusion criteria. Full-text articles were retrieved for study reports not excluded based on title or abstract. The full screening process is depicted in Figure 2.1. Statistical analyses in each of the 7 included studies were found to be appropriate for the design, research questions, and number of subjects. Overall, the studies comprise a moderate-to-high level of data quality per the ROBIS tool assessment (domain 3) (Whiting et al., 2016).

Figure 2.1

Preferred Reporting Items for Systematic Reviews and Meta-analyses flowchart



Of the included studies, 6 used variations of longitudinal study designs and 1 used a cross-sectional design. The reviewed studies consistently used 2 instruments to measure physical disability after stroke: the Barthel Index (Mahoney & Barthel, 1965) and modified Rankin Scale (Rankin, 1957). Five articles (Han et al., 2017; Kruithof et al., 2016; Menon et al., 2017; Pucciarelli et al., 2017; Zhu & Jiang, 2019) used the Barthel Index, 1 article (Oni et al., 2019) used the modified Rankin Scale, and 1 article (Chuluunbaatar et al., 2017) used both scales. Various tools were used to measure CB. Two studies (Han et al., 2017; Kruithof et al., 2016) used the Caregiver Strain Index (B. C. Robinson, 1983), and 1 study (Pucciarelli et al., 2017) used the CB Inventory (Novak & Guest, 1989). One study (Chuluunbaatar et al., 2017) used the Montgomery CB Scale

(Savundranayagam et al., 2011),1 study (Oni et al., 2019) used the Zarit Burden Interview (Zarit et al., 1980), 1 study (Zhu & Jiang, 2019) used the Bakas Caregiving Outcomes Scale (Bakas et al., 2022), 1 study (Pucciarelli et al., 2017) used the World Health Organization Quality of Life-BREF (The WHOQOL Group, 1998), and 1 study (Menon et al., 2017) used a custom caregiving scale.

Collectively, the studies indicated that as the physical disability of stroke survivors increased, CB also increased, with nearly all IFCs reporting some degree of CB (Chuluunbaatar et al., 2017; Han et al., 2017; Kruithof et al., 2016; Menon et al., 2017; Oni et al., 2019; Pucciarelli et al., 2017; Zhu & Jiang, 2019). The physical functioning of stroke survivors was found to have a significant, positive relationship with both IFC and survivor quality of life (Pucciarelli et al., 2017). Studies reported that the extent of poststroke physical disability was the most predictive variable of CB (Han et al., 2017; Menon et al., 2017). Of the longitudinal articles, 3 followed caregiver-survivor dyads, at different intervals, for 1 year (Chuluunbaatar et al., 2017; Kruithof et al., 2016; Pucciarelli et al., 2017); 2 followed dyads for 6 months (Han et al., 2017; Zhu & Jiang, 2019), and 1 followed dyads for 3 months (Menon et al., 2017). Regardless of the interval of follow-up, physical disability was reported as a significant predictor of CB when measured over time (Chuluunbaatar et al., 2017; Han et al., 2017; Kruithof et al., 2016; Menon et al., 2017; Pucciarelli et al., 2017; Zhu & Jiang, 2019), with 1 study reporting that it was the only predictive variable to remain significant over 6 months (Han et al., 2017). Furthermore, even short-term improvements or declines in the stroke survivor's physical functioning were found to significantly impact caregiver quality of life (Pucciarelli et al., 2017). When CB was divided into categories of objective burden,

subjective burden, and demand (or relationship) burden, it was found that only improvements in the stroke survivors physical disability decreased IFCs objective and subjective burden over time (Chuluunbaatar et al., 2017). It was also reported that overall CB did decline over time (Chuluunbaatar et al., 2017; Han et al., 2017; Menon et al., 2017; Pucciarelli et al., 2017; Zhu & Jiang, 2019). This finding was contradicted by 1 study that reported that CB did not decline over time (Kruithof et al., 2016). Notably, that study focused exclusively on romantic partners of stroke patients.

The specific facets of survivor disability that significantly impacted CB included generalized disability (Oni et al., 2019), incontinence (Oni et al., 2019), dysarthria/aphasia (Oni et al., 2019), shoulder pain (Menon et al., 2017), and dysphagia (Menon et al., 2017; Oni et al., 2019). Many IFCs were found to struggle with maintaining the survivor's hygiene and administering medication (Menon et al., 2017). It was also reported that CB was exacerbated when survivors experienced a more severe stroke with more extensive physical disability (Menon et al., 2017). Specifically, those caring for survivors of severe stroke or significantly more likely to report sleep disturbances, physical health deterioration, and distress regarding the survivor's bladder and bowel incontinence, as well as general hygiene needs (Menon et al., 2017). Furthermore, the results indicate that CB is worsened when IFCs are unable to obtain rehabilitation services to treat the survivors disability (Zhu & Jiang, 2019). It was also noted that caregivers of stroke survivors who were discharged home had better outcomes than those who were discharged to inpatient rehabilitation facilities, likely because of the increased disability and survivors who went to inpatient rehabilitation facilities than those who were discharged home (Kruithof et al., 2016). One study also reported that CB

among those caring for hemorrhagic stroke survivors may be greater than those caring for ischemic stroke survivors because of the increased severity of hemorrhagic strokes (Zhu & Jiang, 2019).

Physical disability was found to indirectly impact CB. Poststroke disability severe enough to render a Survivor incapable of employment was found to significantly impact the extent of CB (Chuluunbaatar et al., 2017). The overwhelming majority of caregiver-survivor dyads faced deteriorating financial status as a result of the survivor's physical disability (Kruithof et al., 2016), with financial strain being noted as a significant cause of CB (Chuluunbaatar et al., 2017; Kruithof et al., 2016; Oni et al., 2019). Furthermore, severe stroke and corresponding physical disability were found to increase the time spent caregiving, which significantly impacted CB (Chuluunbaatar et al., 2017; Oni et al., 2019). Specifically, 1 study found that caregiving for more than 8 hours per day was associated with increased CB (Han et al., 2017). One study reported that for every 1-point increase on the Zarit Burden Interview, there was a 400% increase in time spent caregiving (Oni et al., 2019). Another study reported that depression among IFCs may also be linked to the physical dependency of stroke survivors, with depression also being a significant predictor of CB (Han et al., 2017). Caregivers of survivors of more severe stroke reported that their social life was more compromised, further contributing to CB (Kruithof et al., 2016).

The articles reviewed studied dyads from various regions globally (China (Han et al., 2017; Zhu & Jiang, 2019), Nigeria (Oni et al., 2019), the Netherlands (Kruithof et al., 2016), India [Menon et al., 2017), Mongolia (Chuluunbaatar et al., 2017), and Italy (Pucciarelli et al., 2017)]. The mean age of caregivers ranged from 36.9 years

(Chuluunbaatar et al., 2017) to 62.5 years (Kruithof et al., 2016), and the mean age of stroke survivors ranged from 53.0 years (Zhu & Jiang, 2019) to 70.8 years (Pucciarelli et al., 2017). Nearly all results remained consistent, except for those explicitly stated previously in this section. All studies reported that most Caregivers for stroke survivors were female (Chuluunbaatar et al., 2017; Han et al., 2017; Kruithof et al., 2016; Menon et al., 2017; Oni et al., 2019; Pucciarelli et al., 2017; Zhu & Jiang, 2019), and several reported that female caregivers were more likely to be burdened by post-stroke physical disability than male caregivers (Menon et al., 2017; Oni et al., 2019). Specifically, managing bowel and bladder incontinence had a significant impact on CB among female caregivers (Menon et al., 2017). There was 1 report that claimed no significant correlation between sex and CB (Kruithof et al., 2016).

Discussion

The reviewed studies implemented various measures of CB. The lack of consistency and measurement of this variable leads to questionable reliability and validity. This literature review indicates that further psychometric work is necessary to narrow the options for high performing instruments that measure CB. The results of this systematic literature review indicated that post-stroke disability is among the most, if not the single most, predictive variables of CB. Authors consistently reported a positive relationship between stroke survivors physical disability and the extent of CB (Chuluunbaatar et al., 2017; Han et al., 2017; Kruithof et al., 2016; Menon et al., 2017; Oni et al., 2019; Pucciarelli et al., 2017; Zhu & Jiang, 2019). The integrality of this relationship requires a dyadic approach to disability management. Future nursing

research should modify interventions to focus on the caregiver survivor dyad rather than the survivor or caregiver individually.

The analyzed studies used several tools to measure poststroke disability. new instruments should continue to be developed, such as the Longshi Scale (Gao et al., 2021), which measures the extent of disability after stroke based on variables such as stroke severity. Little in the extant literature identify specific dimensions of physical disability that intensify CB. It is essential for researchers to identify and address these dimensions to effectively relieve associated CB. This literature review points to the need for comprehensive measurement of specific aspects of survivors' disability as they relate to CB.

Limitations of the evidence include the variety of measures used for CB. This necessitates caution when synthesizing review results. In addition, there is a lack of consideration of distinct aspects of physical disability that influence CB (i.e., dysphagia, hemiplegia, aphasia). More evidence regarding these specific variables would allow for future research and interventions to be tailored to this unique dyadic population.

Although study populations were drawn from 6 different countries, no study reported the race or income of participants. It is remarkable that none of the studies occurred in the United States where stroke disproportionately affects people of color and people of lower SES (Benjamin et al., 2019; Hickey & Strayer, 2020). Although limiting the generalizability of the review's findings, this gap in the literature strengthens the indication for future research to include people of color and of low SES.

As the results of this review emphasize the significant impact of poststroke disability on CB, nurses and other healthcare professionals can use physical disability as

a rudimentary screening for CB. Considering caregivers were found to struggle with tasks such as physiotherapy, hygiene management, and medication administration (Menon et al., 2017), healthcare providers should include the caregiver in as many interventions as possible when treating social survivors in rehabilitation. With most stroke rehabilitation and improvements in physical disability occurring in the first 6 months post stroke (Hickey & Strayer, 2020), it is essential that early interventions occur with a dyadic approach. Existing literature has shown that the need for further research regarding community-based stroke recovery interventions and the development of community center dyadic interventions may prove beneficial to this patient population (Magwood et al., 2019). Finally, as CB related to physical disability at discharge was a significant predictor of CB 1 year post stroke (Chuluunbaatar et al., 2017; Kruithof et al., 2016; Pucciarelli et al., 2017), CB should be addressed in the early, post discharge stage.

Conclusion

Stroke will continue to rise as a prominent nursing and healthcare issue. Because of its disproportionate effect on people of color and those of lower SES in the United States, it is also a rising social justice issue that demands attention (Benjamin et al., 2019; Hickey & Strayer, 2020). Physical disability among stroke survivors is one of the most predictive variables of CB. Future nursing research should focus on the dyadic approaches to early rehabilitation to maximize the physical function of stroke survivors and minimize CB. Accordingly, these approaches should be administered early to optimize their effects. In this process, CB instruments need replication and refinement to enhance the measurement validity of this concept. Future nursing research is also warranted to explore specific aspects of physical disability that contribute to CB, as well

as to develop targeted interventions to both improve the physical functioning of stroke survivors and subsequently reduce levels of CB.

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CHAPTER THREE

SECOND ARTICLE

The Impact of Health-Related Social Needs on Caregiver Burden Among Informal Care Partners of Stroke Survivors: An Exploratory Cross-Sectional Study

Abstract

BACKGROUND: Stroke survivors often rely on informal care partners (ICPs), who commonly experience caregiver (CB) across multiple domains. Although CB has been widely studied, many interventions remain ineffective, potentially due to a limited understanding of how social needs shape ICP experiences. Health-related social needs (HRSNs), such as food insecurity, transportation barriers, and lack of support, may contribute significantly to CB but remain largely unexamined in stroke care partnership research. **METHODS:** This exploratory cross-sectional study examined the relationship between 12 HRSN domains and both total and domain-specific CB among ICPs of stroke survivors. A sample of 81 ICPs from the US was recruited through social media and stroke support groups. Participants completed a demographic survey, the Accountable Health Communities HRSN Screening Tool, and the Caregiver Burden Inventory (CBI). Descriptive statistics, independent-samples *t*-tests, and stepwise multiple linear regressions were conducted using SPSS v29. **RESULTS:** Nearly all HRSNs domains were positively correlated with significantly higher CB scores. Stepwise regression identified three significant predictors of total CB: transportation needs, family and community support needs, and education (adjusted $R^2 = .374$, $p < .001$). Additional HRSNs emerged as predictors of specific CB domains. Mental health needs predicted both physical and developmental burden, while utility needs predicted emotional burden, for example. Race did not significantly moderate any observed relationships. Reliability of the CBI and its subscales was strong ($\alpha = .822–.952$). **CONCLUSION:** Findings demonstrate that HRSNs significantly contribute to the CB experienced by ICPs of stroke survivors, highlighting actionable HRSNs. Incorporating structured HRSN screening into

stroke aftercare may inform more responsive, equitable approaches to CB reduction and support the development of socially informed clinical pathways.

Background

Stroke remains a leading cause of death and disability in the United States (US), with nearly 800,000 people experiencing a stroke annually (Tsao et al., 2022). Many survivors depend on informal care partners (ICPs), such as unpaid family members or friends, for essential support. Consequently, ICPs frequently experience caregiver burden (CB), with nearly 83% reporting some degree of strain (Achilike et al., 2020). CB is defined as "the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time" (Liu et al., 2020, p.442), encompassing physical, emotional, time-dependent, developmental, and social dimensions (Novak & Guest, 1989).

Interventions to reduce burden among stroke ICPs have yielded limited success (Bakhtiari-Dovvombaygi et al., 2025). A limitation in existing research is the tendency to treat CB as a “one-size-fits-all” construct, overlooking the social and structural factors that likely shape the care partnership experience (Elsheikh et al., 2022). This gap is especially consequential for racial and ethnic minority (REM) ICPs, who experience disproportionate stroke burden and structural inequities, yet remain underrepresented in stroke care partnership studies (Tsao et al., 2022; Young et al., 2020).

Health-related social needs (HRSNs), defined as the conditions in which individuals are born, grow, work, live, and age that directly impact their ability to maintain health and well-being, may meaningfully shape how ICPs experience burden (Centers for Medicare and Medicaid Services, 2024). The Centers for Medicare & Medicaid Services (CMS), through the Accountable Health Communities (AHC) Model, identifies five core HRSN domains (housing instability, food insecurity, transportation

problems, utility help needs, and interpersonal safety) and eight supplemental domains (Centers for Medicare and Medicaid Services, 2017).

Although these domains are increasingly recognized in clinical settings, they remain largely unexamined in stroke care partnership research. Very few studies on ICPs of stroke survivors assess any HRSNs, and none have systematically examined how these domains relate to distinct dimensions of CB (Hill & Livesay, 2024). Even basic demographic information is missing from a significant amount of literature regarding stroke care partnership (Shamoun & Harris, 2022). This is an essential gap in knowledge, as stroke likely triggers and compounds HRSNs, which may in turn differentially impact CB among ICPs of stroke survivors. This relationship, however, is inadequately explored in current literature. This study addresses these critical gaps by using an exploratory, multidimensional approach. The purpose of this study was to examine the relationship between 12 domains of HRSN and CB among ICPs of stroke survivors, including both total burden and its individual dimensions.

Methods

Sample and Setting

This cross-sectional, correlational study used multiple linear regression to evaluate associations between 12 HRSN domains (independent variables) and CB (dependent variable). Participants were recruited using convenience sampling techniques primarily through social media platforms and stroke support groups from November 2024 through June 2025. Phone screening of online participants was conducted to limit fraudulent responses. In-person recruitment was conducted at stroke support groups in southeastern Michigan, with additional outreach across multiple US regions. Flyers were

also placed in outpatient neurology clinics, senior centers, and community centers. To promote inclusive recruitment, the primary investigator (PI) consulted with community leaders and REM nursing experts, adapting strategies based on prior successful approaches (Burns et al., 2022; Ratnapradipa et al., 2024). Eligibility criteria included: (1) self-identification as an ICP of a stroke survivor aged 18 or older, (2) English literacy, and (3) access to the internet via smartphone or computer. All participants received a $20 Amazon e-gift card upon completing the survey. Using G*Power (Faul et al., 2007), the required sample size was calculated as 124 for a multiple regression with 12 predictors, medium effect size ($f^2 = 0.15$), $\alpha = .05$, and power = .80.

Data Collection

Participants completed three electronic questionnaires via Qualtrics. 1.) A 15-item demographic questionnaire developed by the PI which assessed sociodemographic, relational, and care partnership context variables. 2.) The Accountable Health Communities Health-Related Social Needs Screening Tool (AHC-HRSN) (Centers for Medicare and Medicaid Services, 2017), which assessed 26-items spanning 13 domains. The substance use domain was excluded due to concerns about cultural sensitivity based on REM nursing expert consultation. Each of the remaining 12 domains was scored as a binary variable (0 = no need, 1 = presence of need) to provide standardization of scoring throughout the instrument and to reflect current public health practices that prioritize actionable need identification over severity grading (Billioux et al., 2017). If any item within a domain was endorsed, the domain was marked as 1. 3.) The Caregiver Burden Inventory (CBI) is a validated 24-item measure assessing five dimensions of CB: time-dependence, developmental, physical, social, and emotional burden. Items are rated on a

5-point Likert scale (0–4), with a total score range of 0–96, with higher scores indicating greater burden (Novak & Guest, 1989). The CBI has demonstrated strong internal consistency in other care partner samples, with Cronbach's alpha of the overall scale ranging from .91 to .96 across domains (Greco et al., 2017; Shafiezadeh et al., 2020), although no known studies have reported reliability characteristics within ICPs of stroke survivors. In this study, reliability of the total score of the CBI was excellent (Cronbach's $\alpha = .952$) across all 24 items. Reliability within each CBI domain was also strong: Time-dependence burden (Cronbach's $\alpha = .875$, good), developmental burden (Cronbach's $\alpha = .934$, excellent), physical burden (Cronbach's $\alpha = .893$, good), social burden (Cronbach's $\alpha = .822$, good), emotional burden (Cronbach's $\alpha = .908$, excellent). All data were de-identified and stored securely. IP addresses were collected to confirm US residency. Attention check questions were embedded in the survey to minimize inauthentic responses. All aspects of the study were reviewed and approved by the Institutional Review Board.

Data Analysis

All analyses were conducted using IBM SPSS Statistics for Windows, Version 29.0 (IBM Corp., 2023). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist was self-applied to this study (von Elm et al., 2008). Data cleaning included screening for missing data, duplicates, and univariate outliers. Cases with incomplete responses were excluded via listwise deletion. Internal consistency was calculated for the CBI total and individual domain scores. Descriptive statistics were calculated for all demographic variables, and CBI scores.

Independent-samples *t*-tests were conducted to compare CBI total scores between participants with and without each HRSN. Following this, a stepwise multiple linear regression was conducted with all 12 HRSNs as predictors of CBI total burden. Stepwise regression was selected due to the exploratory nature of the study and its utility in identifying the most significant set of predictors when theory does not clearly prioritize specific variables. Separate stepwise multiple regressions were then conducted for each CBI domain as the outcome variable. Assumptions of linearity, normality, homoscedasticity, and multicollinearity were tested and confirmed. Sensitivity analyses were conducted excluding flagged outliers and attention-check failures, and model results were compared to confirm consistency. Moderation analyses tested whether race modified the relationship between each significant HRSN and total CB using interaction terms. Significance was set at $p < .05$ for all analyses.

Results

A total of 81 ICPs of stroke survivors participated in the study, with 78 (96.3%) fully completed questionnaires. Fifty-six (69.1%) participants were female, and the remaining ICPs identified as male. Racial breakdown of participants was as follows: 45 (55.6%) Black; 25 (30.9%) White; 7 (8.6%) Hispanic; 3 (3.7%) Asian, 1 (1.2%) Arab. Most ICPs were the significant other of the stroke survivor (50.6%), followed by adult children caring for stroke survivor parents (17.3%). Additionally, 23 (28.7%) ICPs reported a household income under $40,000, and 24 (29.6%) stated they did not have all the equipment needed to manage the stroke survivor's care. The average length (in years) ICPs cared for their stroke survivor was 6.97 (Minimum = 0.8; Maximum = 40; SD = 8.59), and years spent caregiving was negatively correlated with total CB (r = -.131),

which was not a significant finding (p = .261). A detailed summary of participant characteristics is presented in Table 3.1.

Table 3.1
Demographic Characteristics of the Sample (n = 81)

Demographic Characteristic	N	%
Gender Identity		
Male	25	30.9
Female	56	69.1
Age Group		
18-24	5	6.2
25-30	15	18.5
31-40	22	27.2
41-50	11	13.6
51-60	4	4.9
61+	24	29.6
Race/Ethnicity		
Black	45	55.6
White	25	30.9
Hispanic	7	8.6
Asian	3	3.7
Arab	1	1.2
Marital Status		
Married	51	63.0
Divorced	9	11.1
Separated	3	3.7
Never Married	18	22.2
Education Level		
High School	32	39.5
Undergraduate	21	25.9
Graduate	28	34.6
Employment Status		
Unemployed	15	18.8

Table 3.1 - Continued

Demographic Characteristics of the Sample (n = 81)

Demographic Characteristic	N	%
Part-Time	21	26.3
Full-Time	25	31.3
More than Full-Time	7	8.8
Self-Employed	1	1.3
Retired	11	13.8
Missing	1	1.2
Household Income		
<$20,000	9	11.3
$21,000 - $39,000	14	17.5
$40,000 - $59,000	22	27.5
$60,000 - $79,000	19	23.8
>$80,000	16	20.0
Missing	1	1.2
Relationship to Stroke Survivor		
Significant Other	41	50.6
Child	14	17.3
Grandchild	6	7.4
Friend	9	11.1
Sibling	2	2.5
Parent	8	9.9
Aunt/Uncle	1	1.2
Care-Receiver Race		
Black	42	51.9
White	29	35.8
Hispanic	6	7.4
Asian	3	3.7
Arab	1	1.2
Co-residence with Stroke Survivor		
Yes	60	76.9
No	18	23.1
Missing	3	3.7
Weekly Care Hours Provided		
< 10 Hours	18	22.5
10 - 20 Hours	22	27.5
> 20 Hours	40	50.0
Missing	1	1.2
Skilled Nursing Received		
None	41	51.2
< 10 Hours	22	27.5

Table 3.1 - Continued
Demographic Characteristics of the Sample (n = 81)

Demographic Characteristic	N	%
10 - 20 Hours	6	7.5
> 20 Hours	11	13.8
Missing	1	1.2
Availability of Equipment Needed to Care for Stroke Survivor		
Yes	57	70.4
No	24	29.6

Descriptive statistics were calculated for the AHC-HRSN and CBI. The three most reported HRSNs among ICPs of stroke survivors were mental health (86.4%), physical activity (82.7%), and family and community support (80.2%). The mean CBI total score was M = 36.99, SD = 21.597, with domain means ranging from 3.46 (emotional burden) to 10.99 (time-dependence). Additional details regarding the prevalence of CBI scores are available in Table 3.2.

Table 3.2
Descriptive Statistics for the Caregiver Burden Inventory

Variable	n	Min	Max	Mean	SD	Missing
Time-Dependence Domain Total	79	0	20	10.99	5.246	2
Developmental Burden Domain Total	79	0	20	10.13	6.584	2
Physical Burden Domain Total	79	0	16	6.65	4.699	2
Social Burden Domain Total	78	0	20	5.85	5.022	3
Emotional Burden Domain Total	79	0	20	3.46	4.615	2
TOTAL CBI Score	79	1	93	36.99	21.597	2

Independent-samples *t*-tests compared CBI total scores between participants with and without each HRSN. Equal variances were not assumed, and two-tailed significances were presented for each analysis. CBI total scores were significantly higher among ICPs endorsing each HRSN domain except physical activity. For example, those reporting living situation needs had higher CBI scores (M = 46.12, SD = 18.499) than those without (M = 30.09, SD = 21.379), $t(75.525) = -3.564$, $p = <.001$, $d = .794$, and those with food insecurity needs also had significantly higher CBI scores (M = 45.59, SD = 19.373) than those without (M = 27.71; SD = 20.180), $t(75.948) = -4.010$, $p = <0.001$, $d = .904$. Effect sizes for all analyses were medium-very large except for exercise, which showed a small effect size ($d = .341$). Two separate group comparisons were conducted to evaluate total CBI scores between REM and non-REM ICPs and males and females, which found that REMs experienced significantly more CB (M = 41.43, SD = 20.432) than their non-REM counterparts (M = 27.40, SD = 21.305), $t(45.087) = -2.757$, $p = .008$, $d = -.677$, and no statistically significant impact between males (M = 35.75, SD = 23.756) and females (M = 37.53, SD = 20.793), $t(39.088) = -.317$, $p = .376$, $d = -.082$. Additional details regarding group differences in CBI scores with and without each HRSN can be found in Table 3.3.

Table 3.3
Independent-samples t-test Results for Mean CBI Total Scores by Presence or Absence of HRSNs

HRSN	Group	n	M	SD	df	*t*	*p*	95% CI	*d*
Housing Instability*	Present	34	46.12	18.499	75.525	-3.564	<.001	[-24.986, -7.071]	-.794
	Not Present	45	30.09	21.379					
Food Insecurity*	Present	41	45.59	19.373	75.948	-4.010	<.001	[-26.753, -8.997]	-.904
	Not Present	38	27.71	20.180					
Transportation Needs*	Present	28	51.46	16.950	63.301	-5.297	<.001	[-30.884, -13.966]	-1.191
	Not Present	51	29.04	19.766					
Utility Help Needs*	Present	25	48.64	22.301	41.408	-3.229	.002	[-27.198, -6.271]	-.827
	Not Present	53	31.91	19.215					
Interpersonal Safety*	Present	56	42.32	20.67	45.91	-3.882	<.001	[-27.822, -8.821]	-.914
	Not Present	23	24.00	18.353					
Education	Present	19	51.00	20.782	29.384	-3.401	.002	[-29.538, -7.362]	-.913
	Not Present	60	32.55	20.040					
Employment	Present	37	47.05	18.492	76.924	-4.330	<.001	[-27.643, -10.227]	-.970
	Not Present	42	28.12	20.374					
Family and Community Support	Present	65	41.32	20.779	32.687	-5.966	<.001	[-32.812, -16.120]	-1.250

Table 3.3 - Continued

Independent-samples t-test Results for Mean CBI Total Scores by Presence or Absence of HRSNs

HRSN	Group	n	M	SD	df	*t*	*p*	95% CI	*d*
	Not Present	14	16.86	11.935					
Physical Activity	Present	67	38.10	21.787	15.930	-1.146	.269	[-20.965, 6.256]	-.341
	Not Present	12	30.75	20.231					
Disability	Present	26	51.08	19.942	47.649	-4.468	<.001	[-30.455, -11.548]	-1.088
	Not Present	53	30.08	18.987					
Financial Strain	Present	43	42.23	19.473	72.230	-3.460	<.001	[-25.06, -6.738]	-.787
	Not Present	36	28.33	21.046					
Mental Health	Present	70	39.90	21.043	22.760	-6.628	<.001	[-33.551, -17.582]	-1.271
	Not Present	9	14.33	8.775					

*= Core HRSN Domain

Note. Independent-samples *t*-tests were conducted using 'equal variances not assumed.'

A stepwise multiple regression identified 3 HRSN domains as significant predictors of total CB. Assumptions of normality, linearity, homoscedasticity, outliers, and multicollinearity were met. The final model explained adjusted $R^2 = .374$ ($R^2 = .398$) of the variance, F (3, 74) = 8.458, $p < .001$. Only 3 of 12 domains remained in the model, with significant predictors including transportation needs ($\beta = .310$, $p = .003$), family and

community support (β = .328, p = .001), and education (β = .272, p = .005). Sensitivity analyses excluding flagged outliers and attention-check failures yielded comparable results.

Separate stepwise regressions were conducted for each CBI subscale. Transportation needs were a significant predictor in two subscale domains [physical burden (β = .281, p = .006) and social burden (β = .346, p < .001)] alongside family and community support needs [time-dependent burden (β = .327, p = .003) and developmental burden (β = .284, p = .013)], both of which were significant in the primary stepwise regression. Education [social burden (β = .219, p = .022) and emotional burden (β = .318, p = .004)]; employment [developmental burden (β = .258, p = .013)]; mental health [developmental burden (β = .227, p = .037) and physical burden (β = .289, p = .003)], disabilities [physical burden (β = .309, p = .003)], and utility help needs [emotional burden (β = .279, p = .010)] also appeared as significant predictors of different domains of ICP of stroke survivor burden. Full outputs for both total and domain specific regressions can be found in Table 3.4.

Table 3.4
Stepwise Regression Models for Total and Domain Specific Caregiver Burden

CBI Domain Predictor	B	β	sr	VIF	Tolerance	*p*
Total CBI[a]						
Transportation	13.843	.310	.280	1.230	.815	.003
Support	18.335	.328	.307	1.144	.874	.001
Education	13.604	.272	.262	1.077	.928	.005
Time-Dependence[b]						
Support	4.464	.327	.327	1.000	1.00	.003
Emotional[c]						
Education	3.408	.318	.302	1.110	.901	.004
Utilities	2.753	.279	.265	1.110	.901	.010
Social[d]						
Transportation	3.582	.346	.315	1.210	.826	<.001
Safety	3.481	.316	.293	1.166	.858	.002
Education	2.574	.219	.208	1.105	.905	.022
Physical[e]						
Disability	3.046	.309	.274	1.265	.791	.003
Mental Health	4.209	.289	.275	1.107	.904	.003
Transportation	2.727	.281	.249	1.276	.784	.006
Developmental[f]						
Support	4.792	.284	.241	1.383	.723	.013
Employment	3.356	.258	.239	1.167	.857	.013
Mental Health	4.611	.227	.201	1.280	.781	.037

Note. CI = confidence interval. VIF = Variance Inflation Factor. B = Unstandardized Coefficient. β = Standardized Coefficient. sr = part correlation. All included predictors were from the stepwise model that explained the most variance.
a. Model for Total CBI: R^2 = .398; Adjusted R^2 =. 374.The overall regression was significant, F (3, 74) = 16.319, p = <.001.
b. Model for Time-Dependence CBI: R^2 = .107; Adjusted R^2 = .095. The overall regression was significant, F (1,76) = 9.115, p = .003.
c. Model for Emotional CBI: R2 = .235; Adjusted R2 = .215. The overall regression was significant, F (2,75) = 11.527, p = <.001.
d. Model for Social CBI: R2 = .419; Adjusted R2 = .395. The overall regression was significant, F (3,73) = 17.523, p = <.001.
e. Model for Physical CBI: R2 = .422; Adjusted R2 = .399. The overall regression was significant, F (3, 74) = 18.042, p = <.001.
f. Model for Developmental CBI: R2 = .341; Adjusted R2 = .315. The overall regression was significant, F (3, 74) = 12.781, p = <.001.

Moderation analyses evaluated whether race moderated the relationship between the three HRSNs identified in the stepwise model and CBI total. Race was condensed to REM and non-REM due to the limited sample size in individual REM groups that limited analytic feasibility. No significant interaction effects were found for any of the three predictors ($p > .05$ for all), indicating that the relationships were consistent across racial groups.

Discussion

This study contributes new insights into how specific HRSNs relate to total and domain-specific CB among ICPs of stroke survivors. Firstly, more than half of participants (51.9%) were under the age of 41, which is surprising given that an estimated 75% of strokes occur in individuals 65 years and older (Benjamin et al., 2019). One potential reason for this is that unlike other studies which have found up to 75% of stroke ICPs to be the stroke survivor's significant other (Zhang et al., 2023), only 50.6% fell into that category in this study. Additionally, children and grandchildren comprised 24.7% of ICPs, potentially lowering the average age of participants. It could be possible, however, that we are beginning to see the effect of higher prevalence of stroke among young people, with nearly 10% of ICPs in this study being parents of stroke survivors, with 12% reported in a previous study (Washington et al., 2022). Furthermore, 28.7% of ICPs reported a household income of less than $39,000, substantially lower than the estimated stroke care partnership costs reported in some studies, which can exceed $240,000 (Lucas-Noll et al., 2023).

Second, increased total CB was positively correlated with all HRSN domains, except for physical activity. Independent-samples *t*-tests revealed large effect sizes for

food insecurity, transportation needs, interpersonal safety, education, employment, family and community support, mental health, and disability. These findings underscore the potential compounding effect of social risk on ICP strain and affirm the importance of including social risk screening in stroke aftercare. Notably, the effect size for physical activity needs, while statistically nonsignificant, remained in the small range, suggesting a potential trend that may reach significance in a larger sample.

Third, the stepwise regression model for total CB identified three HRSN domains as significant predictors: transportation, family and community support, and education. This model accounted for 37.4% of the variance in ICP burden, a substantial amount for a novel model with dichotomous predictors. These findings echo prior research highlighting transportation as a structural barrier to equitable care access (Garnett et al., 2022; Lin et al., 2022) and reinforce the protective role of social connection in moderating CB, with social isolation previously being identified as a predictor of ICP burden (Kavga et al., 2021). Education's role in the overall model is difficult to discern given the limited nature of education assessment in the AHC-HRSN. ICPs have, however, previously reported difficulties with understanding discharge instructions (Lin et al., 2022), potentially indicating health literacy concerns associated with CB tied to education. Furthermore, the education domain of the AHC-HRSN was limited in scope, with one of the two items being associated with languages spoken at home, which could also reflect inadequate translation of discharge material.

Fourth, when examining CBI burden domains separately, several additional HRSNs emerged as significant. For example, mental health needs predict both developmental and physical burden, while utility help needs predicted emotional burden.

These patterns suggest that while certain HRSNs contribute broadly to overall burden, others exert domain-specific effects. The presence of employment needs as a predictor of developmental burden may reflect role strain and competing demands experienced by working ICPs, while family and community support may influence time-dependence burden via practical help and other forms of assistance which may reduce time constraints. These differentiated findings strengthen the argument that CB is not a unified concept but rather a multifaceted experience influenced by specific social conditions.

No significant moderation effects by race were found for the three HRSNs predicting total CB. While this may reflect limited statistical power due to sample size constraints, it also raises the possibility that HRSN–CB pathways operate similarly across racial groups. Nonetheless, persistent disparities in stroke incidence and HRSN exposure by race remain well documented (Tsao et al., 2022; Young et al., 2020), and future research should continue to explore models that incorporate both structural and cultural dimensions of CB.

This study represents one of, if not the first comprehensive attempts to map a wide range of actionable HRSNs to both overall and multidimensional CB among ICPs of stroke survivors. These findings offer a foundation for more precise intervention design. By identifying which HRSNs predict which domains of CB, researchers and clinicians can look to tailor strategies to match specific barriers ICPs face. For example, ICPs may benefit from more structural navigation services and further health literacy support, especially if flagged during point-of-care screening. As policy interest in social drivers of health grows, this study offers a timely, data-driven framework for how such factors correlate with stroke care partnership.

Several limitations were identified. Firstly, this study did not reach desired sample size, impacting the generalizability and interpretability of the results. Second, while this study aimed to represent an array of different REM groups, only Black and White participants reached adequate sample size for analysis, limiting generalizability of the results. Additionally, future studies should explore whether these uncovered patterns persist in longitudinal designs with larger, more diverse samples. Furthermore, dichotomization of HRSN variables reduced depth of understanding. Opportunities exist for the development of a psychometrically sound HRSN instrument for use in research.

Conclusion

These findings highlight the impact of HRSNs in shaping the CB experienced by ICPs of stroke survivors and challenge the field to reimagine intervention strategies. Rather than treating CB as a concept to be managed purely through resilience or coping skill development, these findings suggest that HRSNs are a critical target for intervention. Screening for transportation challenges, unmet support needs, and educational barriers in clinical encounters and other points-of-care may additionally offer actionable points of entry for reducing CB among ICPs of stroke survivors.

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CHAPTER FOUR

THIRD MANUSCRIPT

Demographic Disparities in Health-Related Social Needs Among Informal Care Partners of Stroke Survivors: An Exploratory Cross-Sectional Study

Abstract

OBJECTIVES: To investigate the prevalence and demographic disparities of health-related social needs (HRSNs) across 12 domains among informal care partners (ICPs) of stroke survivors, with attention to race/ethnicity and caregiving context. **DESIGN:** Cross-sectional survey employing chi-square tests, independent-samples *t*-tests, and stepwise multiple linear regression to examine disparities and predictors of total HRSN burden. **SAMPLE:** Eighty-one US ICPs (69% female; 56% Black or African American), recruited from diverse geographic areas via social media, support groups, and clinical settings between November 2024 and June 2025. **MEASUREMENTS:** A PI-developed demographic questionnaire, plus the CMS Accountable Health Communities HRSN screening tool assessing 12 domains, scored dichotomously, and summed into a total HRSN score (range 0–12). **RESULTS:** ICPs reported an average of 6.5 unmet social needs. REM ICPs experienced significantly higher total HRSNs than non-REM ICPs (mean 7.8 vs. 3.6; large effect size). Regression analysis showed that stroke survivor race (REM), ICP age (<41), and marital status accounted for 61% of variance in total HRSNs. **CONCLUSIONS:** ICPs of stroke survivors face extensive and inequitable social needs, particularly among those caring for REM stroke survivors, younger ICPs, and married partners. Addressing these disparities requires integrating ICP-focused, equity-oriented social needs screening into stroke care models.

Background

Stroke remains a major public health phenomenon, with over 7.6 million stroke survivors in the United States (US) alone (Tsao et al., 2022). Approximately 75% of strokes occur in individuals aged 65 or older, making older adults the most affected demographic (Benjamin et al., 2019). There has, however, been a significant increase in the quantity of younger people experiencing stroke, likely tied to a higher incidence of stroke risk factors, such as obesity, hypertension, and hyperlipidemia, among young people (Yahya et al., 2020). Stroke is also a leading cause of serious long-term disability, significantly reducing mobility and independence for more than half of survivors aged 65 and older (Tsao et al., 2022). As the US population continues to age, the absolute number of strokes is expected to rise substantially, placing increased pressure on healthcare systems, long-term care facilities, and other points of care (Renedo et al., 2024).

Racial and ethnic disparities in stroke incidence and outcomes are well-documented, indicating that stroke does not affect all people equally. For example, Black or African American (BAA) individuals experience significantly higher stroke rates than White individuals, with a community-based study finding that BAA adults under 65 had a 200% higher incidence of stroke compared to White young adults (Gardener et al., 2020). Following the acute stages of stroke, many stroke survivors find themselves in the dyadic experience of care partnership, alongside family, friends, and others who assist in the care of the stroke survivor, known as informal care partners (ICPs).

While data on racial and ethnic minority (REM) ICPs of stroke survivors is limited, it is known that REM groups provide more care hours (Skolarus et al., 2017), experience more pain and fatigue (Mehdipanah et al., 2024), have higher levels of

depression (Unson et al., 2023), and possess fewer resources to manage the challenges of adapting to the role of care partner (Liu et al., 2022). Despite these known disparities in the stroke care partnership experience, REMs are underrepresented in stroke care partnership research. The underrepresentation of REM ICPs is especially stark in interventional studies. A recent meta-analysis highlights that many stroke ICP interventional studies have small sample sizes and homogenous cohorts, making it difficult to draw conclusions for diverse populations (Rhudy et al., 2023). In practice, this means that evidence-based interventions may have unknown or different effects in REM communities because so few participants in those trials belonged to REM groups. Data regarding REM ICPs is most scarce when examining another underreported dimension of the care partnership experience, health-related social needs (HRSN).

HRSNs are the conditions in which individuals are born, grow, work, live, and age that directly impact their ability to maintain health and well-being (Centers for Medicare and Medicaid Services, 2024). The Centers for Medicare & Medicaid Services (CMS), through its Accountable Health Communities (AHC) model, classifies HRSNs into five core domains: housing instability, food insecurity, transportation difficulties, utility assistance needs, and interpersonal safety (Billioux et al., 2017), alongside eight additional supplemental domains. These domains are highly relevant for stroke survivors and their ICPs, adding dyadic complexity to demands of care partnership.

ICPs who are socially disadvantaged face both the direct strain of care partnership and the indirect, potentially compounding, stress imposed by unmet social needs (Mehdipanah et al., 2024). Addressing HRSNs is increasingly recognized as essential to improving ICP outcomes, particularly in communities with limited access to

resources (Kilmer, 2024). The literature underscores that any strategy aimed at improving ICP well-being in REM populations must be holistic, combining culturally tailored programming with systemic efforts to reduce HRSN disparities (Mehdipanah et al., 2024), yet the prevalence and racial differences of HRSN among ICPs of stroke survivors is inadequately explored (Young et al., 2020). Inadequate information regarding characteristics of ICPs of stroke survivors is not limited to race, with variables such as income, gender, relationship of the ICP to the stroke survivor, and many other demographic characteristics not explored in any regard as it relates to the stroke care partnership experience (Young et al., 2020), let alone explored as these variables relate to HRSNs.

HRSNs are further known to shape stroke incidence and severity. Reshetnyak et al. (2020) found that BAA race, low education, low household income, lack of insurance, and residence in underserved regions correlate with higher stroke incidence. Similarly, individuals with three or more SDOH disadvantages were nearly three times more likely to suffer stroke before age 75 (Reshetnyak et al., 2020). Though these studies focus on survivors, they imply that ICPs, especially in underserved communities, are also exposed to intensified stress and logistical challenges due to the dyadic nature of stroke and stroke severity. However, the literature rarely addresses how HRSNs affect ICP outcomes directly (Young et al., 2020). Domains such as housing accessibility, availability of adaptive equipment, and ICP-specific financial strain remain underexplored in terms of both their prevalence and relationship with HRSNs. Despite growing recognition of HRSNs, few studies have quantified their impact on ICP outcomes and characteristics, with research remaining focused on survivors rather than the care dyad.

Accordingly, the purpose of this study is to examine the prevalence and demographic disparities in 12 domains of HRSNs among ICPs of stroke survivors. Addressing this purpose will allow this study to contribute several novel and significant pieces of information to stroke care partnership and public health nursing literature. Firstly, demographic characteristics of ICPs of stroke survivors are not regularly reported in US based literature, and this study will include demographic data not available in almost any of the reviewed literature. These include availability of equipment essential to the care of the stroke survivor, the relationship of the ICP to the stroke survivor, whether the ICP lives with the stroke survivor, and more. Secondly, there is little available data regarding the prevalence of HRSNs among ICPs of stroke survivors. This study will not only address this gap but will examine racial disparities present in each domain of HRSNs as well as within total HRSN scores. Finally, this study will provide exploratory information regarding which demographic characteristics may place people at highest risk for experiencing multiple unmet social needs, providing robust information for future policy, interventions, and research.

Methods

Study Design, Setting, and Sample

A cross-sectional survey was conducted with a convenience sample of 81 ICPs of stroke survivors from November 2024 to June 2025. Participants were recruited via convenience sampling techniques including social media platforms and stroke support groups. Social media efforts included posts in stroke and care partner focused Facebook groups. Phone screening of online participants was conducted to limit fraudulent responses. In-person recruitment was conducted at stroke support groups in southeastern

Michigan, with additional outreach to groups in northern Michigan, New York, Los Angeles, North Carolina, Tennessee, and Ohio to represent geographic and demographic variation among ICP-stroke survivor dyads. Flyers were also placed in outpatient neurology clinics, senior centers, and community centers. There were focused efforts to recruit REM participants due to their historical underrepresentation in stroke research (Lopez et al., 2022). To promote inclusive recruitment, the PI consulted with community leaders and REM nursing experts, adapting strategies based on prior successful approaches (Ratnapradipa et al., 2024).

Inclusion criteria were as follows: (1) self-identification as an ICP of a stroke survivor aged 18 or older, (2) English literacy, and (3) access to the internet via smartphone or computer. All participants received a $20 Amazon e-gift card upon completing the survey. Using G*Power (Faul et al., 2007), the recommended sample size was calculated as 135 for a multiple linear regression with 14 predictors, assuming a medium effect size ($f^2 = 0.15$), $\alpha = .05$, and power = .80. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist (von Elm et al., 2008) was self-applied to this study to ensure quality.

Ethical Considerations

Ethical approval for this study was obtained from the Institutional Review Board (IRB). The study was deemed exempt following evaluation by the IRB, which agreed that the study design and implementation adequately prevented harm or risk to participants. Participants had the right to terminate their participation at any time, and no information that could be used to personally identify participants was collected. All data was deidentified. Implied consent was given from participants who chose to proceed with the

survey after reading a thorough description of the study and their rights as participants, as well as by checking that they agree to participate. Survey language and applicability were reviewed by a REM nursing consultant to confirm cultural sensitivity. Finally, study recruitment material was sent to the University Disability Support Services to ensure accessibility.

Data Collection

Participants completed three electronic questionnaires via Qualtrics. Of these three surveys, analysis involving two of the questionnaires are included in this manuscript, being a demographic questionnaire and the Accountable Health Communities Health-Related Social Needs Screening Tool (AHC-HRSN) (Centers for Medicare and Medicaid Services, 2017).

Demographic Questionnaire

A 15-item questionnaire developed by the PI (of which 14 are included in this analysis) assessing ICP race, age, gender, marital status, education level, employment status, household income, race/ethnicity of the stroke survivor, relationship to the stroke survivor, use of adaptive equipment, hours spent caregiving per week, duration in the care partner role, amount of skilled nursing care provided, and cohabitation status with the stroke survivor. Demographic variables were recoded into binary variables to allow for inclusion in regression models and to ensure sufficient group sizes for analysis. In the absence of strong theoretical rationale for more granular categorization, groups were collapsed to create approximately even distributions and minimize sparse cell sizes, which can compromise statistical power and model stability, which is especially of concern due to sample size in this exploratory study (Jane & Tatano, 2025). Reference

groups were selected based on either sample distribution or conventional standards in the literature, with all dummy-coded variables using 0 to indicate the reference group and 1 to indicate the comparison group.

The Accountable Health Communities Health-Related Social Needs Screening Tool

AHC-HRSN (Centers for Medicare and Medicaid Services, 2017) includes 26-items spanning 13 domains. The substance use domain was excluded due to concerns about cultural sensitivity based on REM community member consultation, as culturally adapting or removing potentially stigmatizing items is recommended practice to reduce measurement error and improve respondent comfort in diverse populations (Spata et al., 2024). Each of the remaining 12 domains was scored as a binary variable (0 = no need, 1 = presence of need) to provide standardization of scoring throughout the instrument. If any item within a domain was endorsed, the domain was marked as 1. All HRSN domains were dichotomized to reflect the presence or absence of need, consistent with CMS guidelines and common public health practices that prioritize actionable identification over severity grading (Billioux et al., 2017). The scores of each domain were then summed to create a total HRSN score. While this scoring method is exploratory and not yet widely used with this instrument, it aligns with common practices in public health research that quantify overall social risk by summing individual needs (Jones et al., 2024). This total score was used as a continuous outcome variable to represent the overall burden of health-related social needs.

Statistical Analysis

Data were analyzed using the IBM Statistical Package for Social Sciences (SPSS) version 29 (IBM Corp., 2023). The categorical data were described by frequency and percentage, and scale data were described by mean and standard deviation. To prepare for regression and *t*−test analyses, demographic variables with more than two categories were dummy coded into binary variables. Coding decisions were based on both theoretical relevance and distribution balance across groups to preserve model stability. For example, race was coded as 0 = White and 1 = REM; income was coded as 0 = ≥ $40,000 and 1 = < $40,000; and education was coded as 0 = some college or less and 1 = college degree or higher. Age was split at the median, and other variables such as gender (0 = male, 1 = female), employment (0 = unemployed, 1 = employed), and living with the stroke survivor (0 = no, 1 = yes) were also binary coded. This allowed for straightforward interpretation of between−group comparisons in *t*-tests and regression models. Prior to analysis, the dataset was screened for duplicates, missing data, and univariate outliers. Attention check questions embedded in the survey were used to identify inauthentic responses.

Chi-square tests of independence were conducted to examine whether the prevalence of each HRSN domain and demographic differed significantly across race.

Each HRSN domain was treated as a binary variable (0 = no need, 1 = need). Output for each chi-square test included the Pearson chi-square statistic, degrees of freedom, *p*-value, and standardized residuals. Statistically significant results were interpreted as evidence that the likelihood of reporting an unmet social need differed by group.

Independent-samples *t*-tests were conducted to compare the mean total HRSN score (range: 0–12) between binary-coded demographic groups (e.g., REM vs. non-REM, employed vs. unemployed). For demographic variables with more than two levels (e.g., age, income, education), categories were recoded to create two balanced groups for analytic consistency and model parsimony. For group comparisons (chi-square and *t*-tests), race was limited to REM vs non-REM participants due to small sample sizes in other groups. Group comparisons included output of means, standard deviations, t-values, degrees of freedom, *p*-values, and Cohen's *d* effect sizes.

Finally, a stepwise multiple linear regression was performed to assess the extent to which demographic variables predicted participants' total HRSN scores. All 14 demographic variables were entered as independent variables, with the total number of reported HRSNs entered as the continuous dependent variable. Output included R^2, adjusted R^2, F-statistic, standardized and unstandardized beta coefficients, standard errors, significance levels, and variance inflation factors (VIF) to assess multicollinearity.

Sensitivity analyses were conducted by excluding participants who failed attention checks or were flagged as potential outliers. Results of the regression model were compared across the full and restricted datasets to assess consistency and robustness of findings and yielded no significant differences following sensitivity analysis. Statistical significance was set at $p < .05$ for all analyses.

Results

Sample Characteristics

A total of 81 ICPs of stroke survivors were included in this study, with the majority (69.1%) identifying as female. BAA participants consisted of 55.6% of the sample, while White participants made up 30.9% of the sample. While this reflects a degree of racial representation, the remainder of REM groups remained underrepresented, with Hispanic, Asian, and Arab American ICPs combined making up only 13.5% of ICPs. Geographically, the sample included participants from at least 12 different U.S. states based on self-reported ZIP codes. The largest proportion resided in Michigan (n = 41), followed by California (n = 12), New York (n = 6), Georgia (n = 4), and smaller groups from Florida, Illinois, Texas, Minnesota, Vermont, Pennsylvania, Maryland, and Louisiana.

Several indicators of potential social vulnerability were present. Twenty-three (28.7%) participants reported annual household incomes below $40,000, with 36 (45%) working less than full time when not retired, and approximately 30% reported lacking essential adaptive equipment to manage the stroke survivor's care. These conditions reflect key unmet needs in the care partnership context. The care relationships varied across the sample: just over half of participants were significant others of the stroke survivor (50.6%), while others were adult children (17.3%), grandchildren (7.4%), siblings (2.5%), friends (11.1%), Aunt/Uncles (1.2%), or parents (9.9%). Time spent in the care partner role ranged from less than one year to 40 years, with an average of 6.97 years (SD = 8.59), capturing a mix of acute and long-term caregiving experiences.

Prevalence of Health-Related Social Needs

Descriptive analysis of the AHC-HRSN revealed a high prevalence of unmet HRSNs among ICPs of stroke survivors. Table 4.1 presents the frequency and percentage of ICPs reporting unmet needs across each of the 12 HRSN domains. The most prevalent domains overall were mental health (86.4%), physical activity (82.7%), and family and community support needs (80.2%), suggesting widespread psychosocial and functional challenges in this population. Economic hardship was also evident, with food insecurity reported by 51.6% of participants and financial strain by 53.1%.

Table 4.1
Prevalence of HRSN Domains Among ICPs of Stroke Survivors

Domain	Problem Present n (%)	Problem Not Present n (%)	Missing n (%)
Family and Community Support	65 (80.2%)	14 (17.3%)	2 (2.5%)
Education	19 (23.5%)	60 (74.1%)	2 (2.5%)
Physical Activity	67 (82.7%)	12 (14.8%)	2 (2.5%)
Mental Health	70 (86.4%)	9 (11.1%)	2 (2.5%)
Disability	26 (32.1%)	53 (65.4%)	2 (2.5%)
Housing Instability*	34 (42%)	45 (55.6%)	2 (2.5%)
Utility Help Needs*	25 (30.9%)	53 (65.4%)	3 (3.7%)
Food Insecurity*	41 (51.6%)	38 (46.9%)	2 (2.5%)
Interpersonal Safety*	56 (69.1%)	23 (28.4%)	2 (2.5%)
Transportation Problems*	28 (34.6%)	51 (63%)	2 (2.5%)
Employment	37 (45.7%)	42 (51.9%)	2 (2.5%)

Financial Strain	43 (53.1%)	36 (44.4%)	2 (2.5%)	

* = Core HRSN Domain

The five CMS-designated core HRSN domains (housing instability, food insecurity, transportation problems, utility help needs, and interpersonal safety) were all represented in the sample. Housing instability was reported by 42% of ICPs, food insecurity by 51.6%, transportation problems by 34.6%, utility help needs by 30.9%, and interpersonal safety concerns by 69.1%. These domains reflect structural barriers that may limit positive outcomes among ICPs of stroke survivors. Most participants reported more than one unmet need: on average, ICPs endorsed M = 6.47 out of 12 HRSN domains (SD = 3.48, range = 0 to 12), suggesting a substantial cumulative presence of unmet needs.

Less commonly endorsed, but still prevalent, needs included education-related barriers (23.5%) and disability-related challenges (32.1%), while employment-related strain affected 45.7% of participants. The diversity and prevalence of unmet needs across domains underscore the multidimensional nature of HRSNs within the stroke care partnership context. These findings provide essential context for examining demographic disparities and predictors of total HRSN burden in the sections that follow.

Racial Differences: Demographics and HRSN Prevalence

Racial Differences in Demographic Characteristics

Group comparisons were conducted to explore whether ICPs who identified as REM differed significantly from their non-REM counterparts across key demographic and care-related characteristics. Detailed results for all tests are presented in Table 4.2.

A highly significant association was observed between REM status of the ICP and the race of the stroke survivor they supported, χ^2 (4) = 81.00, $p < .001$, with a Cramér's V of 1.000, indicating an extremely strong association. This is likely due to the high racial concordance between ICPs and stroke survivors within dyads. Significant differences (analyzed using 2-sided significance) were also found with age group, household income, education, employment, marital status, and hours of skilled nursing received.

Table 4.2
Chi-Square Tests Group Comparison REM vs Non-REM Participants Across Demographic Variables

Demographic Variable	χ^2 (df)	*p*	Effect Size	Effect Type	Significant
Gender	0.051 (1)	.821	-.053 (Small)	Phi	No
Age Group*	30.682 (5)	<.001	.615 (Large)	Cramer's V	Yes
Household Income	14.871 (4)	.005	.431(Medium)	Cramer's V	Yes
Education	8.105 (2)	.017	.316 (Medium)	Cramer's V	Yes
Employment*	15.991	.007	.447 (Medium)	Cramer's V	Yes
Marital Status*	8.074 (3)	.044	.316 (Medium)	Cramer's V	Yes
Stroke Survivor Race*	81.000 (4)	.001	1.000 (Large)	Cramer's V	Yes
Relationship to Stroke Survivor*	6.224 (6)	.399	.277 (Small)	Cramer's V	No
Access to Equipment	2.464 (1)	.116	.203 (Small)	Phi	No
Cohabitation with Stroke Survivor	1.304 (1)	.253	.161 (Small)	Phi	No
Hours of Care Provided	2.149 (2)	.341	.164 (Small)	Cramer's V	No
Hours of Skilled Nursing Received	11.034 (3)	.012	.371 (Medium)	Cramer's V	Yes

* Violations of chi-square assumptions, specifically that more than 20% of cells had expected counts less than 5. Caution is advised in interpreting results for these comparisons due to limited statistical power and potential instability of the test statistic.

Chi-square tests did not reveal significant differences in the type of relationship between the ICP and stroke survivor, χ^2 (6) = 6.22, p = .399, weekly hours of direct caregiving provided, χ^2 (2) = 2.15, p = .341. REM and non-REM ICPs also did not significantly differ in cohabitation status, χ^2 (1) = 1.304, p = .253, gender χ^2 (1) = .051, p = .821, or access to equipment χ^2 (1) = 2.464, p = .116 (although 36.5% of REM ICPs reported inadequate access to equipment compared to 17.2% of non-REM ICPs). These results underscore potential REM group differences in care context and resource access among stroke ICPs, while also highlighting the need for nuanced interpretation considering sample size limitations and assumption violations.

Caution is advised in interpreting some of these findings due to violations of statistical assumptions in select variables. Specifically, the chi-square assumptions of minimum expected cell size were violated for the variables relationship to stroke survivor, marital status, and stroke survivor race, age, and employment. For 2×2 comparisons (e.g., equipment access, cohabitation), continuity-corrected chi-square values and Phi coefficients were reported instead of Cramér's V to enhance accuracy under small cell conditions.

Racial Differences in HRSN Domains

A series of 2×2 chi-square analyses were conducted to examine disparities in the prevalence of HRSNs among REM ICPs of stroke survivors compared to their non-REM counterparts. These analyses revealed striking and consistent patterns of disparity, with REM ICPs reporting a higher burden of unmet needs across all twelve HRSN domains.

Nine of the twelve domains demonstrated statistically significant group differences, including living situation, food insecurity, transportation, utility help needs,

interpersonal safety, financial strain, education, disability, and employment. In each case, REM ICPs were significantly more likely to report experiencing need. The most pronounced disparities were observed in transportation, financial strain, and living situation, with effect sizes in the large range. For example, more than half of REM ICPs reported transportation barriers compared to fewer than five percent of non-REM ICPs, resulting in a Phi of .509. Similarly, substantial differences in financial strain and living situation yielded Phi values of .516 and .503, respectively. These findings underscore the scope and intensity of structural disadvantage affecting REM ICPs.

Of the remaining five domains, none reached statistical significance; however, the direction of effects remained consistent. In each of these domains, family and community support, education, physical activity, mental health, and disability, REM ICPs reported higher levels of need than their non-REM counterparts. Although effect sizes for these comparisons ranged from small to medium, the uniform pattern across all domains suggests multidimensional disparities in HRSNs by racial and ethnic identity. These findings are presented in Table 4.3.

Table 4.3
Racial/Ethnic Differences in HRSN Domain Prevalence (REM vs. non-REM)

HRSN Domain	% REM with Need	% Non-REM with Need	Continuity-Corrected χ^2	*p*-value	Phi
Living Situation	62.0	10.3	17.93	<.001	.503 (Large)
Food Insecurity	70.0	20.7	15.96	<.001	.476 (Medium)
Transportation	54.0	3.4	18.35	<.001	.509 (Large)
Utility Help Needs	49.0	3.4	15.31	<.001	.472 (Medium)
Interpersonal Safety	86.0	44.8	13.15	<.001	.437 (Medium)
Financial Strain	74.0	20.7	18.94	<.001	.516 (Large)
Employment	64.0	17.2	14.29	<.001	.452 (Medium)
Family/Community Support	86.0	75.9	.692	.255	.128 (Small)
Education	34.0	6.9	5.97	.007	.306 (Medium)
Physical Activity	90.0	75.9	1.86	.173	.190 (Small)
Mental Health	94.0	79.3	2.60	.107	.223 (Small)
Disability	42.0	17.2	4.04	.045	.254 (Small)

Note. All values reflect results of 2×2 chi-square tests comparing REM vs. non-REM ICPs across each HRSN domain. Continuity-corrected chi-square values and Phi coefficients were reported for all comparisons due to the 2×2 structure of each table. All tests used continuity-corrected chi-square values and met assumptions for expected cell size.

Independent Samples *t*-Tests: Demographics and Total Health-Related Social Needs

To examine group differences in total HRSNs, a series of independent samples *t*-tests were conducted using binary condensed demographic variables. All analyses used two-tailed significance tests to account for the exploratory nature of this study and the

possibility of group differences in either direction. Equal variances were not assumed for any test.

Several comparisons revealed statistically significant differences in total HRSNs. ICPs identifying as REMs reported significantly more HRSNs than non-REMs (M = 7.81 vs. 3.56), with a very large effect size (d = -1.480), suggesting a meaningful disparity. Similarly, REM stroke survivors were associated with substantially higher HRSNs reported by their ICPs (M = 8.04 vs. 3.76), again with a large effect (d = -1.522). Younger ICPs aged 18 to 40 reported significantly more HRSNs than those aged 41 and older (M = 8.53 vs. 4.36), also with a large effect size (d = 1.489). Employment status, skilled nursing care, and equipment access also showed significant group differences. Employed ICPs reported more needs than unemployed ICPs (with retired participants counting as unemployed) (M = 7.45 vs. 4.36, d = -0.964), and those whose stroke survivor received skilled nursing care reported higher HRSNs (M = 7.55 vs. 5.46, d = -0.625). ICPs who lacked necessary medical equipment reported more needs (M = 7.96 vs. 5.82, d = -0.637), while those living with the stroke survivor had higher HRSNs than those not living with them (M = 7.05 vs. 4.94, d = 0.629).

Although some comparisons did not reach statistical significance, large mean differences were still observed. For example, gender differences revealed higher HRSNs among male ICPs (M = 7.33 vs. 6.09, d = 0.359), and unmarried ICPs showed a moderate difference compared to married ICPs (M = 5.93 vs. 6.76, d = -0.24), though neither comparison met the $p < .05$ threshold. In every binary demographic comparison, the direction of the means revealed higher HRSN totals among groups traditionally considered at higher social disadvantage, even when these differences did not meet

statistical significance. This consistent pattern supports the theoretical premise that structural and social accumulate in ways that shape ICP experiences.

Household income, when dichotomized for *t*-test comparison, did not yield a statistically significant difference in total HRSNs ($p = .860$, $d = .039$), prompting a follow-up ANOVA using all five income categories. The one-way ANOVA showed a statistically significant difference in total HRSNs by income group, $F(4,73) = 5.120$, $p = .001$, with a large effect size ($\eta^2 = .219$). Post hoc comparisons using the Tukey HSD and Games-Howell tests revealed that participants in the lowest income group (< $20,000) and middle-income groups (e.g., $40,000–$59,000) had higher HRSN totals compared to those earning $80,000 or more. Specifically, ICPs in the $80,000 income bracket reported the lowest HRSN total (M = 3.87), while those in the $40,000–$59,000 group reported the highest (M = 8.55). The income group differences suggest that using a binary income variable may obscure important trends and that HRSNs do not decrease in a strictly linear fashion across income levels. Instead, middle-income ICPs may face unique financial strain not captured when simplifying income categorization.

Finally, a Pearson correlation was conducted between total HRSNs and the number of years the participant had been providing care. Results revealed a statistically significant negative correlation, $r = -0.280$, $p = .014$, indicating that longer duration of care was associated with fewer reported HRSNs. While the effect size was small, this pattern may reflect either adaptive coping mechanisms or differential attrition, where those with higher needs may exit care roles more quickly.

Together, these findings reinforce the social patterning of HRSNs and provide compelling evidence of disparities across racial, age, income, and contextual caregiving

characteristics. The consistently large effect sizes and clear directional trends further emphasize the real-world salience of these group differences. See Table 4.4 for full *t*-test results.

Table 4.4
Group Differences in Total HRSNs by Binary Demographic Variables via Independent-samples t-tests

Grouping Variable	Group 1 (n, M, SD)	Group 2 (n, M, SD)	95% CI (Lower, Upper)	df	*t*	*p*	*d*
Not Married (1) vs Married (2)	n = 28, M = 5.93, SD = 3.150	n = 51, M = 6.76, SD = 3.647	[-2.403, .731]	62.96	-1.066	.290	-.240
Not REM (1) vs REM (2)	n = 25, M = 3.56, SD= 2.123	n = 54, M = 7.81. SD = 3.157	[-5.460, -3.049]	66.66	-7.045	<.001*	-1.480
18-40 (1) vs 41-61+ (2)	n = 40, M = 8.53, SD = 2.792	n = 39, M = 4.36, SD = 2.805	[2.912, 5.420]	76.93	6.615	<.001*	1.489
Male (1) vs Female (2)	n = 24, M = 7.33, SD = 4.040	n = 55, M = 6.09, SD = 3.176	[-6.42, 3.127]	35.96	1.337	.190	.359
No College (1) vs Some College (2)	n = 32, M = 6.81, SD = 3.431	n = 47, M = 6.23, SD = 3.534	[-1.010, 2.167]	68.04	.727	.470	.166
Unemployed (1) vs Employed (2)	n = 25, M = 4.36, SD = 3.081	n = 53, M = 7.45, SD = 3.267	[-4.624, -1.562]	49.76	-4.057	<.001*	-.964
Income <$40,000 (1) vs Income >/= $40,000 (2)	n = 22, M = 6.64, SD = 2.752	n = 56, M = 6.50, SD = 3.707	[-1.405, 1.678]	51.60	.178	.860	.039

Table 4.4 - Continued

Group Differences in Total HRSNs by Binary Demographic Variables via Independent-samples t-tests

Grouping Variable	Group 1 (n, M, SD)	Group 2 (n, M, SD)	95% CI (Lower, Upper)	df	*t*	*p*	*d*
Race of Stroke Survivor Not Rem (1) vs Race of Stroke Survivor REM (2)	n = 29, M = 3.76, SD = 2.370	n = 50, M = 8.04, SD = 3.037	[-5.508, -3.055]	70.29	-6.962	<.001*	-1.522
ICP Significant Other of Stroke Survivor (1) vs Not Significant Other (2)	n = 41, M = 6.24, SD = 3.576	n = 38, M = 6.71, SD = 3.408	[-2.032, 1.098]	76.94	-.594	-.467	-.133
ICP Provide 20 Hours or Less of Care (1) vs More than 20 Hours (2)	n = 39, M = 5.90, SD = 3.262	n = 40, M = 7.03, SD = 3.262	[2.680, .424]	75.59	-1.447	.152	-.326
Stroke Survivor Receives No Skilled Nursing (1) vs Some Skilled Nursing (2)	n = 41, M = 5.46, SD = 3.557	n = 38, M = 7.55, SD = 3.091	[-3.579, -.599]	76.69	-2.792	.007*	-.625
Do Not Have Necessary Equipment (1) vs Have Necessary	n = 24, M = 7.96, SD = 3.394	n = 55, M = 5.82, SD = 3.394	[-3.807, -.473]	43.31	-2.589	.013*	-.637

Equipment (2)							

Table 4.4 - Continued
Group Differences in Total HRSNs by Binary Demographic Variables via Independent-samples t-tests

Grouping Variable	Group 1 (n, M, SD)	Group 2 (n, M, SD)	95% CI (Lower, Upper)	df	*t*	*p*	*d*
Do Not Live With Stroke Survivor (1) vs Live With Stroke Survivor (2)	n = 17, M = 4.94, SD = 2.561	n = 60, M = 7.05, SD = 2.561	[.544, 3.674]	35.20	2.735	.010*	.629

* = p <.05, statistical significance

Note. All independent samples *t*-tests reported used two-tailed significance tests to account for the exploratory nature of this analysis and the possibility of group differences in either direction. Additionally, equal variances were not assumed for any comparison, as a conservative approach was taken to account for unequal sample sizes and potential heterogeneity of variance between groups.

Multiple Linear Regression: Demographic Predictors of Total Health-Related Social Needs

A stepwise multiple linear regression was conducted to examine which demographic characteristics predicted the total number of HRSNs among ICPs of stroke survivors. The dependent variable was the total HRSN score (range 0–12). Thirteen binary demographic predictors were entered into the model using a stepwise selection method. These included marital status, race, age group, gender, education, employment, income, relationship to stroke survivor, stroke survivor race, care hours per week, skilled nursing hours, access to adaptive equipment, living with the stroke survivor, and total years as a care partner was added as a continuous predictor.

In Step 1, stroke survivor race (condensed to REM vs. not REM) emerged as a significant predictor of total HRSNs, F (1, 72) = 48.74, $p < .001$. ICPs caring for a REM stroke survivor reported an average of 4.64 more HRSNs than those caring for non-minority survivors. This variable alone accounted for 40.4% of the variance in HRSNs ($R^2 = .404$). In Step 2, age group (under 41 vs. 41 or older) was added to the model and significantly improved model fit, F (2, 71) = 44.74, $p < .001$. Younger ICPs were more likely to report greater HRSN burden (B = -2.96, $p < .001$). The addition of this variable increased the explained variance to 55.8% ($R^2 = .558$). In Step 3, marital status (married vs. not married) was included and again significantly improved the model, F (3, 70) = 36.58, $p < .001$. ICPs who were married reported significantly more HRSNs (B = 1.74, $p = .003$). The final model accounted for 61.1% of the variance in HRSNs ($R^2 = .611$), with all three predictors maintaining statistical significance. Table 4.5 contains further breakdown of the stepwise multiple regression breakdown.

Table 4.5
Stepwise Multiple Regression Predicting Total HRSNs by Demographics

Model	Predictor	B	SE B	β	t	p	VIF
1	Race of Stroke Survivor	4.635	.664	.635	6.981	<.001	1.000
2	Race of Stroke Survivor	3.459	.623	.474	5.556	<.001	1.169
2	Age Group	-2.959	.595	-.424	-4.970	<.001	1.169
3	Race of Stroke Survivor	3.944	.609	.541	6.477	<.001	1.252
3	Age Group	-2.810	.565	-.403	-4.978	<.001	1.177
3	Marital Status	1.738	.563	.238	3.085	.003	1.072

Note. Race of stroke survivor was coded as Race of Stroke Survivor (0 = Non-REM, 1 = REM), Age Group (0 = 18-40, 1 = 41-61+), Marital Status (0 = Not Married, 1 = Married).

Discussion

This exploratory study aimed to identify demographic predictors of total HRSNs among ICPs of stroke survivors, using a multidimensional analysis of sociodemographic characteristics. Findings reveal substantial variation in HRSN burden, with three key predictors (race of the stroke survivor, ICP age group, and ICP marital status) emerging as significant correlates of total HRSN burden. These results offer new insight into the structural contexts and disparities that shape HRSN exposure in stroke care partnerships.

Across the sample, HRSN prevalence was notably higher among ICPs who identified as members of a REM group. *t*-tests showed that REM ICPs reported significantly higher total HRSNs compared to non-REM ICPs, with a large effect size. This disparity aligns with previous research indicating that REM individuals often face greater structural barriers to healthcare access, financial stability, and community support (Bailey et al., 2017; Town, 2024). However, this study expands on prior work by shifting the focus from the stroke survivor's experiences to the unmet needs of those providing their care. Notably, race of the stroke survivor was also a significant predictor in the regression model, suggesting that broader systemic inequities within the dyad may influence resource access for ICPs as well.

Age also emerged as a significant factor, with younger ICPs (18 - 40 years) reporting significantly higher HRSN burden than their older counterparts. In the final stepwise regression model, age group contributed significantly to model fit, with younger ICPs experiencing nearly four additional unmet needs, on average. These findings may

reflect unique stressors and life-stage demands faced by younger care partners, including competing roles as parents, full-time employees, or students, and may also point to lower financial and social capital compared to older adults. As stroke increasingly affects younger adults (Tsao et al., 2022), future work should investigate the evolving demographic of stroke ICPs and their implications for health equity and long-term care planning.

Marital status was the final predictor retained in the stepwise model. Married ICPs reported significantly more HRSNs than their unmarried counterparts, a somewhat unexpected finding, especially with married ICPs having a statistically higher income than their non-married counterparts. *t*-test results showed a non-significant trend toward higher HRSNs among married individuals compared to unmarried ICPs, but in the multivariate model, marital status added a small but significant increase in explained variance. One interpretation is that married ICPs may take on greater levels of responsibility in care partnerships, perhaps serving as the sole or primary support for the stroke survivor. This deeper involvement may expose them to a broader range of social needs, especially if care partnership responsibilities disrupt employment, income, or mobility. Additional research could clarify the mechanisms through which marital status interacts with HRSN burden.

Interestingly, income, while significant in initial *t*-tests, did not remain a significant predictor in the regression analysis. A sensitivity ANOVA using three income brackets revealed that low-income participants (<$49,999) reported significantly higher HRSNs than high-income participants (>$100,000), with post hoc tests confirming differences across most pairwise comparisons. However, once other demographics were

controlled, income was not retained, suggesting potential collinearity or mediation effects. It is possible that income operates indirectly through other factors such as education, employment, or age, all of which were evaluated as candidate predictors in the model. These findings align with national studies showing that social needs often co-occur within broader systems of disadvantage (Garg et al., 2021).

In total, the final regression model accounted for 61.1% of the variance in HRSN burden, a substantial proportion considering the social and structural complexity of the outcome. Model diagnostics indicated good fit, with no concerning collinearity or residual patterns. Importantly, none of the excluded variables, including gender, education, employment, relationship to the stroke survivor, and years of caregiving, emerged as significant predictors. This may reflect the relative homogeneity of the sample or suggest that some demographic features play a lesser role than assumed in determining exposure to social need among ICPs of stroke survivors.

The overall HRSN burden in this sample was high, with a mean total HRSN of 6.47 out of 12. This underscores the importance of screening and intervening on HRSNs across the stroke survivor-ICP dyad. Interventions targeting ICPs overlook fundamental material and structural needs such as housing instability, food insecurity, or lack of transportation. This is especially important as these results show that ICPs of stroke survivors face significantly more individual HRSN burden when compared with the general population. For example, over 50% of ICPs of stroke survivors reported experiencing food insecurity. Yet, recent national data reports that 13.5% of US households experienced some degree of food insecurity (United States Department of Agriculture, 2025). Given the associations found in this study, future care models may

benefit from embedding ICP-focused social needs screening into stroke discharge and rehabilitation workflows, ideally with structured referral pathways and culturally tailored navigation services.

These findings carry both clinical and policy implications. Clinically, the identification of high-burden subgroups, namely younger ICPs, married ICPs, and those partnered with REM stroke survivors, can inform targeted outreach and resource allocation. At the policy level, these results support expanding HRSN assessments beyond patients and toward the care partners whose health and capacity are tightly linked to stroke outcomes. Moreover, consistent with recent calls from national organizations (Administration for Community Living, 2022), these findings argue for greater investment in infrastructure that recognizes and supports the growing unpaid caregiving workforce.

Several limitations should be acknowledged. The sample was recruited primarily via online and support group settings and did not reach sufficient power, limiting generalizability. The use of self-report measures introduces potential social desirability bias, and the cross-sectional nature of the data prevents causal inference. Additionally, the dichotomization of variables, while necessary for statistical power and interpretability, may obscure more nuanced relationships. Future studies with larger, more diverse samples and longitudinal follow-up can build on this work by exploring how demographic factors interact with care intensity, stroke severity, and dyadic functioning to influence social needs over time.

Despite these limitations, the current study contributes to a small but growing literature on the social context of informal care partnerships in stroke. By identifying

demographic predictors of elevated HRSN burden, it underscores the need for more holistic, equity-oriented care models that center both the survivor and the ICP. In doing so, this work lays the foundation for future interventions that are not only clinically effective but socially responsive.

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CHAPTER FIVE

Overview of Major Research Findings

Overview

This study addressed four research questions that together examined the prevalence, predictors, and impact of HRSNs on CB among ICPs of stroke survivors. Across analyses, findings consistently demonstrated that HRSNs were not only highly prevalent in this population but were also strongly associated with CB and had extensive demographic disparity.

Research Question 1

Research question 1 asked: Is there a relationship between 12 domains of HRSNs and CB among ICPs of stroke survivors? This first research question addressed one of the two primary aims of the study, with the null hypothesis that there is no statistically significant relationship between any domain of HRSNs and CB among ICPs of stroke survivors. The results rejected the null hypothesis via a stepwise multiple regression analysis, which found that three HRSN domains significantly predicted total CB, being transportation needs, family and community support, and education. With these three variables included in the model, they explained 37.4% of the variance.

Relationships between domains of HRSNs and individual domains of CB were also noted, with support being a significant predictor of time-dependence burden; education and utilities being significant predictors of emotional burden; transportation, safety, and education being significant predictors of social burden; disability, mental health, and transportation being significant predictors of physical burden; and support, employment, and mental health being significant predictors of developmental burden.

Beyond the stepwise regression models, group differences assessed mean CBI scores by the presence or absence of each HRSN to further explore the relationship between individual domains of HRSNs and CB. This comparison found that CBI total scores were significantly higher for each HRSN domain except physical activity. Furthermore, effect sizes for each comparison were found to be medium to large for all domains except physical activity, which was small. Together, these results demonstrate significant relationships between domains of HRSNs and the multifaceted concept of CB. Finally, a separate group comparison was run to evaluate whether REMs experienced more total CB than non-REMs. The results of the analysis did find that REMs experienced significantly more total CB than non-REM ICPs of stroke survivors.

Research Question 2

Research question 2 asked: What are the most prevalent HRSNs among ICPs of stroke survivors? This second research question covered the second of the two primary aims of this study and served the purpose of identifying the most encountered HRSNs among ICPs of stroke survivors. ICPs reported an average of 6.47 out of 12 HRSN, indicating a potential for severe HRSN burden. The most prevalent domains of HRSNs among ICPs of stroke survivors were mental health (86.4%), physical activity (82.7%), and family and community support needs (80.2%). The five CMS-designated core HRSN domains demonstrated the following prevalence among all ICPs of stroke survivors: Housing instability (42%), utility help needs (30.9%), food insecurity (51.6%), interpersonal safety (69.1%), and transportation problems (34.6%). Six out of twelve HRSN domains (family and community support, physical activity, mental health, food insecurity, interpersonal safety, and financial strain) were present in more than half of

ICPs of stroke survivors, demonstrating a significant presence of HRSNs among ICPs of stroke survivors.

Research Question 3

Research question 3 asked: Is there a relationship between demographic variables and total HRSNs among ICPs of stroke survivors? This third research question was a secondary/exploratory aim and sought to go beyond evaluations of relationships to assess whether there were differences in binary coded demographic variables and total HRSN scores among ICPs of stroke survivors. The stepwise multiple regression analysis found that 61.1% of the variance in total HRSNs is explained by the race of the stroke survivor, age, and marital status, rejecting the null hypothesis. Other demographic variables with significant group differences included: age, with younger ICPs experiencing more needs; employment status, with employed ICPs experiencing more needs; stroke survivor race, with REM stroke survivors experiencing more needs; utilization of skilled nursing , with those receiving skilled nursing experiencing more needs; and availability of the necessary equipment to manage care, with ICPs lacking equipment experiencing more needs.

Research Question 4

Research question 4 asked: Are there significant differences in the prevalence of HRSN domains between REMs and non-REMs? This final research question aimed to uncover disparities between REMs and non-REMs relating to the prevalence of domains of HRSNs. Group comparisons found that REMs reported significantly more HRSNs than non-REMs, with a very large effect size, therefore rejecting the null hypothesis. REM ICPs of stroke survivors were significantly more likely to report nine out of twelve

HRSN domains, including living situation, food insecurity, transportation, utility help needs, interpersonal safety, financial strain, education, disability, and employment. Even among the three remaining domains that did not reach statistical significance (mental health, physical activity, and family/community support), REMs reported more needs.

Significance of Findings

Overview

The findings of this study offer important implications for research, policy, and clinical practice. By situating CB within the context of HRSN, this study advances understanding of the multidimensional challenges faced by ICPs of stroke survivors. The results highlight novel demographic patterns, reveal domain-specific insights into burden, and identify various disparities across demographic groups. Taken together, these contributions provide a foundation that can inform future scholarship, policy initiatives, and clinical strategies to address structural issues influencing the health of the ICP-stroke survivor dyad.

Research Significance

The results of this study address important gaps in research that were identified during the literature review process. Firstly, contextual variables that were previously either underreported or not uncovered at all are presented. As discussed, much of the current literature relating to stroke care partnership has not sufficiently detailed descriptive data of ICPs such as their race, relationship to the stroke survivor, age, income, education level, and more. By providing this information, this study provides a more thorough understanding of ICPs of stroke survivors. This information is critical as research moves forward with further uncovering information regarding ICPs of stroke

survivors and more importantly as interventions to improve positive ICP outcomes are developed. Descriptive information in this study is occasionally aligned with previous research. For example, the majority of ICPs in this study were female, which is aligned with previous findings (Chuluunbaatar et al., 2017; Mehdipanah et al., 2024; Menon et al., 2017; Oni et al., 2019; Pucciarelli et al., 2017). Furthermore, while previous research had been split on whether sex impacts CB (Achilike et al., 2020; Kavga et al., 2021; Kruithof et al., 2016), this study found no statistically significant impact between males and females.

Building on these descriptive findings, this study also examined relational dynamics within stroke care partnerships. Previous research found that up to 75% of ICPs are the stroke survivors significant other (Zhang et al., 2023). In this study, however, that number was closer to 50%. Presenting descriptive data on the relationship of ICPs to stroke survivors is important because it situates the sample within the broader stroke care partnership literature, highlighting which relational roles predominate in stroke care partnerships, and provides essential context for interpreting burden and HRSN findings. Even in the absence of significant group differences, these variables inform how role expectations may shape care experiences and allows for comparison with national care partner trends. Finally, most of the demographic data presented are entirely unrepresented in current stroke care partnership research. Education level, cohabitation with the stroke survivor, and other variables are novel themselves, yet some findings are more pressing. This study found that an alarming number of ICPs make less than $40,000, do not have access to the equipment necessary to care for the stroke survivor, and provided more than 20 hours of care per week. Time demands are consistently identified as one of the most

influential predictors of CB (Oni et al., 2019), and when combined with financial strain and limited resources, the cumulative effect places ICPs at heightened risk of CB. This study demonstrated that time-dependence burden is the most prevalent domain of CB among ICPs of stroke survivors, which combined with the overall low income level of participants underscores the multidimensional vulnerabilities of stroke ICPs that have previously been linked to poor outcomes (Pucciarelli et al., 2017; Skolarus et al., 2017, 2025).

Furthermore, no study to this point has provided information regarding both total and domain specific CB among ICPs of stroke survivors. The descriptive information alone provides data that has never been reported before in this population, allowing for a more in-depth understanding of the experience of ICPs of stroke survivors. The mean total score on the CBI was 36.99, indicating an average of moderate burden (Manzari et al., 2023). Yet there was a standard deviation of greater than 21, indicating significant heterogeneity in the experience of burden. This wide range of CBI scores also illustrates the importance of developing an in-depth understanding of the experience of ICPs, as each ICP experiences burden in a different way and to a different extent, highlighting the importance of interventions not being one-size-fits-all (Elsheikh et al., 2022). This finding is consistent with previous results showing that an overwhelming majority of ICPs of stroke survivors experience some degree of CB (Achilike et al., 2020). Completely novel is the presentation of descriptives related to individual domains of the CBI. Providing descriptive statistics for each CBI domain, beyond the total score, is valuable because it allows a more nuanced understanding of the care partnership experience. Rather than collapsing burden into a single composite score, the domain-level

descriptives illustrate whether ICPs are more affected by domain specific burdens. This information not only situates the present sample in relation to existing CB research but also offers practical guidance for designing targeted supports, as interventions to reduce burden may need to focus on the domains most elevated in a given population.

Analyzing the impact of HRSN on CB is another novel aspect of this study that addresses major gaps in current literature. A model that explained more than 37% of variance in ICP total CB provided insights into which HRSNs have significant impacts on CB, granting insight into barriers faced by ICPs. By establishing transportation, support, and education as significant predictors of CB among ICPs of stroke survivors, a significant gap in research is addressed, providing foundational information for future work to address these impactful variables. Variables such as transportation (Garnett et al., 2022) and support (Clay et al., 2013) had already been described as potential barriers for ICPs of stroke survivors, which are now further contextualized in this study as a significant part of the care partnership experience. Most other HRSNs and their impact on CB, however, remain novel in their presentation. Analysis of individual CB domains provide insight into individual aspects of CB rather than the umbrella of total CB and may help identify interventions that impact multiple dimensions and overall CB.

The presentation of the prevalence of HRSN addresses major gaps in current literature, with current research significantly neglecting to report on these variables among ICPs of stroke survivors (Young et al., 2020). ICPs endorsed, on average, 6.47 out of 12 HRSNs, which suggests substantial needs among ICPs of stroke survivors. By presenting the prevalence of HRSNs, both total and by domain, this study addresses a substantial research gap that highlights the extent of needs faced by this population.

Documentation of these prevalences establish a baseline that can be used for comparison in future studies, both with future stroke care partnership studies. With this gap in research addressed, future research can track changes over time, compare across cultural/geographic/care partnership groups, or evaluate interventions against a benchmark that previously did not exist. The domain specific descriptives of HRSNs, similar to with the domains of CB, may allow researchers to differentiate between several types of HRSN-barriers, such as structural, interpersonal, and resource barriers. Most importantly, however, this data provides descriptive information that contextualizes the CB experiences by ICPs of stroke survivors.

Beyond the prevalence of HRSNs, this study also detailed predictors of HRSNs. The stepwise multiple regression found that the race of the stroke survivor, age, and marital status explained 61.1% of the variance in total HRSNs. The identification of these three variables as significant gives researchers a target both for future exploration and intervention. Furthermore, the absence of other variables in the final stepwise model may indicate homogeneity of HRSNs across demographic groupings, potentially allowing for more generalizable interventions.

Disparities in HRSN were assessed via two group difference analyses. Firstly, REM differences in HRSN domain prevalence demonstrated widespread disparities in HRSN between REMs and non-REMs. Even when REMs did not experience significant differences in specific HRSN domains, the direction of effects remained consistent, with REM experiencing more HRSNs. Binary condensed demographics were compared with total HRSNs. These analyses further emphasized disparities present among REMs, younger ICPs, the unemployed, and more.

Another important research take-away from this dissertation was the PI's direct experience with the recruitment of REMs. Despite attempting to implement strategies documented in prior work with REM ICPs, such as leveraging community partnerships (Burns et al., 2022), utilizing social media outreach, and engaging with religious institutions (Ratnapradipa et al., 2024), these approaches produced minimal success. Recruitment challenges were compounded by the demographics of accessible networks: the overwhelming majority of attendees at stroke support groups were White, as were most individuals encountered in senior centers, community organizations, and recreation facilities. This discrepancy reflects broader structural realities, such as many commonly recommended recruitment sites are not equitably attended by REM populations, limiting their utility when applied without substantial cultural tailoring. Even as systematic reviews and frameworks continue to outline strategies for equitable inclusion (Nouvini et al., 2022), the PI's experience illustrates how theoretical guidance often fails to translate into meaningful access points for underrepresented populations. Importantly, the difficulty encountered underscores that recruitment barriers are not simply logistical but tied to longstanding inequities in healthcare access, trust, and representation.

Outside of REM recruitment limitations, online recruitment of participants presented difficulties. The primary issue faced was the prevalence of fraudulent responses, which resulted in several "restarts" of recruitment. Initially, participants were able to freely access the survey via a link or QR code without screening, which resulted in several thousand responses within minutes. Following this, all participants had to be screened over the phone if recruited from an online source, which continued to yield fraudulent response attempts, although these were able to be screened out. Documenting

these limitations adds significance to the present study by highlighting the persistent gap between recommended practices and the realities faced in applied research settings, particularly for novice investigators without established community networks or institutional infrastructure.

Policy Significance

The findings of this study also have significant policy implications. The most significant opportunity for policy initiatives is tied to the findings regarding HRSNs. In this study, for example, over 50% of ICPs reported experiencing food insecurity. Yet, recent national data reports that 13.5% of US households experienced some degree of food insecurity (United States Department of Agriculture, 2025). Furthermore, 34.6% of participants reported transportation needs, compared with only 5.7% of US adults (Ng et al., 2024). This overwhelming disparity highlights that caregiving for the stroke survivor puts ICPs in a far more vulnerable position when compared with the general public. Future policy should consider the stark disparities present when developing ICP-focused programs, initiatives, and surveys.

National programs, such as the National Strategy to Support Family Caregivers (Administration for Community Living, 2022), lay essential foundations for the advancement of federal policy that recognizes and aims to support care partners. This study provides information that can assist policy developments across multiple subpoints of this national strategy, especially outcome 3.4, which focuses on five core components of SDOH. This study provides essential information that can inform policies aimed at impacting this outcome, as these points previously have had no foundational data for ICPs of stroke survivors. Opportunities also exist at the local, state, and federal level for

expansion of grant funding to address the most impactful identified HRSNs for families impacted by stroke, as well as to incorporate ICP HRSN measures into health surveys.

Clinical Significance

Clinically, the results of these studies have several significant implications. Firstly, both the review of literature as well as the education data from the AHC-HRSN indicate a need for further refinement of educational material provided to ICPs of stroke survivors. Current guides, such as the Caregiver's Handbook (National Institute on Aging, 2023) and the Guiding an improved dementia experience (GUIDE) (CMS, n.d.), do not reference HRSNs in any meaningful capacity. This presents an opportunity for healthcare institutions to incorporate HRSNs into these educational materials and to ensure they are understood by both members of the stroke survivor-ICP dyad. This is especially important for ICPs of stroke survivors, as previous literature indicated that discharge from the acute care setting was a point of major stress, contributing to a negative experience before the stroke survivor even left the hospital (Robinson et al., 2022; Wabula & Suharyono, 2021). Healthcare systems can also embed routine HRSN for all ICPs of stroke survivors, with potential interdisciplinary collaboration to provide immediate referral pathways. This study provided information that identifies the most impactful HRSNs on the stroke care partnership experience, allowing for targeted interventions on the most relevant needs.

Theoretical Significance

RAM (Roy & Andrews, 2009) provided an essential foundation for this study that framed not only the methodology but also the interpretation of the results. The results of the study further informed each of the adaptive modes that were used in the theoretical

substruction of RAM for this study and offer significant implications related to how RAM can be applied to future studies related to HRSNs and more general research regarding ICPs of stroke survivors.

The physiological mode is well informed by the results of the physical dimension of the CBI. As with all CB domains (and total CB), in this study the amount of physical burden reported varied widely. Yet, physical burden was widely reported and had nearly 40% of its variance explained by three HRSNs. The importance of the physiological mode is not just demonstrated by the results of this study but also by previous research, which found ICPs more likely to face exhaustion (Kazemi et al., 2021), back pain (Abba et al., 2022), chronic illness (Racine et al., 2022), and more. This study demonstrates that the physiological demands of stroke care partnerships are not just a result of the survivor's functional status but are also shaped by the ICP's HRSNs, particularly access to transportation, mental health, and disability services. Transportation may increase fatigue via added travel demands and logistical strain, as well as potentially the physical discomfort of moving a stroke survivor into a vehicle. Disabilities (which were flagged whether the participant marked a physical or mental disability) reflect underlying vulnerability in the ICP's own health, which could be caused by or amplified by the physical burden that the results demonstrate are present when caregiving for the stroke survivor. Mental health concerns may also deplete energy reserves and intensify the physical manifestations of stress, highlighting the interdependence between psychological and physiological adaptation. Beyond CB, HRSN results can also be directly linked to the physiological mode of RAM, with food insecurity, housing instability, and physical activity directly aligning with this mode.The reporting on the

prevalence, predictors, and impact of these HRSNs can significantly impact future work using RAM on this population and others.

The self-concept mode is particularly addressed via the emotional burden subscale as well as several items in both the developmental and time-dependence subscales of the CBI, which address one's personal life. The emotional CB domain was significantly predicted by education and utility help needs. The impact of education on emotional CB may be linked to fewer resources for problem solving and limited health literacy (Reshetnyak et al., 2020), especially when taking into consideration the impact of language (which is an item on the education domain of the AHC-HRSN) and the lack of understanding reported by ICPs at discharge (Robinson et al., 2022). Utility help needs, on the other hand, are a bit more difficult to directly understand regarding the self-concept mode of RAM, but they may demonstrate how fundamental living conditions affect an ICP's sense of self-efficacy. Utility help needs may not only pose practical challenges but may also reinforce feelings of insecurity strong enough to impact an ICP's self-concept. HRSN results also suggest that high prevalences of mental health and financial strain are significantly impact the self-concept mode.

The role-function mode is largely impacted by the results of the time-dependence and developmental burden domains of the CBI. With time-dependence being the most highly scored domain of the CBI, it is reasonable to say that role-function may have been the most widely impacted adaptive mode of RAM among ICPs of stroke survivors in this study. Time-dependence was largely predicted by family and community support. This finding reinforces the idea that role-function adaptation is not simply an individual responsibility but is heavily shaped by the ICP's social environment. When ICPs lack

support, the care partnership role may become more isolating, potentially leading to heightened strain and the impaired ability to balance multiple roles. This source of strain could grant a clue to why many ICPs in this study did not work full time (in their employee role) despite having a younger than average sample, tying into the HRSNs of employment and financial strain.

The interdependence mode directly correlates with the social CB domain of the CBI. The social CB domain was significantly predicted by transportation, interpersonal safety and education. Transportation needs highlight the inability of the ICP to use transportation to connect socially, limiting their ability to not only engage with friends and loved ones, but also with stroke support groups and other resources. Interpersonal safety could indicate impaired social life either because of the assumption of the role of care partner or compounded by the stressors of care partnership. Some ICPs of stroke survivors, for example, report being talked down to by family, which may include the stroke survivor themselves, which could significantly impact social CB. Education may also shape social burden, as ICPs with lower educational attainment may have less access to supportive networks, fewer flexible work opportunities, or fewer resources to navigate the demands of care partnership, intensifying isolation.

These findings highlight the value of RAM as a theoretical foundation for understanding the experience of ICPs of stroke survivors, while also extending the model's relevance into HRSNs. By mapping HRSNs and CB across the four adaptive modes, this study demonstrates that adaptation is not only a function of the ICPs internal resources but also of the diverse environments in which care partnership occurs. The regression models showing various domains of HRSNs as significant predictors of total

and domain specific CB affirm RAM's central premise that stimuli are as critical to adaptation as individual capacities. In demonstrating these links empirically, this study strengthens the case for RAM as a framework that can accommodate the realities of HRSNs and positions it as a foundation for future interventions that address both CB and HRSNs that shape adaptation.

Strengths and Limitations

This study had several notable limitations. Firstly, the study did not achieve the desired sample size, which carries important methodological consequences. A smaller sample decreases statistical power, limiting the ability to detect true effects and increasing the risk of Type II error. Secondly, despite intentional efforts to obtain a diverse sample, including outreach at markets, cultural events, and religious institutions, recruitment yielded too few participants outside of BAA and White groups to meaningfully generalize results to all REMs. This lack of representation is particularly problematic given that the study sought to explore health equity issues, where the experiences of smaller or less studied groups (such as Asian American, Hispanic/Latino, and Native American ICPs) may diverge substantially. The inability to capture these perspectives perpetuates gaps in understanding and underscores structural challenges in engaging REM populations in research and is likely in part due to the survey only being available in English. Additionally, the AHC-HRSN tool presented psychometric limitations. Its limited validation raises concerns about the reliability and construct validity of measured domains, which may affect confidence in the findings. The need to dichotomize HRSN items to ensure consistency across the scale further narrowed interpretability. While dichotomization simplified analyses and reduced measurement

error, it inevitably compressed nuance, limiting distinctions between degrees of need. This simplification may mask important gradations in how unmet needs relate to CB, leading to an underestimation of complexity in the lived experiences of ICPs. Taken together, these limitations highlight issues of statistical power, external validity, and measurement validity. While the study contributes novel insights, these constraints should be considered carefully when interpreting the findings and underscore the need for future research with larger, more diverse samples and more psychometrically robust instruments.

Despite these limitations, this study has several notable strengths. It is one of the first to examine HRSNs and CB simultaneously among ICPs of stroke survivors, using a large enough dataset to explore both prevalence patterns and predictive relationships. The inclusion of novel demographic predictors, such as access to adaptive equipment, employment status, and relationship to the stroke survivor, allowed for a more nuanced understanding of the ways in which structural and contextual factors shape care partner outcomes. Likewise, the application of the CBI to this population provides one of the most comprehensive examinations of multidimensional burden among stroke ICPs in the literature, extending knowledge beyond total burden to highlight specific domains such as time-dependence, physical, and developmental burden. This is paired with the provision of detailed prevalence estimates of total and individual HRSN domains, data that have been almost entirely absent from the stroke caregiving literature, offering a critical baseline for both future research and targeted intervention. Importantly, the study's findings also serve to empirically validate RAM, which has been widely applied in nursing but rarely evaluated with this particular intersection of care partner burden and

social need. The observation that HRSNs predicted burden outcomes affirms RAM's central proposition that adaptation is shaped not only by the individual's internal capacity but also by the contextual stressors and supports within their environment. Taken together, these strengths position the study as both novel and meaningful in research, clinical, and policy settings, while also advancing theoretical understanding in nursing science.

Future Research Implications

The results of this study lay the foundation for several potential future research opportunities. Firstly, the identification of HRSNs that predict meaningful variance of both total and domain specific CB among ICPs of stroke survivors establishes clear targets for interventional research that can begin to directly address the needs of ICPs. Intervention trials may examine whether targeted resources such as transportation support, financial navigation, or social service linkages reduce CB over time. Opportunities may also exist to assess the extent of overlap between HRSNs that increase stroke risk factors and the newly identified HRSNs that impact CB, exponentially improving outcomes. Secondly, more advanced quantitative techniques such as structural equation modeling and factor analysis should be employed to map the strength and direction of relationships between identified predictors and CB outcomes. This will contribute to building a more complete theoretical model of CB among ICPs of stroke survivors, allowing future work to assess causal pathways and mediating or moderating effects.

Another important direction is the development and validation of a psychometrically rigorous instrument for assessing HRSNs in ICPs. While the AHC-

HRSN provided an exploratory platform for this study, the absence of reliability and validity evidence highlights the need for a measurement tool that is specifically designed for and validated with ICP populations. Such a tool would allow for more precise measurement of HRSNs, facilitate comparisons across studies, and enable robust evaluations of interventions.

Future research should also place a greater emphasis on recruitment of diverse populations. The lack of racial and ethnic diversity in this study limits the ability to generalize findings beyond BAA and White ICPs. Future studies must prioritize engagement with communities that are often underrepresented in research by leveraging community based participatory methods, long term partnerships with cultural organizations, and recruitment strategies tailored to different linguistic and cultural groups. Beyond race and ethnicity, further exploration of other demographic factors such as age, gender, income, education, and survivor characteristics will be essential to ensure that interventions and policy recommendations do not adopt a one size fits all approach. Guides and resources for experienced and novice researchers alike should also become more prominent if nursing science is to be successful in its push to include REMs in research.

The application of the RAM in this study also suggests opportunities for theoretical expansion. Future research can continue to assess and refine the conceptual theoretical empirical model that links HRSNs as focal and contextual stimuli to adaptive responses across the four adaptive modes. Longitudinal studies are particularly needed to observe how HRSNs influence CB over time and whether ICPs can adapt or experience

cumulative burden when needs remain unmet. Such studies would allow the RAM framework to be applied dynamically, strengthening both theory and practice.

Finally, this work opens the door to translational and implementation focused research. Testing the integration of HRSN screening into stroke care pathways, evaluating the role of nurses and interdisciplinary providers in addressing identified needs, and examining policy level interventions such as insurance or social program reforms will be critical next steps. Together, these directions represent a comprehensive research agenda aimed at advancing science, informing policy and practice, and ultimately improving the well-being of ICPs of stroke survivors.

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APPENDIX A

Recruitment Flyer

Note. This figure is a flyer to be distributed via email and social media for recruitment.

APPENDIX B

Survey Instructions

Thank you for your participation in this research study. You will find three questionnaires following these instructions. The three questionnaires are (1) a demographic questionnaire that provides basic information about yourself; (2) a Health-Related Social Needs assessment, which provides information about how your life-circumstances may influence your experiences; and (3) a Caregiver Burden Inventory, which will provide information about your experience as a caregiver.

(1) Demographic Questionnaire: Please choose the answer that BEST represents you. Please answer each question and contact the primary investigator with any questions you may have.

(2) Health-Related Social Needs: Please choose the answer that BEST represents you. Please answer each question and contact the primary investigator with any questions you may have.

(3) Caregiver Burden Inventory: Each question is graded on a 0-4 scale. A score of 0 indicates that the question does not describe your experiences, while a score of 4 indicates that the question very much describes your experiences. Please answer each question and contact the primary investigator with any questions you may have.

With any questions, please contact Charles Shamoun

cshamoun@oakland.edu

(586) 464-7457

APPENDIX C

IRB Approval Letter

IRB-FY2025-15 - Modification: Exempt Decision - Modification
1 message

do-not-reply@cayuse.com <do-not-reply@cayuse.com> Tue, May 6, 2025 at 12:46 PM
To: cshamoun@oakland.edu, pittigli@oakland.edu

OAKLAND UNIVERSITY

Institutional Review Board

Date: May 6, 2025

Study #: IRB-FY2025-15

Study Tile: Impact of Health-Related Social Needs on Caregiver Burden Among Informal Care Partners of Stroke Survivors."

Submission Type: Modification

IRB Decision: Exempt

Research Team:
Charles Shamoun
Laura Pittiglio

The IRB has reviewed the Modification submission related to the above referenced study and determined that the changes listed below do not affect the exemption status of the study. The Modification submission is Approved and the study remains Exempt per federal regulations.

The approved modifications are the following:

1. Revise the inclusion criteria to include any unpaid care-partner of a stroke survivor, and not only those who are of racial or ethnic minority as was approved initially.

2. Revise the research flyers to remove reference to the inclusion criteria that participants must be of a racial or ethnic minority.

3. Revise the study information sheet to remove reference to the inclusion criteria that participants must be of a racial or ethnic minority.

4. Revise the study title to remove reference to rational or ethnic minority participants and to state the following: "Impact of Health-Related Social Needs on Caregiver Burden Among Informal Care Partners of Stroke Survivors."

5. Revise the survey to remove racial and ethnic minority screening question and added "White" as an option on the demographic questionnaire.

This submission includes the following approved documents:

- Revised Research Flyers
- Revised Information Sheet V 5/6/2025
- Revised survey

The IRB approved (date-stamped) consent document(s) has been published under Attachments in the Submission Details page. Please make sure to use the most recent IRB approved version of the consent form in consenting participants.

You are approved to implement the aforementioned modifications. Please retain a copy of this notification for your records.

This letter can also be found in Cayuse under the Letters tab in the Submission Details page.

If you have any questions, please contact the IRB office.

Thank you.

The Oakland University IRB

APPENDIX D

Chapter 2 Supplemental Digital Content

Table D.1
Key Aspects of Extracted Data

Author (year)	Purpose	Sample	Design	Instruments	Analyses	Significant Findings
Kruithof, W. J., Post, M. W., Van Mierlo, M. L., Van Den Bos, G. A., Man-van Ginkel, J. M., & Visser-Meily, J. M. (2016).	To determine and predict caregiver burden and associated factors at two months and one-year post stroke.	183 ischemic/hemorrhagic stroke patients admitted to general hospitals in the Netherlands and their partners.	Prospective Cohort Study: Measured at the two-month and one-year post stroke time period.	-Demographic Questionnaire (DQ) -Caregiver Strain Index (CSI) -Hospital Anxiety and Depression Scale (HADS) -General Self-Efficacy Scale -Utrecht Proactive Coping Competence Scale -Social Support List-Interaction -National Institute of Health Stroke Scale (NIHSS) -Barthel Index (BI) -Montreal Cognitive Assessment	*t-tests* for differences between 2- and 12-month indices Pearson correlations for relationships between characteristics and outcome measures Multiple linear regression to demonstrate determinants of outcome measures	Factors associated with burden at the two-month period were largely consistent with factors measured at the one-year period. Factors that influenced burden included the patient's stroke severity and depression and the caregiver's age; relationship satisfaction; coping; support; anxiety; depression; and self-efficacy.
Chuluunbaatar, E., Pu, C., & Chou, Y. (2017).	(1) To identify changes in caregiver burden over the	103 caregiver-survivor dyads from nine different public, tertiary and	Prospective Observational Study: Measured at	- DQ - Montgomery Caregiver Burden Scale	Descriptive analyses *t-tests* for	Factors associated with changes in caregiver burden were the dyads martial status, the strength of the

	course of one year among caregivers of stroke patients; (2) to identify factors associated with caregiver burden.	secondary hospitals in Mongolia.	two intervals. First interview conducted so long as caregiver had been caring for patient for longer than one day; second interview one year following the first interview.	- BI - Glasgow Coma Scale (GCS) - Modified Rankin Scale (mRS)	means of scales between baseline and follow-up Logistic regression to examine explanatory variables	dyad's relationship, financial difficulties, the patient's physical disability, and the patient's sex. The 'demand' domain of burden was found to increase over time while the stress domain decreased, but not significantly over the course of a year.
Han, Y., Liu, Y., Zhang, X., Tam, W., Mao, J., & Lopez, V. (2017).	(1) To describe the experience of caregiving for stroke survivors; (2) to identify the determinants of caregiver burden over 6 months.	164 caregiver-survivor dyads recruited from three hospitals in China.	Prospective Longitudinal Study: Measured over 6-months with time one (T1) being 1-2 days before discharge; T2 3 weeks after discharge; T3 3 months after discharge; T4 6 months after discharge.	-DQ -BI -CSI -Center for Epidemiological Studies-Depression -Short Portable Mental Status Questionnaire -Multidimensional Scale of perceived Social Support	Descriptive Pearson and Spearman correlations to assess relationships between CGB and determinant variables	Determinants of caregiver burden were stroke survivors' physical dependence, caregivers' age, caring hours per day, depressive symptoms, and social support. Caregiver burden remained prominent throughout each of the four time periods measured during the six-month study.
Menon, B., Salini, P., Habeeba, K., Conjeevaram, J., & Munisusmitha, K. (2017).	(1) To examine caregiver burden in the context of physical and mental health, social support, and financial and personal problems; (2) To analyze the variables of stroke survivors that are affecting caregiver burden.	201 caregiver-survivor dyads were included a neurology outpatient clinic in India. Only survivors of ischemic stroke over one year were included.	Longitudinal Cohort Study: Unknown intervals, stated measured over three months.	-DQ -BI -Custom Caregiver Burden Questionnaire	Descriptive Chi-Square	A majority of caregivers experienced moderate-to-severe burden. Managing incontinence, medication administration, physiotherapy, and shoulder pain were the primary concerns of caregivers. A majority of caregivers faced general physical health issues and fatigue. Caregivers of patients with a lower Barthel index score suffered less burden than those caring for more disabled stroke survivors. Females suffered worse burden than their male counterparts.
Pucciarelli, G., Vellone, E., Savini, S., Simeone, S., Ausili, D., Alvaro, R., Lee, C. S. (2017).	(1) to examine changes in stroke survivor and caregiver quality of life (QOL); (2) To determine if changes in survivor physical functioning and	226 caregiver-survivor dyads post discharge from inpatient rehabilitation across Italy.	Longitudinal Prospective: Measured at the 3, 6, 9, 12 months post-stroke.	-DQ -BI -World Health Organization Quality of Life-BREF(WHOQoL-BREF) - HADS	Descriptive Three longitudinal models were tested with hierarchical linear modeling	Caregiver QOL did not significantly change over time. Over 12 months, survivor physical and psychological QOL improved while their social and environmental did not. Improvements in survivor physical functioning were associated with increases in caregiver and survivor

	caregiver burden influenced changes in QOL.					physical and psychological QOL.
Zhu, W., & Jiang, R. (2018).	To assess caregiver burden and its associated factors among patients with hemorrhagic stroke over six months.	202 hemorrhagic stroke survivor-caregiver dyads in China.	Prospective Longitudinal: Measured at three times over 6-months. T1 1-2 days before discharge, T2 3 months after discharge, T3 6 months after discharge.	-DQ -Bakas Caregiving Outcome Scale -Visual Analog Tool for self-rated burden -BI -Scandinavian Stroke Scale -Hamilton Rating Scale for Anxiety -Hamilton Rating Scale for Depression	Descriptive Spearman correlation, Mann-Whitney, and Krusal-Wallis	Caregiver burden was found to decrease over time. The physical function and depression of stroke survivors and self-rated burden of caregivers were the most significant determinants of overall caregiver burden.
Oni, O. D., Olagunju, A. T., Okpataku, C. I., Erinfolami, A. R., Adeyemi, J. D. (2019).	To assess caregiver burden, quality of life, psychiatric morbidity, and predictors of burden.	150 caregiver-survivor dyads at two University Hospitals in Nigeria.	Cross-Sectional	-Demographic/ clinical questionnaire -Zarit Burden Interview (ZBI) -WHOQoL-BREF -Mini-international Neuropsychiatric Interview -mRS.	Descriptive Chi Square, Fischer, *t-test* and ANOVA Correlation and Regression	Caregiver burden was significantly correlated with stroke survivor incontinence, presence of psychological distress, and severe post-stroke disability. There was a statistically significant negative correlation between burden scores and all quality-of-life domains. Females were found to have significantly more burden than males.