

# What We Learned Together: Insights From Stroke Caregivers

CHARLES J. SHAMOUN, RN  
CHARLIESHAMOUN6@GMAIL.COM

Original Research Study

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

Charles J. Shamoun\*

### ABSTRACT

**BACKGROUND:** Stroke survivors often rely on informal care partners (ICPs), who commonly experience caregiver burden (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 United States 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 associated with significantly higher CB scores. Stepwise regression identified 5 significant predictors of total CB: transportation needs, family and community support needs, and education [adjusted  $F = 0.374, P < 0.001$ ]. 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 ( $\alpha = 0.822$  to  $0.952$ ).

**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.<sup>1</sup> Many survivors depend on informal care partners (ICPs), such as unpaid family members or friends, for essential support. ICPs frequently experience caregiver burden (CB).<sup>2</sup> CB is defined as “the level of multifaceted strain perceived by the caregiver from caring for a family

yielded limited success.<sup>3</sup> A limitation in existing research is the tendency to overlook the social and structural factors that likely shape the care partnership experience.<sup>4</sup> 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.<sup>5</sup> Health-related social needs (HRSNs), defined as the conditions in which indivi-

# Overview of Talk

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What did we study?

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What did we find?

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Why does it matter?

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What comes next (I need YOUR help!)

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- Charles Joseph Shamoun, Ph.D., RN, SCRNC, CNRN
  - Presented last year on managing post-stroke fatigue
  - Asked for participation in a research study

# What did we study?

Health-related social needs are individually experienced needs such as food insecurity, housing needs, education, and more, that can influence an individual's ability to achieve a state of health and well-being.

I wanted to explore how health-related social needs are experienced by caregivers.

- How many needs do caregivers experience?
- Do certain caregivers experience more needs than others?
- Are these needs unique to caregivers?

I also wanted to see how health-related social needs impact caregivers.

- Do they cause caregiver burden?
- How do they impact caregivers socially? Emotionally? Time?

# How Did we Study It?

- ↯ With you all!
  - ↯ I asked caregivers of stroke survivors to answer three questionnaires
    - ↯ One about who they are
    - ↯ One about the needs they experience
    - ↯ One about the level of burden they feel in different areas of their life
      - ↯ Socially
      - ↯ Emotionally
      - ↯ In their careers and roles
      - ↯ The time they spend caring
      - ↯ Physically
  - ↯ Then came the fun part, sitting at a computer and crunching numbers

# What did We Find?

- ↵ Prevalence of Health-Related Social Needs Among Caregivers
  - ↵ Most caregivers reported at least one need (the average was 4.5/12 needs!)
  - ↵ The most common needs were:
    - ↵ Mental Health (86%)
    - ↵ Physical Activity (83%)
    - ↵ Support Needs (80%)
  - ↵ Caregivers with lower income reported more needs
  - ↵ Race related differences suggested experiences after stroke are not equal
  - ↵ Women reported more burden than men both overall, emotional, and time related

# What Did We Find Part II

- ▶ Predictors of HRSNs Among Caregivers
  - ▶ Caregivers from racial and ethnic minority groups experienced more needs than non minority caregivers (7.8 vs 3.6)
  - ▶ Younger and married caregivers were more likely to experience more needs
  - ▶ Caregivers lacked necessary adaptive equipment, which was worse among racial and ethnic minority caregivers
- ▶ Together, being a racial/ethnic minority stroke survivor, being younger, and being married explained over 60% of differences in unmet needs.

# What Did We Find Part III

- ▶ Impact of HRSNs Among Caregivers
  - ▶ Almost every social need was linked with caregiver burden.
  - ▶ Caregivers reported greater burden when needs were present in areas such as: Transportation, family/community support, education and understanding care, food access, mental health, employment, disability
  - ▶ Three areas stood out most:
    - ▶ Transportation
    - ▶ Support
    - ▶ Education
    - ▶ These three together explained almost 40% of caregiver burden

# Why Does it Matter?

Our findings suggest opportunities to:

- Screen caregivers for social needs
- Improve discharge preparation
- Include caregivers in rehabilitation
- Connect families to resources earlier
- Build support systems before discharge

STROKE RECOVERY HAPPENS AT HOME.

CAREGIVERS ARE PART OF THE CARE TEAM.

# What Comes Next?

- ▶ How can we do a better job at addressing these needs among caregivers of stroke survivors.
- ▶ Overview of next planned study:
  - ▶ Involvement of caregivers EARLY in stroke admission pathway.
  - ▶ Require caregiver specific nursing education; caregiver involvement in inpatient PT/OT evaluations and work; health-related social need screening and referral by social work.
  - ▶ Evaluate how this impacts stroke survivor recovery and caregiver discharge preparedness
- ▶ Ask yourself, did you feel prepared as a stroke survivor or caregiver when leaving the hospital?
  - ▶ What do you wish was done differently?
  - ▶ This is your chance to inform the future of stroke and caregiving research!

# NeuroReach Network

- ▶ NeuroReach is a website (in development, not yet public) that will connect stroke survivors and their caregivers to support groups and advocacy networks.
- ▶ Neuroreach also connects these survivors and programs to researchers, so that we can make sure ALL neuroscience research is done alongside caregivers and survivors, not on caregivers and survivors.
- ▶ Please share my email with any stroke or neuroscience support/advocacy groups: [charlieshamoun6@gmail.com](mailto:charlieshamoun6@gmail.com)

Thank You



Please reach out with any questions, comments, or concerns to my personal email:



[charlieshamoun6@gmail.com](mailto:charlieshamoun6@gmail.com)