

# Caregiver Experiences of Managing Care for Older Adults with TBI

## A Call to Listen & Take Action

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# Agenda

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What are  
caregivers  
experiencing?

2

What do  
caregivers  
need?

3

How can we  
address their  
unmet needs?



The increasing number of older adults with TBI will place greater strain on healthcare, insurance, and family support systems, requiring more post-injury care and assistance.



Caregivers provide critical support post-injury, but their needs are often overlooked in clinical practice and in TBI research.



**Four** qualitative studies have explored caregivers' perspectives and experiences in caring for older adults with TBI.



# Transforming Research & Clinical Knowledge in Geriatric Traumatic Brain Injury (TRACK-GERI)

NIH Funded R01 NS 1011094; *PI: Dr. Raquel Gardner*

Research Diversity Supplement Awardee: *PI: Dr. Michele Nelson*



1. Study aims to advance knowledge on presentation, outcomes, outcome predictors, and blood-based biomarkers for older adults with TBI
2. The Diversity Supplement aims to understand caregivers' experiences of managing older adults with TBI care, navigating healthcare systems, and uncertainties regarding recovery post-injury.



# What are caregivers experiencing?

# Caregiver Themes from Qualitative Studies

Emotional  
Impact &  
Concerns

Caregiving  
Challenges

Support and  
Resources

Positive  
Adjustments

# TRACK-GERI Caregiver Interview Themes



**Need for Advocacy  
and Decision  
Making**

**Challenges with  
follow-care and  
coordination**



# What do caregivers need?



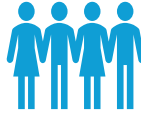
# Caregiver Solutions to Address Gaps in Follow-up care



Technology  
Support for  
Managing Online  
Tasks



Help to Make  
Phone Calls



Designated &  
Knowledgeable Person  
to Help Navigate  
Systems Across the  
Care Continuum



Access to  
Organized TBI  
Specific  
Resources



Caregiver  
Support Groups



# How we can address their unmet needs

# Research-Based Solutions

- Conduct more ***inclusive*** and ***representative*** research that includes older adults with TBI and their caregivers
  - ❖ Participatory Action Research
  - ❖ Quality of life for patients and caregivers' post-injury
- Design interventional studies
  - ❖ Enhance health outcomes and address unmet needs
  - ❖ Integrate innovative technology-based supports
  - ❖ Understand health care utilization and costs post-injury
- Adapt insights from Alzheimer's disease and Alzheimer's Disease Related Dementias (AD/ADRD) caregiver research to benefit older adults with TBI and their caregivers

# Implications for Policy & Practice

- **Advocate** for more inclusive care plans that actively involve TBI patients & their caregivers.
- **Prioritize Partnerships** between healthcare providers, policymakers, start-ups, and support organizations to close gaps in resources.
- **Focus on Prevention** by implementing early intervention strategies that prevent decline and reduce caregiver burden, and policies that ensure access to rehabilitative services, preventative care, and educational resources.

POLICY & VALUE-BASED CARE > ALTERNATIVE PAYMENT MODELS

## Startup Seeks to Bring Value-Based Care Approach to Dementia

Rippl Co-founder and CEO Kris Engskov discusses the company's funding, business model, and participation in CMMI's new GUIDE Model

David Rybins

Oct. 11, 2024



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Effect of Collaborative Dementia Care via Telephone and Internet  
on Quality of Life, Caregiver Well-being, and Health Care Use  
The Care Ecosystem Randomized Clinical Trial

# Call to Action: How Will We Listen and Respond?



**Researchers:** Do we study the unique needs of caregivers for older adults with TBI, or adapt existing models to evaluate interventions?



**Policymakers and funders:** Do we prioritize creating policies and funding streams for this population, or should we specifically adapt existing policies and allocate funds to better serve this population?



**Stakeholders (health institutions, startups, etc.):** Can we create partnerships to address caregiver challenges in TBI, or use models from other populations for scalable solutions?



**Clinicians:** How can you provide personalized care tailored to the needs of caregivers of older adults with TBI, based on those seen in your clinic or institution, and partner with local resources to enhance support?