

# How are families involved in the care of hospitalized older adults?: Protocol for a qualitative evidence synthesis

Judith B. Vick, Blair P. Golden, Sarah Cantrell, Melissa Harris-Gersten, Mollie R. Selmanoff, S. Nicole Hastings, Tolu O. Oyesanya, Karen M. Goldstein, Courtney Van Houtven

Submitted to: JMIR Research Protocols on: September 30, 2023

**Disclaimer:** © **The authors. All rights reserved.** This is a privileged document currently under peer-review/community review. Authors have provided JMIR Publications with an exclusive license to publish this preprint on it's website for review purposes only. While the final peer-reviewed paper may be licensed under a CC BY license on publication, at this stage authors and publisher expressively prohibit redistribution of this draft paper other than for review purposes.

## Table of Contents

Original Manuscript	5
Supplementary Files	
Multimedia Appendixes	23
Multimedia Appendix 1	

### How are families involved in the care of hospitalized older adults?: Protocol for a qualitative evidence synthesis

Judith B. Vick<sup>1, 2, 3</sup> MD, MPH; Blair P. Golden<sup>4</sup> MD, MS; Sarah Cantrell<sup>5</sup> MLiS, AHIP; Melissa Harris-Gersten<sup>1</sup> PhD, RN; Mollie R. Selmanoff<sup>6</sup> LCSW-C, CCM; S. Nicole Hastings<sup>1, 2</sup> MD; Tolu O. Oyesanya<sup>7</sup> PhD, RN; Karen M. Goldstein<sup>1, 2</sup> MD, MSPH; Courtney Van Houtven<sup>1, 8</sup> PhD

#### **Corresponding Author:**

Judith B. Vick MD, MPH Durham VA Health Care System 701 W. Main Street Durham US

#### Abstract

**Background:** Older adults are frequently hospitalized. Family involvement during these hospitalizations is incompletely characterized in the literature.

**Objective:** To better understand how families are involved in the care of hospitalized older adults and to develop a conceptual model describing the phenomenon of family involvement in the care of hospitalized older adults.

Methods: We describe the protocol of a qualitative evidence synthesis (QES), a systematic review of qualitative studies. We chose to focus on qualitative studies given the complexity and multifaceted nature of family involvement in care, a type of topic best understood through qualitative inquiry. The protocol describes our process of developing a research question and eligibility criteria for inclusion in our QES based on the SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation, Research type). It describes the development of our search strategy which was used to search MEDLINE (via Ovid), Embase (via Elsevier), PsycINFO (via Ovid), and CINAHL Complete (via EBSCO). Title/abstract screening and full text screening will occur sequentially. Purposive sampling may be used depending on the volume of studies identified as eligible for inclusion during our screening process. Descriptive data regarding included individual studies will be extracted and summarized in tables. Results from included studies will be synthesized using qualitative methods and used to develop a conceptual model. The conceptual model will be presented to community members via engagement panels for further refinement.

**Results:** The protocol has been submitted for registration in PROSPERO (ID 465617). As of September 2023, we have assembled a multidisciplinary team including physicians, nurses, health services researchers, a librarian, a social worker, and a health economist. We have finalized our search strategy and executed the search, yielding 8862 total citations. We are currently screening titles and abstracts, and anticipate that full-text screening, data extraction, quality appraisal, and synthesis will be completed by January 2024. Conceptual model development will then take place with community engagement panels occurring in Spring 2024. We anticipate submitting our manuscript for publication in Summer of 2024.

**Conclusions:** This paper describes the protocol for a qualitative evidence synthesis of family involvement in the care of hospitalized older adults. We will use identified themes to create a conceptual model to inform further intervention development and policy change.

(JMIR Preprints 30/09/2023:53255)

DOI: https://doi.org/10.2196/preprints.53255

<sup>&</sup>lt;sup>1</sup>Durham VA Health Care System Durham US

<sup>&</sup>lt;sup>2</sup>Department of Medicine Duke University School of Medicine Durham US

<sup>&</sup>lt;sup>3</sup>National Clinician Scholars Program Duke Clinical and Translational Science Institute Durham US

<sup>&</sup>lt;sup>4</sup>Department of Medicine University of Wisconsin School of Medicine and Public Health Madison US

<sup>&</sup>lt;sup>5</sup>Medical Center Library and Archives Duke University School of Medicine Durham US

<sup>&</sup>lt;sup>6</sup>Department of Care Management Johns Hopkins Hospital Baltimore US

<sup>&</sup>lt;sup>7</sup>Duke University School of Nursing Durham US

<sup>&</sup>lt;sup>8</sup>Department of Population Health Sciences Duke University School of Medicine Durham US

#### **Preprint Settings**

- 1) Would you like to publish your submitted manuscript as preprint?
  - Please make my preprint PDF available to anyone at any time (recommended).
  - Please make my preprint PDF available only to logged-in users; I understand that my title and abstract will remain visible to all users.
- **✓** Only make the preprint title and abstract visible.
  - No, I do not wish to publish my submitted manuscript as a preprint.
- 2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?
- ✓ Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).

Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain very Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in <a href="https://example.com/above/participate-in-very make-in-very make

## **Original Manuscript**

## How are families involved in the care of hospitalized older adults? Protocol for a qualitative evidence synthesis

Judith B. Vick, MD MPH<sup>1,2,3\*</sup>
Blair P. Golden, MD MS<sup>4</sup>
Sarah Cantrell, MLIS AHIP<sup>5</sup>
Melissa Harris-Gersten, PhD RN<sup>1</sup>
Mollie R. Selmanoff LCSW-C, CCM<sup>6</sup>
S. Nicole Hastings, MD<sup>1,2</sup>
Tolu O. Oyesanya, PhD RN<sup>7</sup>
Karen M. Goldstein, MD MSPH<sup>1,2</sup>
Courtney Van Houtven, PhD<sup>1,8</sup>

701 W. Main Street; Durham, NC 27701; judith.vick@duke.edu

Authors' contributions: Judith B. Vick (judith.vick@duke.edu) Conceptualization-lead, Data curation, Investigation, Methodology, Writing-original draft, Writing-review and editing; Blair P. Golden (bpgolden@medicine.wisc.edu) Conceptualization, Writing-review and editing, Supervision; Sarah Cantrell (sarah.cantrell@duke.edu) Methodology, Writing-review and editing; Melissa Harris-Gersten (melissa.harris@va.gov) Conceptualization, Writing-review and editina: Mollie (mselman1@jhmi.edu) Writing-review and editing; S. Nicole Hastings (susan.hastings@duke.edu) editing, Conceptualization, Writing-review and Supervision; Tolu O. Oyseanya (tolu.oyesanya@duke.edu) Conceptualization, Methodology. Writing-review and editing. Supervision; Karen M. Goldstein (karen.goldstein@duke.edu) Conceptualization, Methodology, Writing-review and editing, Supervision; Courtney Van Houtven (courtney.vanhoutven@duke.edu) Conceptualization, Methodology, Writing-review and editing, Supervision-lead

Funding: This study was not supported by extramural funding but used resources provided by Durham Center of Innovation to Accelerate Discovery and Practice Transformation (ADAPT), (CIN 13-410) at the Durham VA Health Care System. Dr. Vick is supported by ADAPT at the Durham VA and the Duke Clinical and Translational Science Institute (CTSI). Dr. Golden is supported by the National Institute on Aging of the National Institutes of Health (1K23AG081458-01, PI, Golden). Dr. Oyesanya is supported by the National Institute of Nursing Research of the National Institutes of Health (R01NR020818, PI, Oyesanya). Dr. Van Houtven is supported by the U.S. Department of Veterans Affairs, Veterans Health Administration, Office of Research and Development, Research Career Scientist Program (RCS-21-137).

The contents do not represent the views of the U.S. Department of Veterans Affairs or the United States Government.

#### **ABSTRACT**

**Background:** Older adults are frequently hospitalized. Family involvement during these hospitalizations is incompletely characterized in the literature.

Objectives: To better understand how families are involved in the care of hospitalized older adults

<sup>&</sup>lt;sup>1</sup>Durham VA Health Care System

<sup>&</sup>lt;sup>2</sup>Department of Medicine, Duke University School of Medicine

<sup>&</sup>lt;sup>3</sup>National Clinician Scholars Program, Duke Clinical and Translational Science Institute

<sup>&</sup>lt;sup>4</sup>Department of Medicine, University of Wisconsin School of Medicine and Public Health

<sup>&</sup>lt;sup>5</sup>Medical Center Library and Archives, Duke University School of Medicine

<sup>&</sup>lt;sup>6</sup>Department of Care Management, Johns Hopkins Hospital

<sup>&</sup>lt;sup>7</sup>Duke University School of Nursing

<sup>&</sup>lt;sup>8</sup>Department of Population Health Sciences, Duke University School of Medicine

<sup>\*</sup>Corresponding author

and to develop a conceptual model describing the phenomenon of family involvement in the care of hospitalized older adults.

Methods: We describe the protocol of a qualitative evidence synthesis (QES), a systematic review of qualitative studies. We chose to focus on qualitative studies given the complexity and multifaceted nature of family involvement in care, a type of topic best understood through qualitative inquiry. The protocol describes our process of developing a research question and eligibility criteria for inclusion in our QES based on the SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation, Research type). It describes the development of our search strategy which was used to search MEDLINE (via Ovid), Embase (via Elsevier), PsycINFO (via Ovid), and CINAHL Complete (via EBSCO). Title/abstract screening and full text screening will occur sequentially. Purposive sampling may be used depending on the volume of studies identified as eligible for inclusion during our screening process. Descriptive data regarding included individual studies will be extracted and summarized in tables. Results from included studies will be synthesized using qualitative methods and used to develop a conceptual model. The conceptual model will be presented to community members via engagement panels for further refinement.

Results: The protocol has been submitted for registration in PROSPERO (ID 465617). As of September 2023, we have assembled a multidisciplinary team including physicians, nurses, health services researchers, a librarian, a social worker, and a health economist. We have finalized our search strategy and executed the search, yielding 8862 total citations. We are currently screening titles and abstracts, and anticipate that full-text screening, data extraction, quality appraisal, and synthesis will be completed by March 2024. Conceptual model development will then take place with community engagement panels occurring in Spring 2024. We anticipate submitting our manuscript for publication in Summer of 2024.

**Conclusions:** This paper describes the protocol for a qualitative evidence synthesis of family involvement in the care of hospitalized older adults. We will use identified themes to create a conceptual model to inform further intervention development and policy change.

**Keywords:** Systematic Review; Family; Patient participation; Hospital Medicine; Aged; Geriatrics; Qualitative Research

#### INTRODUCTION

Older adults comprise less than 20% of the U.S. population [1], yet account for over 40% of hospitalizations at 13.2 million per year [2]. These hospitalizations confer increased risks of infection, functional decline, and cognitive disability [3-7]. There is an urgent need to identify strategies to mitigate the negative sequelae associated with these hospitalizations both by preventing those that are preventable and attenuating the harmful effects of those that are not. Improving family involvement in care may be one strategy to mitigate negative downstream consequences of hospitalization for older adult patients [8-10]. For example, systematic family involvement in the discharge planning process reduces the risk of readmission for hospitalized older adults, and is now written into policy in 42 states by the CARE Act [11-12]. Implementation of the CARE Act is associated with measures of improved patient experience, such as communication with nurses and physicians and receipt of discharge information [12]. There is a critical need to better understand family involvement in the full range of care for hospitalized older adults in addition to discharge planning.

Family involvement in older adults' care has been better described in community and outpatient settings. Up to 36 million family members and friends provide care to community-dwelling older adults in the US through medication management, care coordination, personal care, and nursing assistance [13]. This work totals roughly 30 billion hours of care annually [14]. A metaanalytical review showed that roughly 40% of adult patients are accompanied by family to primary care visits [15]. This review showed that the presence of family is associated with greater biomedical information-giving while increasing the average visit length by 20%, findings that may contribute to patient-centered outcomes like satisfaction with care and that have consequences for workflow and reimbursement [15]. Other work has shown that families participate in ways that can be both helpful and harmful to communication, satisfaction, and the delivery of care in outpatient visits [15-19]. There was some national attention to the importance of family for the delivery of care for hospitalized patients (e.g., in information exchange and decision-making) with the imposition of hospital visitor restrictions at the onset of the COVID pandemic [20-22]. However, the full range of extant qualitative evidence describing the roles, tasks, experiences, and outcomes of family involvement in care for hospitalized older adults has not been systematically reviewed, and a conceptual model for this topic has not been developed in the peer-reviewed literature.

Our objective in this study is to better understand how families are involved in the care of hospitalized older adults. An improved understanding of the interactions of family members and the professional medical team can inform future process innovation and policy change. To accomplish our objective, we chose to conduct a systematic review of qualitative studies, known as a qualitative evidence synthesis (QES), regarding family involvement in the care of hospitalized older adults. We chose to focus on qualitative research given that the complex nature of family involvement may be incompletely described through quantitative data. The themes identified in the review will be used to

develop a conceptual model of family involvement in the care of hospitalized older adults, building on a prior model of family involvement in other settings (Figure 1) [15]. We anticipate our refined model will establish a shared language for future multidisciplinary work, inform future intervention development and testing, and motivate workflow and policy changes [23]. The current paper describes the protocol for our QES.

#### **METHODS**

#### Overview

The research question of this review is: How are families involved in the care of hospitalized older adults? Qualitative research provides in-depth understanding of human experience and multifaceted social phenomena that cannot be conveyed as richly with quantitative data alone [24]. Family involvement in the care of hospitalized older adults is this kind of complex social phenomenon. We chose a qualitative evidence synthesis, a systematic review of qualitative evidence, for this study given our goal to be comprehensive in characterizing the existing literature on the complex phenomenon of family involvement in the care of hospitalized older adults [25]. We have submitted our review protocol on PROSPERO (ID 465617) and adhere to PRISMA-P (PReferred Items for reporting Systematic reviews and Meta-Analyses for Protocols) guidelines in this protocol (Table 1) [26-27]. Review results will be reported in the final manuscript using the ENhancing Transparency in REporting synthesis of Qualitative research (ENTREQ) guidelines [24].

#### **Eligibility Criteria**

Key elements of eligibility for inclusion in the review were specified using the SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation, Research type), a standardized approach to systematic review eligibility criteria for qualitative systematic reviews as an alternative to the PICOT (Population, Intervention, Comparison, Outcome, Time) tool used for quantitative systematic reviews [28]. We define older adults as adults 65 years of age or older, or as defined by an individual study's authors as studying "older adults." We use the term family broadly to refer to any family member, friend, or neighbor who is involved in a hospitalization of an older adult motivated by a personal relationship rather than financial renumeration [29]. For the purposes of eligibility in our OES, we do not distinguish between "family members" and "family caregivers" or require that this person be involved in the care of the older adult before or after a hospitalization. We define involvement broadly as inclusion in care processes, and include search strategy cognate concepts such as engagement, participation, teamwork, collaboration, and coproduction [30, 31]. Only original research studies using primary qualitative data collection and analysis methods and published in peer-reviewed journals are eligible for inclusion. Reference lists of reviews or protocols identified in our search will be manually checked to identify completed original studies that may be eligible in our review. Full inclusion and exclusion criteria, based on our SPIDER guestion, appear in Table 2.

#### Information sources

Our review uses the following databases: MEDLINE (via Ovid), Embase (via Elsevier), PsycINFO (via Ovid), and CINAHL Complete (via EBSCO).

#### Search strategies

The search strategies used a mix of database-specific subject headings and keywords searched in the title or abstract for the following concepts: family; informal caregivers; older adults; acute care; and the hospital setting. The search was developed and executed by an expert medical librarian, with input on keywords from the other authors. The search strategy was peer-reviewed by another expert librarian using a modified PRESS checklist [32]. The search was executed in all four databases on August 23, 2023, and yielded 8862 citations in total. The full reproducible search strategies for all databases are included here as an appendix.

#### Study records

#### Data management

Citations resulting from the database searches were uploaded to Covidence [33] and duplicates removed.

#### Study selection

We first piloted our title/abstract screening process by having four members of the study team (JBV, BPG, MRS, MHG) each independently screen the first 50 titles/abstracts according to the inclusion/exclusion criteria specified above; we discussed discrepancies as a group until we reached consensus. We are currently in the title/abstract screening stage in which each title/abstract will be screened in Covidence by two reviewers from the study team. When disagreements cannot be resolved by discussion between the two reviewers, a third study team member will adjudicate. Full texts of articles included for the next stage of screening will then be retrieved and uploaded to Covidence. Each full text article will be read by two reviewers from the study team and assessed for eligibility based on the inclusion/exclusion criteria, with disagreement again resolved through discussion. If the two reviewers are unable to reach consensus, a third reviewer from the study team will adjudicate. If data from a single research study is presented and analyzed in multiple articles, we will retain each article in our review and will denote when a single study is included multiple times. We will include a PRISMA flow diagram in our final manuscript which will include reasons for exclusion of articles at the full text stage [34]. If a study team member has been involved in one of the articles being considered for inclusion in the review, that team member will not be involved in decisions regarding its inclusion or quality (i.e., will not be involved in screening its eligibility for inclusion, data extraction, or methodological assessment).

#### Data collection process

A data extraction tool will be created (using Microsoft Excel or a similar software) and piloted for use with two full text publications by two members of the study team. After piloting and

subsequent modification of the data extraction tool, data will be extracted by one team member for each included publication, with a second member auditing the data extraction for accuracy.

#### Data extraction items, and Outcomes and Prioritization

Data elements to extract will include characteristics such as journal, journal discipline, publication date, study location, sample size, research design, data collection techniques, data analysis techniques, study setting, funding sources, and theoretical/conceptual framework. This descriptive data will be entered into the data extraction tool. The results section of each included study will also be extracted. All qualitative results related to family involvement in care will be extracted; we do not prespecify or prioritize particular outcomes of interest.

#### Sampling of Studies

Should the number of eligible studies exceed our ability to perform a high-quality synthesis, we will use purposive sampling to select a sample of studies for synthesis and analysis [35]. We expect to use purposive sampling if the number of eligible studies after full text review exceeds 40. We will prioritize studies that (1) take place in the United States (the review authors' country), (2) include older adult patients with cognitive impairment (given the greater need for family involvement for patients with impaired decision-making capacity) [36], and (3) that are data-rich [37]. Data-richness will be determined using a previously published data richness scale to score studies on a data richness scale ranging from 1 to 5, with a score of 4 or higher being considered data-rich [37].

#### Assessing the quality of included studies

Two independent reviewers will independently assess the methodological quality of the included studies using the QualSyst Tool for Qualitative Studies,<sup>38</sup> with resolution of final quality assessments reached through discussion. Quality assessments will be entered into Excel along with data extraction. We will report the findings of our quality assessment for each study in a table in the final manuscript.

#### **Data Synthesis**

Descriptive data about the studies (e.g., journal name, journal discipline, publication date) will be presented in a table and summarized narratively. We will analyze and synthesize the results from included studies using qualitative methods. Specifically, results will be uploaded from into a qualitative data analysis software such as Dedoose which we will use to facilitate our synthesis [39]. We will choose a synthesis method appropriate to the available pool of evidence, guided by published guidance on doing so, with the expectation that we will likely use thematic synthesis [40-42]. Thematic synthesis includes coding the text of each study's results to develop descriptive themes which are then used to generate analytical themes [41]. We anticipate using both inductive and deductive methods to identify themes. Deductively, we will consider domains identified in prior models of family involvement in outpatient and long-term care settings and in decision-making including caregiving context; facility context; family tasks, actions and roles (e.g., information

exchange, emotional support, relationship rapport); and patient and family outcomes [15,18,43]. We will meet as a team regularly to discuss review progress and iterate on emerging themes, and will present a summary of our findings in a Summary of Qualitative Findings table.

#### **Conceptual Model Development**

Once we have formulated a list of themes, we will use them to develop a conceptual model of family involvement in the care of hospitalized older adults to inform intervention development, measurement approaches, and policy needs. We will build on previously published conceptual models of family involvement in healthcare processes to refine our conceptual model for family involvement in care during hospitalizations of older adults [15,43]. As lead author, JBV will draft the initial model from themes identified in our synthesis of included articles. The study team will then meet iteratively to refine the model. Afterwards, we will obtain community input by eliciting feedback on our themes and conceptual model from family caregiver informants as a form of member checking [44,45]. We plan to perform this step through the Duke Clinical and Translational Science Institute Community Engaged Research Initiative (CTSI CERI) and the Durham VA Veteran Research Engagement Panel (VetREP) to gather feedback and further refine themes and the conceptual model. We expect this step to take place in the Spring or Summer of 2024.

#### **Review Author Reflexivity**

Our multidisciplinary review team includes members with expertise in hospital medicine, general internal medicine, geriatric medicine, nursing, information science, evidence synthesis, social work, and health services research. Throughout all stages of the review process and subsequent model development, we will each be cognizant of how our own backgrounds, views, and beliefs could influence our decisions regarding study eligibility decisions and interpretation of the data. We will include discussions of potential bias in our regular team meetings. As a review team, we have a variety of backgrounds which may help to overcome systematic bias in decision-making and analysis. Seven of us have clinical backgrounds (four in medicine: JBV, BPG, KMG, SNH; two in nursing: MHG, TOO; one in clinical social work: MRS). Five of us are family caregiving researchers (JBV, BPG, TOO, CVH, MHG) and four of us have formal training in qualitative methods (JBV, BPG, MHG, TOO). One of us is a senior medical librarian (SC) and one of us is a health economist (CVH). Four of us have formal training in evidence synthesis (JBV, SC, KMG, TOO). Six have been involved in the care of hospitalized older adults as family members (JBV, MHG, MRS, SNH, KMG, CVH). We all work in academic settings. As lead author, JBV will keep an account of the review process and decisions made to document and reflect as the project progresses.

#### **RESULTS**

The study was submitted for registration in PROSPERO (ID 465617). As of September 2023, we have assembled a multidisciplinary team, developed the research question and

inclusion/exclusion criteria, and finalized our search strategy. We executed the search for all four databases (MEDLINE, Embase, PsycINFO, and CINAHL Complete), yielding 8862 citations. We are currently screening titles/abstracts, and anticipate that full text screening, data extraction, quality appraisal, and synthesis will take place by January 2024. Conceptual model development will then take place, with initial drafting by the study team followed by community input via CERI and VetREP in the Spring of 2024. We anticipate submitting our review manuscript in the Summer of 2024.

#### DISCUSSION

The importance of family involvement in healthcare delivery has been increasingly recognized, [9,10,15,18,46] but family roles, tasks, and interactions with the professional clinical team in the hospital has received less attention than in the outpatient and community settings. Systematic review of family involvement in discharge planning for hospitalized patients supported policy implementation of the CARE Act in the majority of US states requiring systematic family involvement in discharge planning [11]. More comprehensive evidence synthesis of how families are involved with other aspects of care for hospitalized older adults has the potential to similarly impact intervention development and policy change that can positively affect public health. The proposed work aims to complete this synthesis via a systematic review of existing qualitative literature regarding family involvement in the care of hospitalized older adults, followed by the development of a conceptual model of family involvement in the care of hospitalized older adults.

#### **Strengths and Limitations**

The strengths of the proposed study include its comprehensive approach and the focus on an incompletely understood phenomenon of interest. Systematic reviews of qualitative research are growing in use, but our qualitative evidence synthesis method can still be considered an innovative strength [47]. The multidisciplinary team, including physicians, nurses, a librarian, a social worker, a health economist, and health services researchers with expertise in qualitative methods, evidence synthesis, and clinical care is another strength of the proposed study. Limitations will likely stem from ambiguity in the phenomenon of interest which may lead us to miss relevant studies that exist in the literature. This ambiguity surrounding the similar concepts of involvement, engagement, participation, teamwork, and other terms has been previously described [30,32]. We attempt to ameliorate this potential limitation by including as many cognate concepts in our search strategy as keywords based on prior work. Another limitation is intentional and that is the lack of inclusion of quantitative research. It is possible that prior experimental or observational studies which collected quantitative data only would give important information about the experiences of family involvement in the care of older adults that we will not be able to assess in a review of qualitative data alone. However, we maintain that a qualitative approach will identify richer data than that which is available with existing quantitative data. We anticipate that our included studies will identify roles that family

members play. This will help identify narrower topics of interest within the larger phenomenon of family involvement that will be better suited to systematic review of quantitative studies in the future (e.g., a systematic review of interventions designed to involve families for the purposes of delirium prevention for older adults).

#### Conclusion

This paper describes the protocol for a qualitative evidence synthesis of family involvement in the care of hospitalized older adults. Themes identified through this review will be used to develop a conceptual model of the phenomenon of interest. We anticipate that the review and conceptual model will be used in the future to improve the health and wellbeing of hospitalized older adults and their families through optimizing family involvement.

Acknowledgements: We wish to thank Leila Ledbetter, MLIS of the Duke University Medical Center Library and Archives for her peer review of our search strategy.

Data availability: The full search strategy is available as an appendix. Full search results are available by request from the corresponding author, JBV.

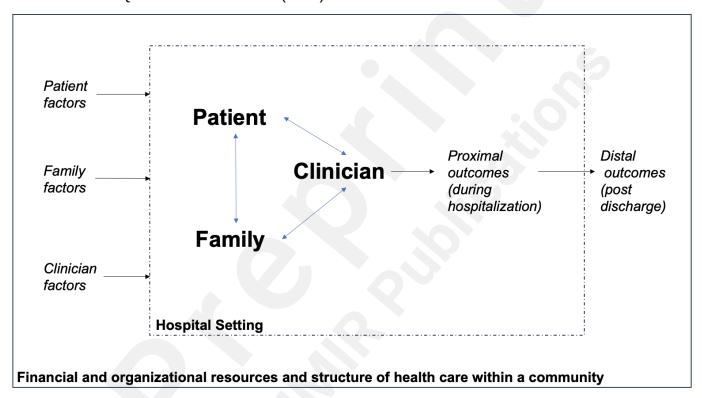
#### **REFERENCES**

1 *United States Census Bureau Quick Facts*, <a href="https://www.census.gov/quickfacts/fact/table/US/PST045222">https://www.census.gov/quickfacts/fact/table/US/PST045222</a> (2022).

- 2 HCUPnet. (Agency for Healthcare Research and Quality, Rockville, MD).
- Tesini, B. L. & Dumyati, G. Health Care-Associated Infections in Older Adults: Epidemiology and Prevention. *Infect Dis Clin North Am* **37**, 65-86 (2023). https://doi.org:10.1016/j.idc.2022.11.004
- 4 Skains, R. M. *et al.* Hospital-associated disability due to avoidable hospitalizations among older adults. *J Am Geriatr Soc* **71**, 1395-1405 (2023). https://doi.org:10.1111/jgs.18238
- Covinsky, K. E., Pierluissi, E. & Johnston, C. B. Hospitalization-associated disability: "She was probably able to ambulate, but I'm not sure". *JAMA* **306**, 1782-1793 (2011). https://doi.org:10.1001/jama.2011.1556
- Boyd, C. M. *et al.* Recovery of Activities of Daily Living in Older Adults After Hospitalization for Acute Medical Illness. *Journal of the American Geriatrics Society* **56**, 2171-2179 (2008).
- Loyd, C. *et al.* Prevalence of Hospital-Associated Disability in Older Adults: A Meta-analysis. *J Am Med Dir Assoc* **21**, 455-461 e455 (2020). https://doi.org:10.1016/j.jamda.2019.09.015
- 8 Rohlfing, A. B., Kelly, A. E. & Flint, L. A. Make the Call: Engaging Family as a Critical Intervention. *J Gen Intern Med* **38**, 523-524 (2023). https://doi.org:10.1007/s11606-022-07913-7
- 9 Sperber, N. R. *et al.* Including Family Caregivers In Seriously III Veterans' Care: A Mixed-Methods Study. *Health Aff (Millwood)* **38**, 957-963 (2019). https://doi.org:10.1377/hlthaff.2019.00012
- Leykum, L. K. *et al.* Recommendations to Improve Health Outcomes Through Recognizing and Supporting Caregivers. *J Gen Intern Med* **37**, 1265-1269 (2022). https://doi.org:10.1007/s11606-021-07247-w
- 11 Rodakowski, J. *et al.* Caregiver Integration During Discharge Planning for Older Adults to Reduce Resource Use: A Metaanalysis. *J Am Geriatr Soc* **65**, 1748-1755 (2017). https://doi.org:10.1111/jgs.14873
- Lee, C. R., Taggert, E., Coe, N. B. & Chatterjee, P. Patient Experience at US Hospitals Following the Caregiver Advise, Record, Enable (CARE) Act. *JAMA Netw Open* **6**, e2311253 (2023). https://doi.org:10.1001/jamanetworkopen.2023.11253
- Giovannetti, E. R. & Wolff, J. L. Cross-survey differences in national estimates of numbers of caregivers of disabled older adults. *Milbank Q* **88**, 310-349 (2010). https://doi.org:10.1111/j.1468-0009.2010.00602.x
- Mattingly, T. J., 2nd & Wolff, J. L. Caregiver economics: A framework for estimating the value of the American Jobs Plan for a caring infrastructure. *J Am Geriatr Soc* **69**, 2370-2373 (2021). https://doi.org:10.1111/jgs.17269
- Wolff, J. L. & Roter, D. L. Family presence in routine medical visits: a meta-analytical review. Soc Sci Med 72, 823-831 (2011). https://doi.org:10.1016/j.socscimed.2011.01.015
- Wolff, J. L., Clayman, M. L., Rabins, P., Cook, M. A. & Roter, D. L. An exploration of patient and family engagement in routine primary care visits. *Health Expect* **18**, 188-198 (2015). https://doi.org:10.1111/hex.12019
- Vick, J. B. *et al.* "Let him speak:" a descriptive qualitative study of the roles and behaviors of family companions in primary care visits among older adults with cognitive impairment. *Int J Geriatr Psychiatry* **33**, e103-e112 (2018). https://doi.org:10.1002/gps.4732
- Laidsaar-Powell, R. C. *et al.* Physician-patient-companion communication and decision-making: a systematic review of triadic medical consultations. *Patient Educ Couns* **91**, 3-13 (2013). https://doi.org:10.1016/j.pec.2012.11.007
- Wolff, J. L. *et al.* Examining the context and helpfulness of family companion contributions to older adults' primary care visits. *Patient Educ Couns* **100**, 487-494 (2017). https://doi.org:10.1016/j.pec.2016.10.022
- 20 Lamas, D. To My Patients' Family Members, My Apologies. New York Times (2020).
- 21 Azad, T. D., Al-Kawaz, M. N., Turnbull, A. E. & Rivera-Lara, L. Coronavirus Disease 2019 Policy Restricting Family Presence May Have Delayed End-of-Life Decisions for Critically III

- Patients. *Crit Care Med* **49**, e1037-e1039 (2021). https://doi.org:10.1097/CCM.000000000005044
- Brown, R. T. *et al.* Benzodiazepine and antipsychotic use among hospitalized older adults before versus after restricting visitation: March to May 2020. *J Am Geriatr Soc* **70**, 2988-2995 (2022). https://doi.org:10.1111/jgs.17947
- Brady, S. S. *et al.* Development of Conceptual Models to Guide Public Health Research, Practice, and Policy: Synthesizing Traditional and Contemporary Paradigms. *Health Promot Pract* **21**, 510-524 (2020). https://doi.org:10.1177/1524839919890869
- Tong, A., Flemming, K., McInnes, E., Oliver, S. & Craig, J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* **12**, 181 (2012). https://doi.org:10.1186/1471-2288-12-181
- Grant, M. J. & Booth, A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Info Libr J* **26**, 91-108 (2009). https://doi.org:10.1111/j.1471-1842.2009.00848.x
- Shamseer, L. *et al.* Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ* **350**, g7647 (2015). https://doi.org:10.1136/bmj.g7647
- Moher, D. *et al.* Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Syst Rev* **4**, 1 (2015). https://doi.org:10.1186/2046-4053-4-1
- Cooke, A., Smith, D. & Booth, A. Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qual Health Res* **22**, 1435-1443 (2012). https://doi.org:10.1177/1049732312452938
- 29 Schulz R, E. J. Families Caring for an Aging America. (2016).
- Menichetti, J., Libreri, C., Lozza, E. & Graffigna, G. Giving patients a starring role in their own care: a bibliometric analysis of the on-going literature debate. *Health Expect* **19**, 516-526 (2016). https://doi.org:10.1111/hex.12299
- Vick, J. B. & Wolff, J. L. A scoping review of person and family engagement in the context of multiple chronic conditions. *Health Serv Res* **56 Suppl 1**, 990-1005 (2021). https://doi.org:10.1111/1475-6773.13857
- McGowan, J. *et al.* PRESS Peer Review of Electronic Search Strategies: 2015 Guideline Statement. *J Clin Epidemiol* **75**, 40-46 (2016). https://doi.org:10.1016/j.jclinepi.2016.01.021
- 33 Covidence systematic review software, <www.covidence.org> (
- Page, M. J. et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. Rev Esp Cardiol (Engl Ed) 74, 790-799 (2021). https://doi.org:10.1016/j.rec.2021.07.010
- Suri, H. Purposeful Sampling in Qualitative Research Synthesis. *Qualitative Research Journal* **11** (2011).
- Kasper, J. D., Freedman, V. A., Spillman, B. C. & Wolff, J. L. The Disproportionate Impact Of Dementia On Family And Unpaid Caregiving To Older Adults. *Health Aff (Millwood)* **34**, 1642-1649 (2015). https://doi.org:10.1377/hlthaff.2015.0536
- Ames, H., Glenton, C. & Lewin, S. Purposive sampling in a qualitative evidence synthesis: a worked example from a synthesis on parental perceptions of vaccination communication. BMC Med Res Methodol 19, 26 (2019). https://doi.org:10.1186/s12874-019-0665-4
- Kmet LM, L. R., Cook LS. Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields.; 2004. *Alberta Heritage Foundation for Medical Research* (2014).
- 39 SocioCultural Research Consultants LLC. Dedoose Version 9.0.17, cloud application for managing, analyzing, and presenting qualitative and mixed method research data. (2021).
- Noyes, J. *et al.* Cochrane Qualitative and Implementation Methods Group guidance seriespaper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *J Clin Epidemiol* **97**, 49-58 (2018). https://doi.org:10.1016/j.jclinepi.2017.06.020
- Thomas, J. & Harden, A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* **8**, 45 (2008). https://doi.org:10.1186/1471-

- 2288-8-45
- Barnett-Page, E. & Thomas, J. Methods for the synthesis of qualitative research: a critical review. *BMC Med Res Methodol* **9**, 59 (2009). https://doi.org:10.1186/1471-2288-9-59
- Gaugler, J. E. Family involvement in residential long-term care: a synthesis and critical review. *Aging Ment Health* **9**, 105-118 (2005). https://doi.org:10.1080/13607860412331310245
- 44 Mays, N. & Pope, C. Qualitative research in health care. Assessing quality in qualitative research. *BMJ* **320**, 50-52 (2000). https://doi.org:10.1136/bmj.320.7226.50
- Giacomini, M. K. & Cook, D. J. Users' guides to the medical literature: XXIII. Qualitative research in health care A. Are the results of the study valid? Evidence-Based Medicine Working Group. *JAMA* **284**, 357-362 (2000). https://doi.org:10.1001/jama.284.3.357
- in Families Caring for an Aging America (eds R. Schulz & J. Eden) (2016).
- 47 Flemming, K. & Noyes, J. Qualitative Evidence Synthesis: Where Are We at? *International Journal of Qualitative Methods* **20** (2021).



**Figure 1:** Preliminary conceptual model of family involvement in the care of hospitalized older adults, adapted from Wolff 2012 [15]. Triadic relationships among patients, families, and clinicians in the hospital setting occur within the broader context of the financial and organizational resources and structure of health care within a community, and are affected by pre-hospitalization patient factors, family factors, and clinician factors. The nature of the triadic involvement of patients, families, and clinicians in the hospital setting may affect proximal outcomes during a hospitalization and more distal outcomes post discharge.

Location

ritie:					
Identification	1a	a Identify the report as a protocol of a systematic review  Title			
Update	1b				
Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number  Methods			
Authors:					
Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author	Title page		
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	Title page		
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state Not applicable plan for documenting important protocol amendments			
Support:					
Sources	5a	Indicate sources of financial or other support for the review	Title page		
Sponsor	5b	Provide name for the review funder and/or sponsor	Not applicable		
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol  Not ap			
INTRODUCTION					
Rationale	6	Describe the rationale for the review in the context of what is already known	Introduction		
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	Methods		
METHODS					
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review	Methods		
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature Methods sources) with planned dates of coverage			
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	Appendix		
Study records:					
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	Methods		
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, Methods screening, eligibility and inclusion in meta-analysis)			
Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for Methods obtaining and confirming data from investigators			
Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications	Methods		
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	Methods		
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	Methods		
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised	Not applicable		
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I², Kendall's τ)	Not applicable		
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)	Not applicable		
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	Methods		
	ep <b>fli6</b> t/	53 <b>256</b> cify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)	Methods		
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)	Methods		
		checklist) is held by the PRISMA-P Group and is distributed under a Creative Commons Attribution Licence 4.0.			

Table 1: PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol\*

Checklist item

Section and topic

ADMINISTRATIVE INFORMATION

Item No

[unpublished, peer-reviewed preprint]

**JMIR Preprints** 

Element	Definition	Inclusion Criteria	Exclusion Criteria
SAMPLE	Who is the sample or population of interest?	<ul> <li>Family of hospitalized older adults</li> <li>A study is eligible for inclusion if the majority (&gt;50%) of included patients are older than 65 if the average age of patients is over 65, or if the study authors define the patient population of interest as being "older adults" (e.g., if a study purports to examine hospitalized older adults which authors define in their study as being age 60 or older)</li> <li>If age of patients is not specified in the abstract but is otherwise appropriate for inclusion, the title/abstract will advance to full text review.</li> </ul>	Hospitalized older adult patients without family involvement  Majority/average of included patients are not older adults (as defined by individual study authors or greater than 65)
PHENOMENON of INTEREST	What do you hope to understand?	Family involvement in the care of hospitalized older adults  The term family broadly refers to any family member, friend, or neighbor who is involved in a hospitalization of an older adult motivated by a personal relationship rather than financial renumeration.  Family involvement in care is defined broadly as any type of participation, engagement, interaction with the professional medical team, support, or caregiving.  The settings of interest include:  • Emergency department (ED) prior to inpatient admission  • Medical ward  • Medical or cardiac intensive care unit (ICU)  Transitions of care will be included if they include care prior to hospital discharge. If exclusively concerning care after discharge, it will not be included.	Involvement in the care of older adults in in non- Emergency Department, non-medical, or non-medical or cardiac ICU settings, such as:
<b>DESIGN</b> os://preprints.jmir.org/p	What types of study methods are you interested in? preprint/53255	Qualitative designs, e.g.:  Phenomenological studies  Ethnographies  Grounded theory studies  Case studies  Narrative inquiries  Discourse analyses	Quantitative studies:

[unpublished, peer-reviewed preprint]

MIR Preprints		Qualitative data collection techniques, e.g.:  • Interviews  • Participant observation  • Focus groups  • Review of documents or artifacts  • Open-ended surveys  Qualitative data analysis techniques, e.g.:  • Thematic analysis  • Framework analysis  • Content analysis  Qualitative components of mixed methods studies	Protocols (though will use protocols to search for completed studies that meet inclusion criteria) Non-research:
EVALUATION	What are the evaluation outcomes?  (These may be subjective such as feelings, attitudes, opinions, etc.)	will be retained in the review.  All outcomes, including:  Roles of family  Tasks performed by family  Experiences of family in care delivery  Impacts of family on patient care  Perceptions of family by professional staff	None
RESEARCH TYPE	What type of research best suits your question? (Qualitative, quantitative, and mixed methods)	<ul> <li>Qualitative</li> <li>Mixed methods (qualitative aspect)</li> </ul>	Quantitative studies
Language	Language of publication	Any	None  Non-English publications will not be included in the analysis, but citations will be included in the appendix.
Years	Year of publication	Any	None
Countries	Country where research took place	Any	None
Publication types	Type of publication	Original research studies in a peer-reviewed journal	<ul> <li>Non-peer reviewed journals</li> <li>Dissertations</li> <li>Conference abstract</li> <li>Gray literature</li> <li>Lay press</li> <li>Books</li> <li>Multimedia</li> </ul>

https://preprints.jmir.org/preprint/53255 [unpublished, peer-reviewed preprint]

Vick et al

# **Supplementary Files**

## **Multimedia Appendixes**

Search strategies.

URL: http://asset.jmir.pub/assets/68fb18c5739fbfb6351cad70f80bdb75.docx