


# Adults Without Advocates and the Unrepresented: A Narrative Review of Terminology and Settings

Gerontology & Geriatric Medicine  
Volume 9: 1–8  
© The Author(s) 2023  
Article reuse guidelines:  
sagepub.com/journals-permissions  
DOI: 10.1177/23337214221142936  
journals.sagepub.com/home/ggm  


Rachel Brenner, MD<sup>1,2</sup>, Linda Cole, MS<sup>3</sup>,  
Gail L. Towsley, PhD, NHA, FGSA<sup>3</sup>, and  
Timothy W. Farrell, MD, AGSF<sup>2</sup>

## Abstract

Socially isolated adults, including those with and without the ability to make medical decisions, are encountered in clinical practice and are at risk for adverse health outcomes. Consensus is lacking on appropriate terminology to describe subpopulations of these patients. In addition, little is known about the settings in which they present. These gaps prevent clinicians and policymakers from identifying and understanding these populations and deploying appropriate resources to meet their complex needs. We conducted a narrative review of literature on socially isolated adults aged 50 and older to assess and integrate the available evidence regarding the terminology used to describe unrepresented patients and adults without advocates to inform consensus on terminology. We also identified the settings in which unrepresented patients and adults without advocates are described in the literature, including both within and outside health care settings. Our results indicate that there is heterogeneity and inconsistency in the terminology used to describe socially isolated adults, as well as heterogeneity in the settings in which they are identified in the literature. Our findings suggest that future work should include achieving consensus on terminology and integrating proactive interdisciplinary interventions across health systems and communities to prevent adults without advocates from becoming unrepresented.

## Keywords

social determinants of health, public health/public policy, literature review, health care disparity, gerontology, decision-making, clinical geriatrics, unrepresented, unbefriended, elder orphan, adult orphan, adult without advocate, social isolation, literature review

**Manuscript received:** September 6, 2022; **final revision received:** October 27, 2022; **accepted:** November 15, 2022.

## Introduction

Social isolation among older adults is increasingly common (Carney et al., 2016; Margolis & Verdery, 2017) in a world of changing societal norms (Carr & Utz, 2020), relative increased ease and frequency of relocations, often far from family (AARP, 2012), and estrangement from family members (Scharp & Curran, 2018). Approximately 43% of adults over age 60 in the United States describe feeling lonely, and these older adults have an increased risk of both functional decline and death (Kotwal & Meier, 2022; Perissinotto et al., 2012). The literature on issues older adults face at the intersection of cognitive decline and social isolation remains nascent (Kim & Song, 2018), but we know these issues extend beyond the clinical into the ethical, psychosocial, and legal realms (Farrell et al., 2017). The literature that does exist spans across multiple disciplines that use heterogeneous and inconsistent terminology to describe those

individuals who lack medical decision-making capacity and/or lack family, friends, or an executable advance health care directive to act in surrogate or default decision making. Table 1 shows several terms that have been used in the literature to refer to these populations.

<sup>1</sup>VA Salt Lake City Geriatric Research, Education, and Clinical Center

<sup>2</sup>Spencer Fox Eccles School of Medicine at the University of Utah, Salt Lake City, USA

<sup>3</sup>University of Utah College of Nursing, Salt Lake City, USA

\* Timothy W. Farrell is also affiliated with the VA Salt Lake City Geriatric Research, Education, and Clinical Center

### Corresponding Author:

Rachel Brenner, Division of Geriatrics, Spencer Fox Eccles School of Medicine, University of Utah, 500 Foothill Dr, Mail Code 182H, Salt Lake City, UT 84148, USA.

Email: Rachel.brenner@hsc.utah.edu



Henceforth, we use the term unrepresented to refer to patients lacking medical decision-making capacity and lacking an avenue for surrogate decision making (including a surrogate decision maker, guardian, or executed advance directive). We will use the term adult without advocate to refer to those adults who maintain capacity to make medical decisions but lack an avenue for surrogate decision making should they lose medical decision-making capacity.

Little is known about the settings in which unrepresented adults and adults without advocates typically present. Studies that do address frequency of encounters with adults lacking decision making capacity or representation are often specific to one setting. For example, it has been estimated that 16% of patients admitted to the ICU setting lack decision-making capacity (White et al., 2006) and that 3% to 4% of patients in long-term care settings are unrepresented (Karp & Wood, 2003). These estimates were published nearly 20 years ago. Within that time frame, the Baby Boomer population has grown with more than 10 million living alone and 20% childless (Redfoot et al., 2013). For adults without advocates, even less is known about where they are first encountered in the healthcare system. Farrell et al. (2021) found that among 122 American Geriatrics Society members caring for older adults, 90.4% reported they were “moderately” to “extremely likely” to know when a patient is an adult without advocate, and outpatient clinicians reported encountering adults without advocates as often as inpatient clinicians.

Without more robust data on where to look for socially isolated adults, and lacking consensus on what to call these highly vulnerable and often disadvantaged patients, healthcare systems cannot easily identify, adequately study, or monitor these individuals. Thus, they may remain invisible until a crisis situation occurs. The invisibility of adults without advocates is likely a major contributor to healthcare systems’ difficulties in caring for them, resulting in poor outcomes such as providing care or interventions not consistent with what the patient would want could they or an advocate represent them. The use of clear terminology within the medical and social sciences may foster consistent identification of these individuals and promote coherent academic and policy conversations to inform solutions to the problems these patients face within and outside healthcare settings.

The primary objective of this study is to assess and integrate the terminology used to describe unrepresented adults and adults without advocates in the available literature to inform future consensus on terminology. In turn, we anticipate that accurate and consistent use of terminology will enable attention and resources—including community supports and additional research—to be directed to appropriate populations of socially isolated adults. Our secondary objective is to better understand the settings in which unrepresented adults and adults without advocates are identified, including both within and outside health care settings.

**Table 1.** Various Terminology Describing Socially Isolated Older Adults (Pope, 2017).

---

Unbefriended patient
Unrepresented patient
Friendless patient
Patient alone
Solo citizen
Patient without a surrogate decision maker
Patient without proxy
Adult orphan

---

## Methods

Our review follows the overall structure outlined by Whitemore and Knafl (2005) for integrative narrative reviews of problem identification, literature search, data evaluation, data analysis, and presentation. A narrative review allows rapid review of a small and diverse evidence base, and the integrative method allows incorporation of data collection and analysis that goes beyond a typical narrative review to best address the above focused objectives.

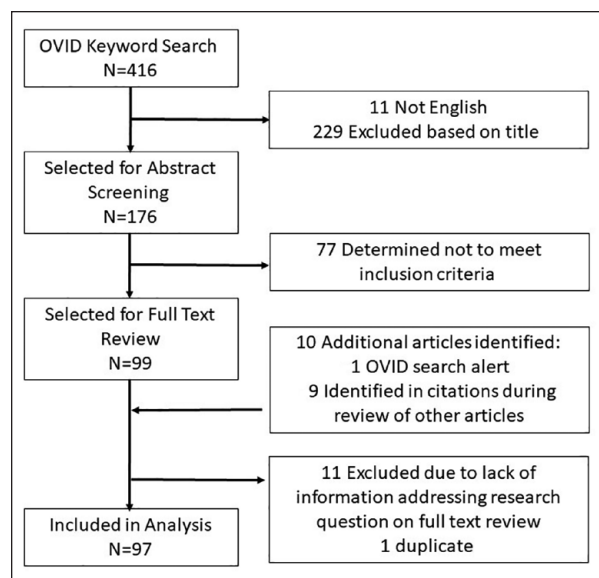
### Search Strategy and Inclusion Criteria

We selected the keywords “unbefriended,” “elder orphan,” “adult orphan,” “unrepresented patient,” “patients without proxies,” and “incapacitated patients without surrogates” as search terms based on terms known to refer to the populations of interest (Pope, 2017) for which results were available, as well as search terms used in other review articles of issues affecting unrepresented adults (Kim & Song, 2018). Based on exploratory searches, we also included the keyword searches “decision making capacity AND surrogates,” “aging alone,” and “elderly AND guardian NOT children.”

We conducted keyword searches in a single database. Medline (Ovid) was chosen as the database based on relevance and number of search results from exploratory searches conducted in Medline, Embase (Embase.com), Web of Science, PsychInfo, and Legal Collection (Ebscohost). One database was selected to avoid problems related to the burden of duplicate results between other databases noted in the exploratory searches. We did not limit our search by the year that an article was published given the relatively limited quantity of papers on this topic and to better elucidate how terminology has changed over time.

Given the limited results available from database searching and the nature of the research question, we also included citation index searching for the most pertinent articles as this has been noted to be efficient for nascent fields with fewer seminal works (Conn et al., 2003). We also used the citation index searching method to identify grey literature sources (Figure 1).

We screened titles and abstracts of keyword search results and included for full review only those articles



**Figure 1.** Article selection.

relevant to our research question. Articles with known common terms in the title for adults who lack a friend or family member (such as unbefriended, unrepresented, adult orphan, and elder orphan) to act as a surrogate were all included for full text review. We included all articles including adults over 50 years of age who lack a friend or family member to act as a surrogate decision maker. While much of the discussion of these issues to date has focused on older adults (age 65 years and older), this situation can and does apply to adults less than 65 years of age as well. Therefore, the age minimum of 50 years was selected to determine appropriately inclusive terminology. We excluded articles that addressed solely decisional capacity assessment and patients lacking decision making capacity except when a lack of an available surrogate was mentioned in the abstract.

We included full text articles in our data extraction when articles contained language relevant to terminology. Eleven articles that did not contain any written references to the population or question of interest, such as terminology or descriptions, were excluded at this stage.

### Data Evaluation and Analysis

We used a data extraction tool in Microsoft Excel and organized the data extraction by elements of the primary and secondary research objectives. We collected article information (PMID, title, author, year, county, discipline, stated aim/purpose, and study type), reviewed terminology (as described below), and collected information on the setting in which individuals in the population of interest were identified (e.g., outpatient clinic, hospital setting, ICU, legal setting, community settings, etc.), how the population of interest was defined, and the age of the population (when available). The data extraction tool also included a section for notes relevant to the research question and other miscellaneous notes.



**Figure 2.** Articles by year published.

To organize our extraction of information relevant to terminology, the team initially met and agreed a priori on elements of relevant terms. Specifically, we tracked terms used for those (1) lacking both capacity and surrogacy (“unrepresented” by our working definition), (2) lacking capacity only, and (3) those lacking surrogacy and maintaining capacity (“adults without advocates” by our working definition). The team achieved consensus on these elements and applied these elements uniformly during the data extraction process. Each of these three groups was represented by a different column in our data extraction tool.

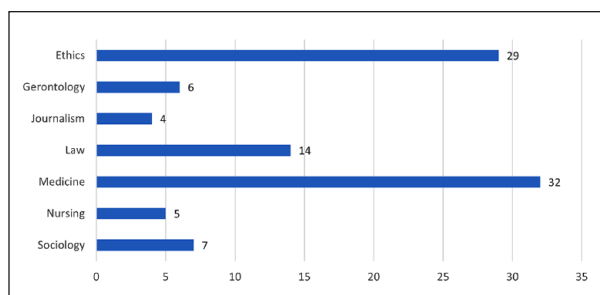
Analysis of the terminology data obtained from the data extraction tool was conducted by the column. A given column of the data extraction tool was reviewed across all articles for all relevant terminology, alongside the comments and notes. We completed a hand tally to quantify which terms were used most frequently for the various combinations of definitional elements and qualitative observations. Settings and article information were evaluated similarly; miscellaneous qualitative observations were less often applicable to these categories.

## Results

We identified 97 articles relevant to the objectives of interest. Year of publication ranged from 1990 to 2022, with increasing numbers of articles noted over time, especially after 2015 (Figure 2). The articles were written from the vantage point of seven different academic disciplines. The largest category of reviewed articles came from the discipline of medicine, followed by ethics and law (Figure 3).

### Terminology

**Individuals Without Surrogates.** The element of surrogacy was heterogeneous in terms of language used as well as scope. Variations on the term “surrogate” were largely present in articles that focused on clinical decision making in crisis situations. However, a variety of other terms described the potential for surrogacy and social situations that impact availability of a surrogate. Examples of these terms include alone, without advocates, no identifiable family or friends, without proxies, isolated, solo citizens, and kinless.



**Figure 3.** Article disciplines.

The terms and language used to identify and describe patients who maintained capacity but lacked a (presumably potential) surrogate decision maker were the most heterogeneous and inconsistently applied. Of all the papers reviewed, 61% did not mention or name the population of individuals without potential surrogates. Varying terms used to name this population included elder orphan, [individuals] aging alone, adult orphan, kinless, unrepresented, and unbefriended. The most common strategy for identifying individuals without potential surrogates was to be descriptive rather than to assign any specific term. Notably, the terms used to describe this population were also frequently used in other ways. “Adult orphan” was also used to describe an adult who has lost both of their parents. “Unbefriended” and “unrepresented” were terms also used as we have defined them to describe a population lacking both capacity and surrogates, as discussed further below. Other terms, such as “kinless” and “alone,” captured a sense of social isolation but lacked specificity regarding the availability of surrogate decision makers.

**Individuals Without Capacity.** Seventy-three percent of the articles we reviewed mentioned capacity. However, discussions about individuals who lack capacity and have a surrogate were more limited in the articles we reviewed related to our inclusion criteria. Language describing a lack of capacity was consistently intuitive but imprecise; articles used “incapacitated” and “lacking in capacity” but often lacked further definition or discussion of capacity determination. Capacity was implied to be present when not explicitly noted as missing in defining a term of interest. When the process of capacity determination (Appelbaum, 2007) was discussed in detail, which only occurred in 6% of the articles in which capacity was mentioned, this process was described as being in the context of a specific decision at a specific point in time (Carney et al., 2016; Connor et al., 2016; Patel & Ackermann 2018; Pope, 2019).

Additional articles without detailed descriptions of capacity determination did still note a lack of capacity to be an explicitly temporary state either due to acute illness or in the context of a specific pressing medical question. Those few articles that referred to incapacity as a long-term state

due to chronic mental or cognitive illnesses all lacked a detailed discussion of capacity determination and were largely found in discussions specifically addressing guardianship (Björkstén et al., 2014; Catlin et al., 2021; Coker & Johns, 1994).

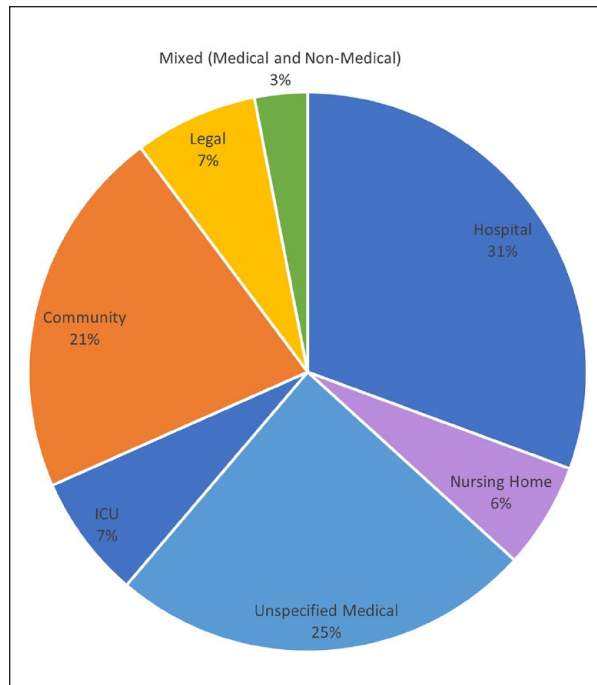
**Individuals Lacking Both Capacity and a Surrogate.** Nearly three-quarters (74%) of articles reviewed named or described patients lacking both capacity and a surrogate decision maker. Many articles used more than one term to refer to these individuals for clarity given the lack of consensus on terminology to date. The most common term used to name these adults in the articles reviewed was unrepresented, which was the primary term in 43 of the articles reviewed. The second most common term was unbefriended, which was the primary term in 38 articles reviewed. Thirty-four articles (including some of those that used unbefriended or unrepresented as primary terms) also referred to unrepresented adults using a description of the combination of both components of the definition (e.g., incapacitated and alone, incapacitated and without surrogates, incapacitated adults without advocates.) The medical ethics literature contained the majority of the publications about patients lacking both capacity and a surrogate, in which case articles addressed an acute medical crisis situation, often in a hospital setting.

### Settings

Among the articles we analyzed, all either implied or specifically named a setting in which adults without advocates or unrepresented adults may be identified in the context of the specific article. The majority (68%) of these were healthcare or medical settings, with 31% specific to hospitalized patients, 6% specific to patients in nursing homes, 7% specific to patients in intensive care units, and 25% referring to other unspecified or mixed medical settings.

Many of the articles classified as referring to “unspecified or mixed medical” settings were medical ethics articles and those providing general clinical guidance applicable to medical providers generally but not specific to one healthcare setting. While some of these “unspecified” medical articles included outpatient clinical settings, there were no articles that specified adults without advocates or unrepresented patients presenting to outpatient clinics. In other words, no articles specifically addressed these populations in the outpatient clinical setting. This is in stark contrast to the number of articles specific to these patients and the issues they face when they present specifically in the hospital environment.

Several articles referred to adults outside of medical settings (28%), either in the community (21%) or in the legal system (7%). Three percent of the articles referred to populations identified in multiple (both medical and non-medical) settings (Figure 4).



**Figure 4.** Settings.

## Discussion

Socially isolated adults including unrepresented adults and adults without advocates are among the most highly vulnerable patients in health care systems (Farrell et al., 2017). There is not consensus on appropriate terminology to describe these populations and scant data on the settings and circumstances in which these individuals present.

### Terminology

Prior articles defined individual terms such as “unbefriended” (Farrell et al., 2017), “unrepresented” (Pope, 2019), “adult orphans” (Montayre et al., 2019), and “elder orphans” (Carney et al., 2016) in the context of discussing important clinical issues surrounding these groups without always addressing competing or equivalent terminology. When competing terminology has been explicitly discussed (Pope, 2017), recommendations to inform consensus terminology have not been present. Prior reviews of unrepresented adults have identified variability in terminology used to describe these patients (Kim & Song, 2018), consistent with our findings of heterogeneous terminology describing adults lacking surrogates. To the best of our knowledge, this is the first review article to evaluate terminology for both unrepresented adults and adults without advocates at risk of becoming unrepresented.

Our findings reinforce the need for consensus on terminology used to refer to vulnerable adults lacking social support. Consensus in terminology is especially important for those who retain medical decision-making capacity but

who are one crisis away from becoming unrepresented (i.e., “adults without advocates”), who our study uniquely addresses. Notably, almost two-thirds of the articles we reviewed did not mention this critical population. Our study thus demonstrates a significant gap in the existing literature and a need for more research specifically addressing adults without advocates.

We observed a noticeable shift from the term “unbefriended” to “unrepresented” beginning in about 2015 among the 74% of articles that named these adults. We advocate for the use of the term “unrepresented” instead of the term “unbefriended.” The term “unrepresented” captures all the elements of a situation in which an adult cannot represent themselves due to their lack of capacity to make their own medical decisions, in which they cannot be represented by another due to the lack of a surrogate decision maker, and in which they cannot be represented by a health care proxy since there is not an executable advance directive. We also prefer the term “unrepresented” to the term “unbefriended” as it is possible to have friends, acquaintances, or relatives that are unwilling or unable to serve as surrogate decision makers.

### Settings

Prior studies of unrepresented patients have focused on individual settings such as the ICU (White et al., 2006) or long-term care (Karp & Wood, 2003). Studies looking at adults without advocates (Farrell et al., 2021) provided only indirect measures of the frequency with which clinicians encounter these patients. Prior studies that described more broadly the prevalence and characteristics of both unbefriended adults (Chamberlain et al., 2018) and adults without advocates (Carney et al., 2016) lack analyses of the settings in which these individuals are identified. To the best of our knowledge, our study is the first review to attempt to address this question across both medical and non-medical settings.

The heterogeneity of settings in which we found that unrepresented adults are encountered—both within and outside healthcare settings—is striking. Although the most common setting identified was the hospital, the second most common setting was the community, and overall, about one-fourth of the articles we reviewed were based in community and non-health care settings. Interestingly, none of the articles discussed unrepresented patients solely in the outpatient setting, despite prior findings that outpatient clinicians reported encountering adults without advocates as often as inpatient clinicians (Farrell et al., 2021). This heterogeneity of settings suggests that approaches to meeting the needs of unrepresented adults will likely be unsuccessful if these approaches do not span the continuum of health care settings and professions, and link with legal services, social services, and other community-based supports.

## Strengths and Limitations

Strengths of this narrative review include a robust and multidisciplinary search strategy for this type of review with inclusion of multiple terms to capture evidence on the topic comprehensively and involvement of an interdisciplinary team to conduct the literature review. Additionally, our approach including a priori defined elements, a data extraction process, and quantitative evaluation provided additional rigor to our approach to this narrative review. Our relatively narrow focus on terminology and settings is an additional strength as it allowed for an in-depth evaluation of areas where consensus is lacking in this field. Our rigorous and broad search strategy also allowed us to accommodate for the relative nascency of this area of study and the relatively limited number of articles available for review.

Limitations of our approach include that the format of a narrative review is inherently limited relative to a more comprehensive scoping review. Our search strategy and a priori defined elements may also introduce a degree of selection bias given that we had to select search terms to address our question of terminology, thus articles using those terms selected a priori are likely to be overrepresented in our sample. Additionally, the nature of a narrative or integrative review does not allow us to synthesize results as a systematic review would; however, we do not believe there is adequate existing research in this field to support a systematic review. We considered including demographic descriptions of unrepresented patients in our review, however, the heterogeneity of definitions and approaches to identifying this group limits the ability to apply such findings.

## Clinical Implications and Future Directions

We suggest the term *adult without advocate* to describe those who are socially isolated and maintain capacity to represent themselves and their interests in medical decisions but lack a friend or family member to act as a surrogate should they lose medical decision-making capacity. We suggest the term *unrepresented* to describe those who are not able to represent themselves (due to lack of medical decision-making capacity) and do not have surrogate representation in the form of a family member, friend, executable advance directive, or legally appointed guardian. The use of consensus terminology to describe unrepresented adults—and adults at risk of becoming unrepresented—will serve at least two purposes. First, consistent terminology will provide health systems and researchers with a common language to care for and study this population, enabling resources to be concentrated more directly to their care (e.g., facilitating the use of ICD-10 [International Classification of Diseases-10] codes to assist in clinical documentation as well as data analysis and extraction within electronic health records). Second, naming adults without advocates and unrepresented populations will help to ensure that their interests are presented to and understood by health care policymakers.

We believe that our findings support a shift to a proactive rather than a reactive approach to caring for adults without advocates and unrepresented adults. It is critical to understand where adults without advocates and unrepresented patients typically interact with the health care system so that health care resources and other supports—including social, financial, and legal supports—can be deployed accordingly. This will be difficult for health systems and communities to accomplish without knowing how to name these populations or how to screen for them. For adults without advocates, it is especially critical to understand where they interact with health care professionals because there is an opportunity to identify these patients at the point of care before they become unrepresented, thus preventing the attendant difficulties such as inability to identify their health care wishes, delays in obtaining a guardian, and excessive healthcare expenditures. For unrepresented patients, if the costs of implementing interventions to support them fall on only one part of the health care continuum, the benefits of these interventions may not be realized by the same entity and thus may be financially unsustainable. For example, community investment in creating a volunteer guardianship program for unrepresented patients may benefit hospitals by reducing length of stay, without any investment from hospitals. As a result, we anticipate that cross-sector collaboration with multiple stakeholders will be needed to build the necessary infrastructure (including but not limited to health care, legal, and social services such as housing) to meet unrepresented patients' needs.

Interprofessional education and practice will be critically important to prepare the health care workforce to meet these patients' complex needs across various health care settings. For example, capacity assessment, appropriate inclusion of caregivers in discussions about patients' goals and preferences (such as supported decision making), and knowledge of the roles and responsibilities of community agencies are not routinely taught in health professions education, yet interprofessional competencies such as understanding the roles and responsibilities of other team members (Interprofessional Education Collaborative, 2016) are essential to provide appropriate care for socially isolated adults. In addition, health care professionals should be aware of the adverse health outcomes of social isolation, such that the lack of a caregiver should prompt action to identify a surrogate decision maker. Using consistent and agreed-upon language potentially improves the quality of these assessments and conversations.

We envision a future in which primary care clinics and community agencies screen for patients at risk of becoming unrepresented, triggering needed social supports. From a value-based care standpoint, upstream preventive interventions are likely to be much more cost-effective since they have potential to avoid long lengths of stay while patients await a surrogate decision maker and to reduce the likelihood of requiring nursing home placement. This cost-benefit analysis is an area that is deserving of future study.

## Conclusion

This structured narrative review of the interdisciplinary literature addressing unrepresented patients and adults without advocates illustrates the lack of consistent language and highlights the need for consensus regarding the terminology used to identify and describe these populations. The use of consistent terminology can allow community services and healthcare systems to identify patients who could become unrepresented in a medical crisis that impairs their medical decision-making capacity and direct essential medical, social, financial, and legal supports to these patients.

The context in which unrepresented adults and adults without advocates are described in the literature spans the continuum of geriatric care in the community. Approaches to meet these highly vulnerable patients' needs should thus involve interprofessional education and cross-sector collaboration. Future work should explore proactive approaches to better identify adults without advocates both within and outside of acute care settings to provide necessary supports before they become unrepresented in a crisis situation. Future work should also identify the infrastructure and financial resources necessary to meet the complex needs of unrepresented patients.

## Acknowledgments

The authors acknowledge the University of Utah Eccles Health Sciences Library staff in providing education and guidance on review types and methodologies, which helped to inform the scope and design of this study.

## Author Contributions

All authors contributed to defining the research question. RB developed the search strategy with input from other authors. RB conducted the search and initial title and abstract screening. RB, LC, GT, and TF participated in data extraction, evaluated data, and contributed to the final manuscript.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

## Supplemental Material

Supplemental material for this article is available online.

## References

- AARP. (2012). *Family today: A study of U.S. families*. [https://www.aarp.org/content/dam/aarp/research/surveys\\_statistics/general/2012/Family-Today-A-Study-of-US-Families-AARP.pdf](https://www.aarp.org/content/dam/aarp/research/surveys_statistics/general/2012/Family-Today-A-Study-of-US-Families-AARP.pdf)
- Appelbaum, P. S. (2007). Assessment of patients' competence to consent to treatment. *The New England Journal of Medicine*, *357*(18), 1834–1840. <https://doi.org/10.1056/NEJMcp074045>
- Björkstén, K. S., Fälldin, K., & Ulfvarson, J. (2014). Custodian for elderly with memory impairment in Sweden – A study of 260 physicians' statements to the court. *BMC Geriatrics*, *14*(1), 94. <https://doi.org/10.1186/1471-2318-14-94>
- Carney, M. T., Fujiwara, J., Emmert, B. E., Liberman, T. A., & Paris, B. (2016). Elder orphans hiding in plain sight: A growing vulnerable population. *Current Gerontology and Geriatric Research*, *2016*, 4723250. <https://doi.org/10.1155/2016/4723250>
- Carr, D., & Utz, R. L. (2020). Families in later life: A decade in review. *Journal of Marriage and Family*, *82*(1), 346–363. <http://dx.doi.org.ezproxy.lib.utah.edu/10.1111/jomf.12609>
- Catlin, C. C., Connors, H. L., Teaster, P. B., Wood, E., Sager, Z. S., & Moye, J. (2021). Unrepresented adults face adverse healthcare consequences: The role of guardians, public guardianship reform, and alternative policy solutions. *Journal of Aging & Social Policy*, *34*(3), 418–437. <https://doi.org/10.1080/08959420.2020.1851433>
- Chamberlain, S., Baik, S., & Estabrooks, C. (2018). Going it alone: A scoping review of unbefriended older adults. *Canadian Journal on Aging*, *37*(1), 1–11. <https://doi.org/10.1017/S0714980817000563>
- Coker, L. H., & Johns, A. F. (1994). Guardianship for elders: Process and issues. *Journal of Gerontological Nursing*, *20*(12), 25–32. <https://doi.org/10.3928/0098-9134-19941201-07>
- Conn, V. S., Isaramalai, S. A., Rath, S., Jantarakupt, P., Wadhawan, R., & Dash, Y. (2003). Beyond medline for literature searches. *Journal of Nursing Scholarship*, *35*(2), 177–182. <https://doi.org/10.1111/j.1547-5069.2003.00177.x>
- Connor, D. M., Elkin, G. D., Lee, K., Thompson, V., & Whelan, H. (2016). The unbefriended patient: An exercise in ethical clinical reasoning. *Journal of General Internal Medicine*, *31*(1), 128–132. <https://doi.org/10.1007/s11606-015-3522-0>
- Farrell, T. W., Catlin, C., Chodos, A. H., Naik, A. D., Widera, E., & Moye, J. (2021). Caring for unbefriended older adults and adult orphans: A clinician survey. *Clinical Gerontologist*, *44*(4), 494–503. <https://doi-org.ezproxy.lib.utah.edu/10.1080/07317115.2019.1640332>
- Farrell, T. W., Widera, E., Rosenberg, L., Rubin, C. D., Naik, A. D., Braun, U., Torke, A., Li, I., Vitale, C., & Shega, J., & Ethics, Clinical Practice and Models of Care, and Public Policy Committees of the American Geriatrics Society. (2017). AGS Position statement: Making medical treatment decisions for unbefriended older adults. *Journal of the American Geriatrics Society*, *65*(1), 14–15. <https://doi.org/10.1111/jgs.14586>
- Interprofessional Education Collaborative. (2016). *Core competencies for interprofessional collaborative practice: 2016 update*. <https://ipec.memberclicks.net/assets/2016-Update.pdf>
- Karp, N., & Wood, E. (2003). *Incapacitated and alone: Health care decision-making for the unbefriended elderly*. American Bar Association Commission on Law and Aging. <https://www.americanbar.org/content/dam/aba/adminis->

- trative/law\_aging/2003\_Unbefriended\_Elderly\_Health\_Care\_Descision-Making7-11-03.authcheckdam.pdf
- Kim, H., & Song, M. K. (2018). Medical decision-making for adults who lack decision-making capacity and a surrogate: State of the science. *American Journal of Hospice and Palliative Medicine*, *35*(9), 1227–1234. <https://doi.org/10.1177/1049909118755647>
- Kotwal, A. A., & Meier, D. E. (2022). A paradigm shift—Loneliness as a root cause of symptom distress among older adults. *Journal of the American Geriatrics Society (JAGS)*, *70*(8), 2201–2204. <https://doi.org/10.1111/jgs.17880>
- Margolis, R., & Verdery, A. M. (2017). Older adults without close kin in the United States. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *72*(4), 688–693. <https://doi.org/10.1093/geronb/gbx068>
- Montayre, J., Montayre, J., & Thaggard, S. (2019). The elder orphan in healthcare settings: An integrative review. *Journal of Population Ageing*, *12*(4), 515–532. <http://dx.doi.org/10.1007/s12062-018-9222-x>
- Patel, J., & Ackermann, R. J. (2018). Issues in geriatric care: Medical decision-making. *FP Essentials*, *468*, 35–38. <https://pubmed.ncbi.nlm.nih.gov/29714995/>
- Perissinotto, C. M., Stijacic Cenzer, I., & Covinsky, K. E. (2012). Loneliness in older persons: A predictor of functional decline and death. *Archives of Internal Medicine*, *172*(14), 1078–1084. <https://doi.org/10.1001/archin-ternmed.2012.1993>
- Pope, T. M. (2017). Unbefriended and unrepresented: Better medical decision making for incapacitated patients without healthcare surrogates. *Georgia State University Law Review*, *33*(4), 923–1019. <https://readingroom.law.gsu.edu/gsulr/vol33/iss4/3>
- Pope, T. M. (2019). Five things clinicians should know when caring for unrepresented patients. *AMA Journal of Ethics*, *21*(7), E582–E586. <https://doi.org/10.1001/amajethics.2019.582>
- Redfoot, D., Feinberg, L., & Houser, A. (2013). *The aging of the baby boom and the growing care gap: A look at future declines in the availability of family caregivers*. AARP Public Policy Institute. <https://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html>
- Scharp, K. M., & Curran, T. (2018). Caregiving when there is family conflict and estrangement. *Generations*, *42*(3), 51–56. <https://www.jstor.org/stable/26591703>
- White, D. B., Curtis, J. R., Lo, B., & Luce, J. M. (2006). Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. *Critical Care Medicine*, *34*(8), 2053–2059. <https://doi.org/10.1097/01.CCM.0000227654.38708.C1>
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, *52*(5), 546–553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>