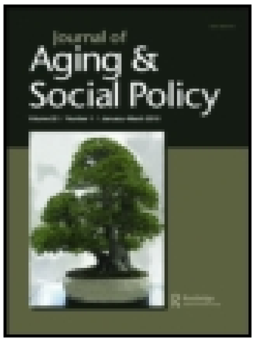

Journal of Aging & Social Policy

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/wasp20

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To cite this article: Casey C. Catlin , Heather L. Connors , Pamela B. Teaster , Erica Wood , Zachary S. Sager & Jennifer Moye (2021): Unrepresented Adults Face Adverse Healthcare Consequences: The Role of Guardians, Public Guardianship Reform, and Alternative Policy Solutions, Journal of Aging & Social Policy, DOI: 10.1080/08959420.2020.1851433

To link to this article: https://doi.org/10.1080/08959420.2020.1851433

JOURNAL OF AGING & SOCIAL POLICY
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Unrepresented Adults Face Adverse Healthcare Consequences: The Role of Guardians, Public Guardianship Reform, and Alternative Policy Solutions

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ABSTRACT

Persons without family or friends to serve as healthcare agents may become "unrepresented" in healthcare, with no one to serve as healthcare agents when decisional support is needed. Surveys of clinicians (N = 81) and attorneys/guardians (N = 23) in Massachusetts reveal that unrepresented adults experience prolonged hospital stays (66%), delays in receiving palliative care (52%), delays in treatment (49%), and other negative consequences. Clinicians say guardianship is most helpful in resolving issues related to care transitions, medical treatment, quality of life, housing, finances, and safety. However, experiences with guardianship are varied, with delays often/always in court appointments (43%) and actions after appointments (24%). Policy solutions include legal reform, education, and alternate models.

ARTICLE HISTORY
Received 20 December 2019
Accepted 17 August 2020

KEYWORDS
Unrepresented; unbefriended; guardian; public guardianship; support

Introduction

Individuals with significant decisional impairments, no advance directive, and no family or friends to serve as healthcare agents are often referred to in the research literature as "unbefriended" or "unrepresented" (Farrell et al., 2017) (See Table 1 for additional definition). Within healthcare settings, unrepresented adults comprise 3–10% of hospital and long-term care populations and are mostly older adults (Connor et al., 2016; Isaacs & Brody, 2010; Teaster, 2002). When a decision-maker is needed for unrepresented adults, approaches vary and include public guardianship (Kim & Song, 2018).

Guardianship is a legal process designed to provide decisional support and protection for individuals determined by a court to be in need of a legal guardian (American Bar Association and American Psychological Association Assessment of Capacity in Older Adults Project Working Group

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Supplemental data for this article can be accessed on the publisher's website.

Table 1. Definitions of used in this study.

Unrepresented Person: An adult with significant decisional impairments surrogate.[a]	no advance directive	and no family or friends to serve as advocate	supporter or
Guardian: A person appointed by a court to make personal or health decisions for another. (A person appointed by the state to make financial decisions is called a conservator.[b] In this survey	for brevity	we will use the general term guardian to refer to both roles). Guardians may be related to the person or unrelated.	
Unrelated Guardian: A professional providing guardianship services as part of their business	with no prior familial or social relationship with the person. Unrelated guardians may be paid or *pro bono*.		
***Pro Bono* Guardian**: A subset of Unrelated Guardians	who receive little or no compensation for their work. *Pro Bono* Guardians often are lawyers	but not always.	

[a] The field has yet to agree on the preferred term. Some find "unbefriended" stigmatizing and prefer "unrepresented." However, some attorneys find fault with this term as indicating the person lacks legal representation. Alternate phrases such as "adults without surrogates" fail to capture all three criteria – having no surrogates while having decisional impairments and no advance directive. In this paper, we will use the term "unrepresented."

[b] Terminology varies across states. Some states use the term guardian to describe a person who makes personal decisions and a conservator to describe a person who makes financial decisions; some states use the term "guardian" for both functions and other states use "conservator" for both functions. For ease of expression in this paper, we use the term "guardian" to describe a legally appointed individual who advocates, supports, and makes personal and/or financial decisions with and for another.

(ABA-APA), 2006). Guardianship appointments are sought for adults with significant decisional or functional challenges who remain at serious risk of harm associated with an inability to meet essential needs for health and safety (National Conference of Commissioners on Uniform State Laws, 2017). Often courts distinguish two types of guardianship, those for personal decisions versus those for financial decisions (in some states called a conservator); the specific authority of each guardianship is set out in the guardianship order. In the U.S., qualifications to serve as a guardian vary, but tend to be minimal. For example, in Massachusetts although family members are preferred guardians, the judge may appoint "any person the court deems appropriate" Massachusetts General Law (MGL)190B § 5–305 (2009) including professionals or agencies.

Guardianship removes fundamental rights, and thus is perceived as a last resort, after use of less restrictive decisional options, such as health-care advance directives, have been tried. Advocates for individuals with disabilities promote the use of supported decision-making rather than guardianship. Supported decision-making is defined as "a series of relationships, practices, arrangements, and agreements of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others, decisions about the individual's life" (Dinerstein, 2012). Similarly, persons with dementia are often supported by caregivers, also named as healthcare agents on advance directives, obviating the need for guardianship. These mechanisms require family and friends to serve as supporters, caregivers, and healthcare agents, which by definition may not be accessible to unrepresented adults.

In two recent systematic reviews, empirical study of unrepresented adults subject to guardianship is characterized as erratic and sparse (Chamberlain et al., 2018; Kim & Song, 2018). The handful of existing studies focus on either *characteristics* or *health outcomes*, relating these to policy solutions (Figure 1). An understanding of the *characteristics* of unrepresented adults may inform clinical or legal approaches to prevent persons from becoming unrepresented. Unrepresented adults are more likely to have small social networks (be single and childless; have few siblings), estranged from family, have fewer financial resources, more cognitive impairment, multiple chronic diseases, and/or a history of homelessness or substance abuse (Chamberlain et al., 2018, 2019). An understanding of the *health outcomes* faced by unrepresented adults may inform strategies to avoid adverse outcomes. Unrepresented adults are likely to have a longer length of stay when hospitalized (Chen et al., 2016; Ricotta et al., 2018; White et al., 2006) and are likely to be discharged to nursing homes (Bandy et al., 2010). Authors of these reviews emphasize the pressing need to expand the literature base, particularly focusing on unrepresented adults in long-term care (Chamberlain et al., 2018; Kim & Song, 2018).

Related scholarship focuses on *policy solutions* for unrepresented adults including clinical or legal approaches. In terms of clinical approaches, various professional societies have issued policy guidance recommending clinical systems to address concerns for unrepresented adults (Farrell et al., 2017; Pope et al., 2020). These policy statements emphasize the need to identify

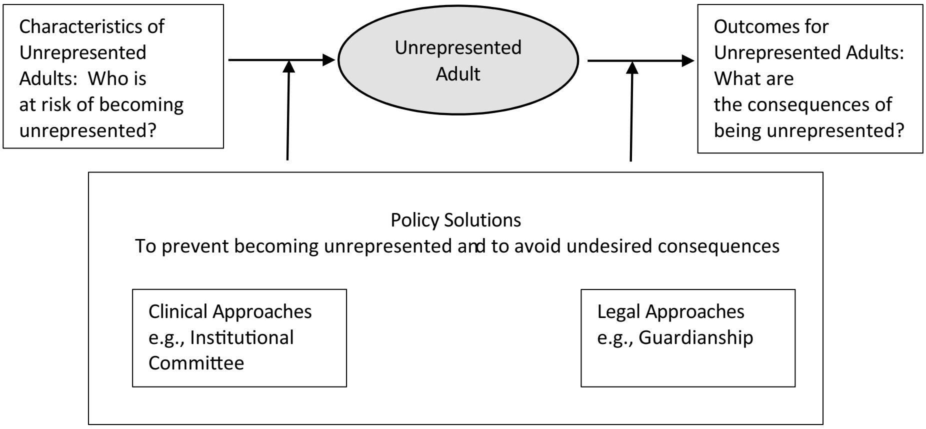

Figure 1. Conceptual framework for understanding and resolving issues related to unrepresented adults.

adults at risk of becoming unrepresented so that it can be avoided by finding possible healthcare agents and executing advance directives. In addition, the statements recommend clinical approaches for avoiding negative consequences such as reducing overtreatment or postponement of treatment, relying on institutional committees when possible.

The most common legal approach for unrepresented adults is public guardianship. Most U.S. states have a public guardianship mechanism to provide professional guardians when needed which may operate as an independent office, or more commonly through the courts, county, or a state agency (Teaster et al., 2010). There are multiple challenges in finding suitable guardians for unrepresented adults as follows. Public guardianship programs often have inadequate funding and staffing to meet community needs (Karp & Wood, 2003; Teaster et al., 2007). Further, most states do not require training for new guardians, and many people are uncomfortable taking on the responsibility of making major personal, medical and end of life decisions for another, and relatively unknown, person (Wood, 2012). The professional or "stranger" guardian (Bandy, 2009) may not have expertise in the many health, social, and ethical challenges that a person under guardianship faces. Finally, without adequate court oversight, the person subject to guardianship is at risk of being harmed by a guardian's mistakes or outright exploitation. A 2010 U.S. Government report identified hundreds of cases of abuse by guardians across the country (United States Government Accountability Office, 2010). While the prevalence of abuse, neglect, and financial exploitation by guardians is unknown (United States Government Accountability Office, 2016) although most of those who abuse elders are family members (Weissberger et al., 2020). In situations in which the person in need of guardianship is unrepresented and the guardian is uncompensated – referred to as a *pro bono* or volunteer guardian (Table 1) – it may be even more challenging to identify a suitable guardian. If the guardian is not being paid for their time, they may not visit regularly or develop a robust care plan for the person under guardianship (Moye et al., 2016).

Our work focuses on Massachusetts (within the U.S.), where no formal public guardianship program exists. In a previous study, we interviewed 20 local stakeholders in legal, government, and healthcare settings to describe the informal patchwork system of *pro bono* guardianship used in Massachusetts for unrepresented adults (Moye et al., 2016). While the departments of Elder Affairs, Mental Health, and Disability Services provide some guardianship services, in most cases, healthcare institutions seek attorneys to serve *pro bono* in an ad-hoc unregulated effort to fill the gap not provided for by the state. This ad-hoc approach was associated with negative health outcomes including delays in care; inabilities to meet a patient's healthcare needs; and ethical discomfort among interviewees (Moye et al., 2016).

The primary goal of the present study was to describe clinical outcomes for unrepresented adults as described by clinicians. We supplement perceptions of clinicians with views of hospital counsel and guardians. Given the limited research in this area, we sought to more fully characterize issues facing unrepresented adults, integrating views of clinicians and attorneys to inform legislative initiatives within Massachusetts as well as additional policy solutions in Massachusetts and elsewhere.

Methods

Study design and setting

We used a cross-sectional mixed-methods survey of clinicians, hospital counsel, and guardians to characterize three dimensions related to unrepresented adults illustrated in Figure 1**: (1)** Health outcomes for unrepresented persons; (2) Experience with clinical policy solutions for resolving issues with unrepresented adults. (3) Experience with legal policy solutions, specifically guardianship, for resolving issues with unrepresented adults. Our rationale in pursuing survey data was to determine whether we would substantiate (or not) the reports of negative health outcomes found in our qualitative study within a larger survey study. We aimed to use quantitative ratings to provide some estimate of frequency of negative outcomes and qualitative approaches to provide description of these outcomes. Our hypotheses based on our previous qualitative study and the literature were: (H1): Clinicians experience delays in guardianship appointments and in getting appointed guardians to respond; (H2): These delays are associated with negative healthcare consequences for the patient and distress for the clinician.

Participants

Clinicians

The clinician sample was comprised of 81 persons, primarily social workers (48%), nurses (7%), physicians (6%), and others (39%; e.g., master's level psychologists/or did not indicate discipline), who worked in skilled nursing facilities (SNF; 44%), hospitals (35%), or other settings (21%; e.g., rest home). Clinicians reported working in their current setting between 1 and 35 years (M = 8.12, SD = 8.52).

Counsel/Guardians

The counsel/guardian sample was comprised of 23 persons, 12 who serve as hospital counsel (all attorneys) and 11 individuals who serve as guardians, seven of whom were attorneys; others listed their degrees as BS, MS, PA (Physician Assistant) but we are not certain of their profession.

Procedure

Clinicians

The research population was clinicians involved in discharge procedures within Massachusetts hospitals (medical and psychiatric, n = 97), skilled nursing facilities (n = 418), and other clinical settings where clinicians might encounter unrepresented adults (e.g., rest homes, homeless shelters, n = 132). We targeted these settings because we posited that individuals without families or friends are most likely to encounter the need for a supporter/surrogate decision-maker during an acute medical or psychiatric crisis or when moving from acute to residential settings.

To recruit participants, the Project Coordinator contacted healthcare facilities and asked to speak to a discharge social worker. She then explained the purpose of the project and asked if the social worker would receive an e-mail message with the survey and study information. If unable to speak to the clinician after three attempts a voice mail was left. If the clinician indicated interest, a survey link was sent via e-mail; some clinicians requested the survey via letter or fax, which we accommodated.

Of 649 total clinical facilities, phone outreach was completed to 629 (97%); accurate phone information could not be found for 18 sites. Of these, 161 clinicians could be reached and expressed interest (26%) and 81 (50% of those interested) returned surveys, for an overall response rate of 15%, consistent with recent clinician survey response rates (Wiebe et al., 2012).

Counsel/Guardians

We recruited counsel/guardian participants by referral from clinician participants and by directly contacting healthcare institutions. In addition, announcements were distributed through professional organizations including the Massachusetts Guardianship Association, Guardian Community Trust, a local meeting of the National Academy of Elder Law Attorneys, and probate court bulletin boards. Given these multiple points of distribution, we are unable to determine a specific response rate.

Ethical approval

The Research and Development Committee of the VA Boston Healthcare Institution approved the study. Participant responses were anonymous. Participants were not compensated for their time but could enter a survey to win one of four iPads using a link that was distinct from the survey link to maintain anonymity.

Measure

We developed a survey instrument for each participant group (clinicians, hospital counsel, guardians) based on prior qualitative interviews (Moye et al., 2016). An iterative approach to instrument development was employed in which the research team developed item and response formats, made refinements based on expert review by both clinicians and attorneys familiar with guardianship, and additional refinements based on pilot testing with clinician and attorney colleagues.

Clinician survey

After defining terms (Table 1), we asked clinicians to provide background information. First, we asked clinicians to estimate frequency (*weekly, monthly, quarterly, annually*) and quantity (*1–5, 6–10, 11–20, 21+)* of encountering *pro bono* guardians in the past year. Second, clinicians rated their overall experience (*always good, usually good, varies, usually poor, always poor)* and provided examples of helpful and not helpful guardians in open-ended text. Third, clinicians rated the frequency of delays in appointment or action following appointment (*always, often, sometimes, seldom, never*).

Next clinicians rated (*yes, no*) whether they had observed any of nine difficulties which had been reported in our prior study and the literature (Table 3). For this set of items, the internal consistency reliability $\alpha = .86$. We summed these items to create a total scale score for analytic purposes. Clinicians then rated the availability and helpfulness (*not helpful to very helpful*) of five mechanisms (Figure 3) when a serious medical decision is needed for an unrepresented adult (e.g., consultation with an ethics committee). Lastly, we asked clinicians to report the type of facility in which they worked, the facility bed size, their degree, and years in practice. We did not collect demographic data from the clinician participants.

Counsel survey

The counsel survey was focused on articulating problems hospital counsel may have in finding individuals willing to serve as *pro bono* guardians. Again, after defining terms (Table 1), we asked counsel to describe how frequently they served for *pro* bono guardians on an annual basis. Next, we asked them to indicate methods they use to find guardians willing to serve, and typical reasons for individuals refusing to serve from a checklist. Finally, we asked counsel to estimate how long it typically takes to find a person to serve and how many refusals are typical.

Guardian survey

The guardian survey was focused on articulating experiences working as *pro bono* guardians. We asked guardians to indicate reasons for serving as a *pro* *bono* guardian and aspects of their work that are most challenging. All surveys are provided in Appendix A.

Data analysis

Quantitative analyses

We use descriptive analyses to summarize survey responses including percent endorsement for nominal and ordinal data, and mean endorsement for interval data. Cross-tabular comparisons examined differences between sample subgroups based on the clinical setting using the contingency coefficient for nominal data. We used a multivariate analysis of variance with posthoc Bonferroni corrected comparisons to further examine the potential impact of site (hospital, long-term care, other), bed size, and clinicians' years of experience on summed adverse outcomes. Missing data existed at the item level and were not imputed.

Qualitative analyses

We use inductive thematic analysis (Braun & Clarke, 2006)), meaning we coded semantic content of open-ended responses to questions without an *a priori* framework but instead representing the content that emerged. Three coders independently coded each response entered in an excel data file. More than one code could be assigned to a response if indicated. Coding was discussed in one-hour review sessions attended by the three coders and an arbiter. Coding discrepancies were resolved through team consensus, whereas the creation of new codes and definitions was achieved through team discussion. After each coding session, code names and definitions were revised and updated in a code book. We used this approach for the entire data set in an iterative fashion. After full coding, the Project Coordinator checked all responses for consistency with the final codebook. Following the generation of specific codes, two members of the team grouped the coded units into three themes: interventions, attitudes, and behaviors. In describing results, we focus primarily on interventions to illuminate the roles guardians play for unrepresented adults.

Results

Clinician survey

Frequency and quality of interactions with *pro bono* guardians

Most clinicians (81%) encountered between 1 and 5 *pro bono* guardians in the last year, while a few encountered more (6–10 guardians per year, 9% of sample; 11–20 guardians, 8%, 21+ guardians, 3%). Clinicians reported interacting with these *pro bono* guardians at varying frequencies: weekly, 5%; monthly, 27%; quarterly, 46%; annually, 22%.

When describing their overall experiences with guardians, about one-half (56%) said their experiences varied, and about one-third (37%) said it was usually or always good. Only 6% said their experiences with guardians were usually or always poor. Clinicians working in hospital settings rated their experiences with guardians more negatively than those working in skilled nursing facilities ($F(2,71) = 3.04$, $p = .05$). In qualitative comments, clinicians rated six areas where responsive guardians were helpful, and conversely, where less responsive guardians were not helpful: care transitions, medical problems, quality of life, housing, financial, and safety (Table 2). As seen in the exemplar responses, domains of helpfulness were often inter-related – for example, a guardian resolved a financial or housing problem leading to needed care transition and enhancing quality

Table 2. Interventions or actions by guardians in six domains emerging in qualitative analysis.

	Exemplar Quote	
Domain	Helpful/responsive Guardian	Not helpful/responsive Guardian[a]
Care transitions	"Guardian participated in a conference call with family to address advanced directives, resulted in hospice services for it. Guardian was respectful of family wishes, attentive to resident's quality of life." (#30)	"Sometimes the guardian is in place, but the process to get authority to make decisions like nursing home placement or hospice care takes way too long and the patient suffers." (#22)
Medical problems	"I know one pro bono guardian who met regularly with the client, providers and family. This person really made a difference in the quality of care the person received." (#67)	"Guardian did not have authority to make end of life decisions and had to go back to court to get it. Patient had to be treated on a vent until court would hear the case. Took 24 hours." (#3)
Quality of life	"Guardian very actively appealed loss of services for consumer, actively pursued alternative housing, very involved with quality of life for consumer." (#36)	Guardian stated inability to decide advance directives without a special court permission. Causes unnecessary discomfort, even harm to very ill, elderly patient." (#56)
Housing	"[Guardian] getting a patient reluctantly out of an unsafe home setting and into an assisted living facility which they ultimately liked very much." (#35)	"Guardian totally dragged feet on working during a very small window of opportunity to transition consumer to an assisted living residence." (#64)
Financial	"The court-appointed guardian has taken control of the elder's finances to the point of distributing her check to her weekly." (#35)	" … The ward lost his [Medicaid Insurance] because guardian did not file paperwork. The ward's dementia progressed significantly and he became at-risk and unsafe in his assisted living program – requiring more level of care. He faced eviction for the two previously stated reasons." (#66)
Safety	"Pro-bono attorney responded quickly to very serious case of elder neglect. Was able to get comfort measures for elderly patient quickly who was suffering and alternative living/care arrangements were made quickly while working with law enforcement against neglectful party." (#40)	" … Another patient could not be admitted to long term care facility due to no guardianship in place. This patient was prone to wandering from my unlocked facility. (#19)

Note. Subject numbers in parentheses. Minor edits made for grammar and clarity.

[a] Some responses speak more to problems with the guardianship system rather than a particular guardian.

Table 3. Clinician perception of negative consequences associated with delays in guardian appointment or action.

Consequence	Yes %
I experienced distress in my clinical role because of an inability to act	67.5
Prolonged hospital stay, past a medically necessary point	65.8
Unable to provide the patient something that may improve quality of life	57.0
Delay in appropriately transitioning the patient to hospice or end of life care	51.9
Delay in treatment or surgery	49.4
We just had to make a healthcare decision on behalf of the patient	48.1
The patient was in physical or psychological pain	48.1
Delay in authorizing charges/coverage for care	40.3
We had to continue with what seemed like medically non-beneficial care	39.0

of life. Clinician descriptions of unhelpful guardians revealed that it may not be the person of the guardian per se who is not helpful but rather issues related to the guardian's legal authority, or simply the length of time it takes (presumably to complete legal paperwork and obtain a court hearing date). Other responses suggested that the guardian did not respond in a time-sensitive manner needed for the dynamic healthcare context.

In addition to these specific actions, clinicians also described attitudes of helpful guardians: knowledgeable, caring, altruism, and involved. They also described helpful behaviors: communicative, visits person, participates in team meetings, respects wishes, and involves family. These same codes applied to guardians who lacked these qualities. Clinicians' frustrations with limited or unclear authority of guardians included whether they had the authority to make end of life care decisions.

Experiences of delays and negative outcomes

As shown in Figure 2, perceptions of reasons for delays associated varied, with 43% reporting they often or always experienced delays in initial appointments, and 24% reporting they often or always experienced delays in action once appointed.

As shown in Table 3, the most commonly reported negative outcomes for unrepresented patients were a prolonged length of hospital admission (66%) and the clinician's own personal distress (68%). About half of the participants reported delays in transitioning to end of life care, postponements in surgery, inability to improve quality of life, and mismanagement of patient pain (Table 3). The occurrence of adverse outcomes differed by facility type ($F = 3.01$, $p < .05$), but not facility size ($F = 2.12$, $p = .13$), or years of work at the facility ($F = 1.42$, $p = .24$). In posthoc analyses, clinicians who worked in a hospital setting reported more adverse outcomes than those who worked in other settings (Table 4).

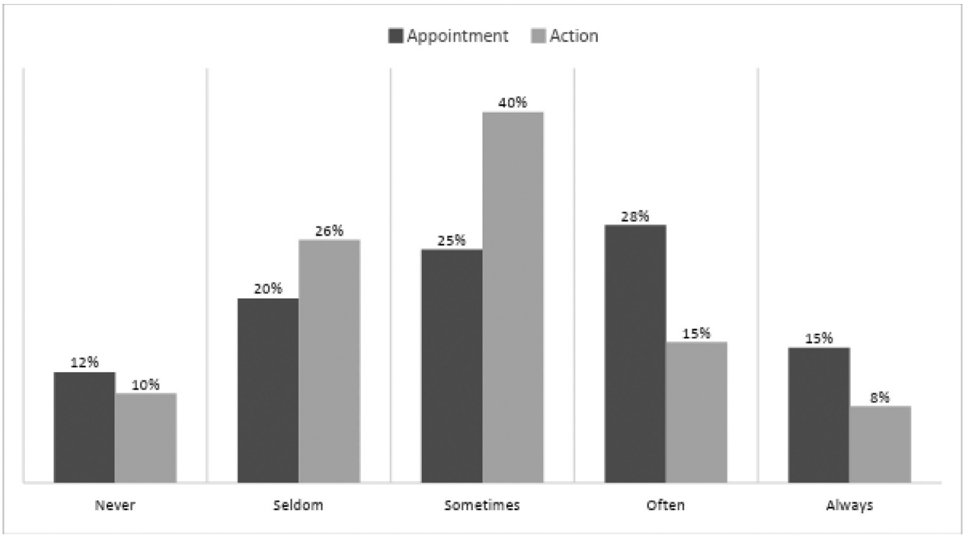

Figure 2. Clinician perception of frequency of delays in guardian appointment or in action by an appointed guardian.

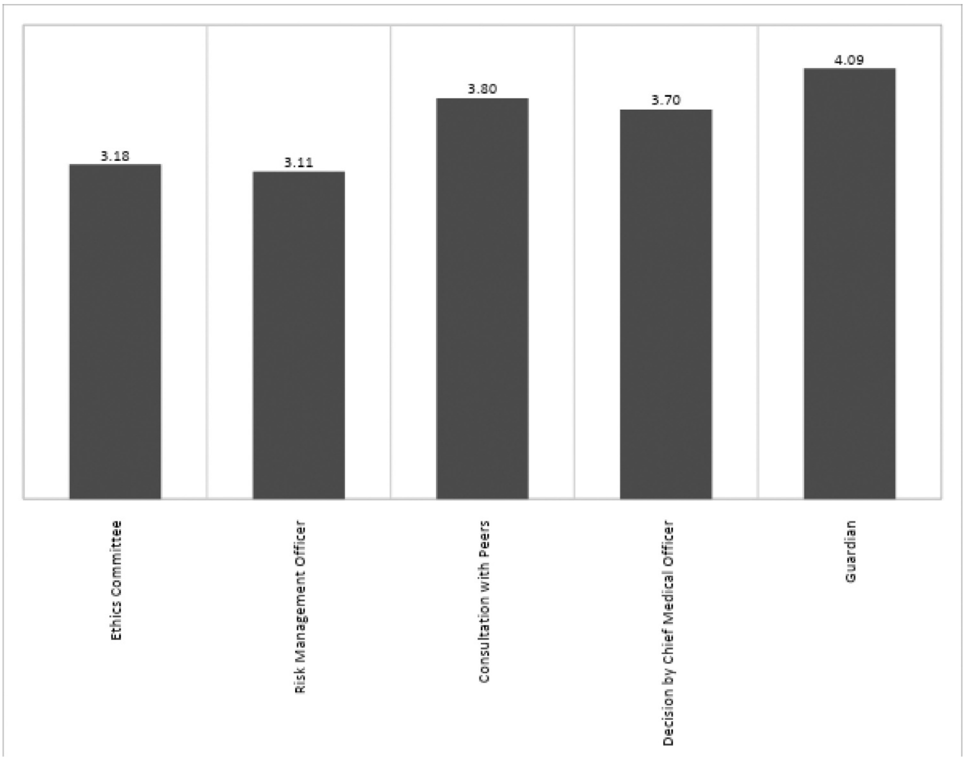

Figure 3. Clinician perception of the helpfulness of mechanism when "you need a serious medical decision made for an incapacitated adult without a surrogate" (1 = not helpful to 5 = very helpful).

Table 4. Adverse outcomes by facility type and size.

Facility Characteristic										
Facility Characteristic	*n*	Mean	*SD*	*n*	Mean	*SD*	*n*	Mean	*SD*	F
Type[a]		Hospital			Long Term Care			Outpatient/Other		
	25	6.20	2.27	30	3.73	3.17	6	4.17	3.19	3.01*
Bed Size		Small (0–100 beds)			Medium (101–200 beds)			Large (201± beds)		
	26	4.19	2.84	20	4.15	3.31	15	6.67	2.26	2.12

Note. Corrected total model F = 2.37, *p* =.030, controlling for clinician years at current facility.

[a] Clinicians in hospitals report significantly more adverse outcomes than those in skilled nursing or outpatient facilities.

*p <.05.

Procedural and policy solutions

Despite varied experiences with guardians, clinicians rated guardianship as the most helpful mechanism when a decision is needed for an individual who does not have family or friends unable to make such decisions him or herself and (Figure 3). Consultation with an institutional ethics committee and institutional risk management officer was less available in long-term care versus hospital settings (Table 5).

Counsel and guardian surveys

Counsel

Hospital counsel (N = 12) estimated they search for *pro bono* guardians to serve unrepresented adults an average of 36 times per year, although this varied considerably amongst those surveyed (ranging from 2 to 200, *M* = 35.83, *SD* = 55.59), presumably related to the size of the hospital, characteristics of the patient population, and the total need for guardians, information not collected. To identify such guardians, they keep lists of those who served in the past (58%), reach out to friends and associates (58%), and ask judges or judicial case managers (42%). On average, five individuals (*SD* = 2.86) declined before a person agreed to serve, taking an average of 17 days (*SD* = 16.03). Common reasons counsel heard for guardians who decline to serve unrepresented adults included preference for paid work

Table 5. Availability of mechanisms to address issues with unrepresented adults by facility type.

Mechanism	Hospital %	Long term Care %	Outpatient/Other %	*C*
Institutional Ethics Committee	96.0	60.0	50.0	.38*
Institutional Risk Management Officer	92.0	51.4	50.0	.38*
Consultation with Peers	96.0	76.5	83.3	.24
Consultation or Decision by Chief Medical Officer	72.0	84.8	75.0	.15
Obtain a Guardian	100.0	94.3	83.3	.24

*p <.05.

(92%), not enough time in schedule (75%), difficulty or complexity of case (67%), or refusal of certain types of cases (42%).

Guardians

The main reasons guardians (N = 11) stated they serve as *pro bono* for unrepresented adults is because they find it personally rewarding (43%, agree "very much"), it encourages other referrals (17%) and because they perceive pressure coming from courts and colleagues (14%). Aspects of their work rated as "very" challenging include completing a Medicaid application (50%), determining supervised living placements (38%), and making end of life care decisions (25%).

Discussion

The findings of this research are three-fold. To summarize, first, clinicians' experience with guardians for unrepresented adults varies but is more positive than negative. Guardians serve critical roles that impact care transitions, medical care, quality of life, and resolve practical issues related to housing, finances, and safety. Second, clinicians and hospital counsel experience delays in guardianship appointments for unrepresented persons, as well as delays in actions after appointments, and these delays are associated with a wide range of adverse consequences for the unrepresented patient and for the clinician – confirming our hypotheses. Third, clinicians still see guardianship as the best mechanism for resolving these issues, although ethics committees and risk managers can be helpful if available. We next discuss these findings in the context of the literature and policy solutions.

These results are consistent with other studies in painting a complex picture of decisional support for unrepresented adults (Bandy et al., 2010; Chamberlain et al., 2019; Teaster et al., 2007). Many clinicians reported positive experiences with guardians and described these guardians as fulfilling key roles on behalf of those they serve. There are also reports of unresponsive guardians, leading to problems accomplishing key tasks critical to advancing the care of the individual. Both findings suggest that guardianship or some responsive mechanism for decisional support is needed – when present, it moves care forward in critical areas such as care transitions, medical care, housing, financial paperwork, and elder abuse. When absent, progress to resolve these key clinical actions is stymied. Guardians in our surveys reported serving *pro bono* for a variety of reasons but most often because it is rewarding. Clinicians themselves refer to guardianship as the most helpful mechanism for resolving issues on behalf of unrepresented adults.

Hand in hand with these findings are also those that find problems with guardians and with the guardianship system. Some guardians lacked key qualities of good guardians from the perspective of the clinician, such as communicating with the team, visiting the person, and participating in team meetings. Guardians too describe the challenges of fulfilling their roles such as completing Medicaid applications and making crucial decisions about placement and end of life care. These results indicate the need for training and support to ensure that guardians are equipped to fulfill roles and make complex care decisions. Further, these findings suggest the need for robust oversight, and in particular, the development of a process accessible to clinicians and the lay public, by which clinicians and others can report concerns about guardians. For example, within Massachusetts, there is no system of public guardianship and no consumer-friendly system of reporting guardianship concerns or abuse. The proposed Office of Adult Decisional Support Services in Massachusetts, currently under legislative consideration, would support an accessible reporting process, which could partner with Adult Protective Services for individuals in hospital settings. The Office could further partner with the State Ombudsman program to promote adequate decision-making for persons in nursing facilities. These partnerships would ensure there are advocates tasked with reporting to the Office of Adult Decisional Support Services when guardians are unresponsive. Furthermore, the Department of Public Health could be tasked with awarding deficiencies to nursing facilities when unrepresented, incapacitated residents are identified, which would provide incentive to the facility to seek decisional assistance for those in need. These suggestions do, however, beg the question of whether clinicians would report problematic guardians if their experience and that of their institutional counsel suggests it is difficult to find guardians to serve unrepresented adults in the first place, such as found here.

The adverse consequences faced by unrepresented adults – extended hospital admissions, delays in transitions to appropriate care, continuation of medically non-beneficial care to name a few – are consistent with prior studies (Chen et al., 2016; Ricotta et al., 2018; White et al., 2006). These data emphasize the vulnerability of persons who are unable to advocate for themselves within healthcare systems and who are without family and friends to do so, adding to the growing body of literature finding adverse health consequences for those who have limited social networks (Courtin & Knapp, 2017). This study largely confirms findings in a handful of studies examining health outcomes for unrepresented adults and extends it by providing data from a larger scale survey and via its inclusion of perspectives from long-term care settings. In this sample, some of the negative consequences were reported more frequently by those in hospital settings, perhaps related to differences in setting or acuity (e.g., a decision may be more urgently needed on a surgery or discharge in a hospital than in a long-term care setting). Also noteworthy is the finding that those who worked in skilled nursing facilities had lower access to institutional ethics committees. This finding is consistent with prior studies documenting lower access to institutional ethics services (Hogstel et al., 2004), and points to the need to develop policy solutions for skilled nursing facilities and to expand access to ethics consultation in these settings (Hogstel et al., 2004; Weston et al., 2005).

Further, this study is the first to document the extent of clinician distress associated with such situations. Given the high degree of concern about clinician burn-out (National Academies of Sciences, 2019) measuring and addressing clinician burn-out related to caring for unrepresented persons may be a fruitful area for future study. Altogether, these facts point to a need to develop nimble systems and innovative solutions to mobilize supporters, and guardians as a last resort, when needed for unrepresented adults.

There are at least two legal approaches to the issues outlined in these findings, namely (1) the passage of statutes or formation of court procedures to enhance guardian oversight so that unresponsive (and abusive) guardians can be replaced, and less restrictive options used when possible; and (2) the passage and funding of public guardianship programs. Such legal reforms are consistent with long-standing consensus conferences on guardianship in 1988 ("Wingspread"), 2001 ("Wingspan"), and 2011 (National Guardianship Network, 2020). However, calls for statutory reform may go unheeded, such as in Massachusetts, or if passed may be under-funded (Teaster et al., 2007), and although rarely studied, guardianship reform may not alter outcomes (Keith & Wacker, 1992).

In response, advocates call for the creation of ongoing state-problem-solving entities to address guardianship reform, entitled WINGS (Working Interdisciplinary Networks of Guardianship Stakeholders) (Wood, 2014). These networks include judicial, legal, disability, aging, and mental health stakeholders. Such interprofessional networks may be particularly valuable to resolving issues related to unrepresented adults where interprofessional co-located teams may best serve complex clients. Other policy solutions may be useful when focusing more narrowly on the issue of unrepresented adults in hospital settings in need of supports and decision-makers to guide and direct care. For example, it may be helpful to conduct an especially thorough search for family and friends to be sure none can be identified. If family/friends are found, it may be helpful to attempt to have the unrepresented person execute an advance directive naming that family/friend as healthcare agent, if the unrepresented person is able and all parties are agreeable (Moye et al., 2016). Such processes take time, which must be balanced with the severity of the clinical picture, especially for hospitalized seriously ill patients who may not have the luxury of a long search process.

When guardianship is necessary it might be helpful to formulate specialized guardianship courts modeled after mental health, drug, or domestic violence courts in which clinical and legal professionals work collaboratively in a treatment-oriented framework (Brown, 2010; Landess & Holoyda, 2017; Morgan et al., 2016). In the case of the hospitalized unrepresented older adult, ideally such courts would be adapted to the needs of medically compromised older adults (Rothman & Dunlop, 2006), while ensuring equal access to due process.

Our data emphasize the importance of including clinicians in interprofessional activities such as WINGS and other collaborative solutions. Clinicians have important perspectives on the challenges faced by unrepresented adults, knowledge of healthcare structures (e.g., what is hospice and palliative care and when is it appropriate), and on solutions that are responsive to the healthcare context. For example, our data suggest delays in appropriate transitions to hospice and palliative care approaches for terminally ill persons while waiting for guardian appointment or judicial review of authority for appointed guardians. These processes may obstruct healthcare access to these critical interventions for unrepresented adults (Sager et al., 2019) potentially representing both a healthcare and justice disparity. When involving clinicians, it is important to avoid clinical conflicts-of-interests such as those outlined in recent policy statements (Farrell et al., 2017; Pope et al., 2020).

In addition to legislative and court procedure reform, education and support for guardians should be part of the network of solutions to the problems faced by unrepresented adults. As of 2017, 11 states required certification for guardians at some level; Massachusetts does not. States vary in the type of education offered and required, with some offering a short webinar and others requiring certification from the Center for Guardianship Certification (Hurme, 2017). Training may be offered by states, courts, or organizations and cover topics from the basics of guardianship law to ethical decision-making. Serving as a *pro bono* guardian for an unrepresented adult is, at the end of the day, most often an altruistic act. It is important to provide such guardians with more resources for completing practical (e.g., Medicaid applications) and ethically complex (e.g., end of life care decisions) tasks. Further, the network of solutions might include programs that provide decisional support outside of guardianship. As noted in the introduction advocates for individuals with disabilities promote the use of supported decision-making rather than guardianship. For the older adult without an advocate who may have a reduced social network, solutions might draw upon the emerging body of literature of interventions to build social networks (Gardiner et al., 2018), as well as more focused programs designed to identify and train volunteers to serve as healthcare agents (Bandy et al., 2014). Suffice to say a critical next policy step would be to develop algorithms to identify those adults at risk for becoming "unrepresented" and intervene early such as in an annual primary care visit to identify health-care agents and to execute advance directives using validated techniques (Freytag et al., 2020), drawing from a pool of trained volunteers. Funding to develop, implement, and evaluate such programs should be a critical consideration.

Limitations

This study has numerous limitations. Many clinicians we called did not express interest in completing the survey, and of those who did, only half returned surveys, such that our findings may have response bias, and the frequency rates reported here may not generalize to all clinicians. Further, estimates of the frequency with which clinicians encountered *pro bono* guardians may be subject to recall bias. We developed a new survey based on previous study, literature review, and team consensus but do not have data on the psychometric characteristics of the survey. In addition, we did not collect demographic data from our participants. We also were unable to calculate a response rate for the hospital counsel and guardians included here, but we struggled to obtain participants and our sample size for this group is very low. We include their responses because the body of literature regarding unrepresented older adults is so small (only five studies in a 2018 scoping review) (Chamberlain et al., 2018) and they provide additional insights on the challenges of identifying guardians and serving as guardians, but their responses should be viewed through a more qualitative lens.

Conclusions

Guardians may fulfill critical roles in advancing the care of unrepresented adults in advancing care transitions, medical treatment, quality of life, housing, finances, and safety. However, in Massachusetts, the current ad hoc *pro bono* approach to providing decisional support to unrepresented adults through guardianship is inadequate to meet these needs, with these individuals often facing prolonged hospital admissions, delays in transitions to palliative care, other adverse outcomes. Legal solutions such as enhanced guardianship oversight, a thorough search for less restrictive options, and a fully manifest public guardianship system are needed. In addition, innovative approaches to education and enhancing social networks are needed that incorporate the views of clinicians who provide a voice for unrepresented adults unable to advocate for themselves.

Acknowledgments

We thank the individuals who participated in our research survey who each gave generously of their time to share their perspectives about this important issue.

Disclosure statement

The authors have no conflicts of interest to report.

Funding

This project was funded by the Guardian Community Trust. In addition, this material is the result of work supported with resources and the use of facilities at the Veterans Administration (VA) Boston Healthcare System. The contents do not represent the views of the U.S. Department of Veterans Affairs or the United States Government.

Key points

- Unrepresented adults (decisionally impaired with no one to serve as healthcare agents) face adverse healthcare consequences.
- Guardians are key in resolving needs for unrepresented adults.
- However, there are often delays in appointment or actions; some guardians are unresponsive.
- Policy responses combining legal and clinical expertise must inform efficient solutions.

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