

Ethical Concerns and Procedural Pathways for Patients Who are Incapacitated and Alone: Implications from a Qualitative Study for Advancing Ethical Practice

Jennifer Moye¹ · Casey Catlin^{1,2} · Jennifer Kwak¹ · Erica Wood³ · Pamela B. Teaster⁴

© Springer Science+Business Media Dordrecht (outside the USA) 2017

Abstract Adults who are incapacitated and alone, having no surrogates, may be known as “unbefriended.” Decision-making for these particularly vulnerable patients is a common and vexing concern for healthcare providers and hospital ethics committees. When all other avenues for resolving the need for surrogate decision-making fail, patients who are incapacitated and alone may be referred for “public guardianship” or guardianship of last resort. While an appropriate mechanism in theory, these programs are often under-staffed and under-funded, laying the consequences of inadequacies on the healthcare system and the patient him or herself. We describe a qualitative study of professionals spanning clinical, court, and agency settings about the mechanisms for resolving surrogate consent for these patients and problems therein within the state of Massachusetts. Interviews found that all participants encountered adults who are incapacitated and without surrogates. Four approaches for addressing surrogate needs were: (1) work to restore capacity; (2) find previously unknown surrogates; (3) work with agencies to obtain surrogates; and (4) access the guardianship system. The use of guardianship was associated with procedural challenges and ethical concerns including delays in care, short term gains for long term costs, inability to meet a patient’s values and preferences, conflicts of interest, and ethical discomfort among interviewees. Findings are discussed in the context of resources to restore capacity, identify

✉ Jennifer Moye
Jennifer.moye@va.gov

¹ VA Boston Healthcare System and Harvard Medical School, 150 South Huntington Ave, Jamaica Plain, MA 02130, USA

² Boston VA Research Institute, Inc., 150 South Huntington Ave, Jamaica Plain, MA 02130, USA

³ American Bar Association Commission on Law and Aging, 1050 Connecticut Ave NW, #400, Washington, DC 20036, USA

⁴ Virginia Tech, 230 Grove Lane, Blacksburg, VA 24061, USA

previously unknown surrogates, and establish improved surrogate mechanisms for this vulnerable population.

Keywords Guardianship · Surrogates · Ethics · Healthcare providers · Incapacitated adults · Unbefriended

Introduction

Adults who are incapacitated and alone, having no surrogates, may be known as “unbefriended.” Decision-making for these particularly vulnerable patients may be a concern for healthcare providers and hospital ethics committees (Pope and Sellers 2012). Finding solutions to the care of these patients is an issue that spans healthcare, law, and ethics.

There are at least four approaches to healthcare decision-making when individuals cannot make decisions themselves (Table 1) (Sabatino 1991/1992). In an ideal world, adults direct or delegate family or friends to make health decisions for themselves, planning for a time when they may lack the capacity to do so themselves. When there is no advance planning, health decisions may devolve to a “default surrogate” as defined in state law. These laws set out a hierarchy of family and friends who are authorized to make selected health care decisions if no advance directive was executed. When these mechanisms fail—in states with no default consent law, or when patients have no family or friends to serve as surrogates, or when those family and friends are unsuitable or abusive—clinicians may displace the decision to others such as hospital ethics committees. In some cases, hospitals may ask the court to appoint a decision maker through a guardianship mechanism (Castillo et al. 2011; Connor et al. 2016).

We are in critical need of studies that estimate the prevalence, dimensions, and care consequences of the population of adults who are incapacitated and alone (Karp and Wood 2003). The prevalence of adults who are incapacitated and alone ranges

Table 1 Four mechanisms for surrogate decisions

Mechanism	Description
Directed	Allows a person to specify certain decisions in advance in written instructions, such as a living will
Delegated	Allows a person to delegate authority to an agent through a healthcare power of attorney; the individual maintains autonomy by specifying who will decide about treatment and which factors to take into account in the event of later incapacity
Devolved	Occurs under default surrogate-consent laws enacted in more than thirty-five states, which specifically authorize family members or others to make choices about treatment if no advance directive exists
Displaced	Refers to judicial intervention through guardianship or special court transactions; although guardianship can meet needs and offer necessary protection with court oversight, it removes basic human rights and can be costly and cumbersome. It is a last resort

Adapted from (Sabatino 1991/1992)

from 3 to 10% of hospital and long-term care populations, affecting adults of all ages, most often older adults (Connor et al. 2016; Isaacs and Brody 2010; Teaster 2002). Most clinicians report encountering these patients and participating in the medical decision-making process on behalf of such patients (Bandy et al. 2010; Torke et al. 2007). In fact, a study of patients in a medical intensive care unit (ICU) found that one in six admitted patients remained incapacitated and without a surrogate during their entire ICU stay, and the median length of stay for these patients was twice as long compared to their counterparts in the medical ICU (White et al. 2006). In one survey, 75% of physicians reported having made a medical decision within the past month for a patient who lacked that capacity (Isaacs and Brody 2010). Another study found that 81% of life support decisions for patients who were incapacitated and alone were made by physicians without hospital or judicial oversight (White et al. 2006, 2007).

When clinicians don't make the healthcare decision on behalf of the patient, and all other avenues for resolving the need for surrogate decision-making fail, patients who are incapacitated and alone may be referred for "public guardianship." Some states create an Office of the Public Guardian, while others states organize this through the courts, county, or a state agency (Table 2) (Teaster et al. 2007). In theory, such offices provide guardians for individuals who lack family members or friends to serve in this role and provide other crucial oversight of this vulnerable population (Teaster et al. 2010). However, the suitability of public guardianship is tainted by the wide variation and potential and real inadequacies of these systems (Teaster et al. 2007).

In this paper, we describe a qualitative examination of public guardianship and its consequences for hospital patients within the Commonwealth of Massachusetts as a

Table 2 Public guardianship mechanisms within the United States as of 2016

Independent state office 5 States	Within social service agency model 32 States			County model 10 States	Court model 6 States
AK	AR	MA	RI	AL	DE
IL	CO	MI	SC	AZ	HI
KS	CT	MN	SD	CA	MS
NM	FL	MT	TN	DE	WA
OR ^a	GA	NH	TX	IL	DC
	IN	NJ	UT	NV	NE ^a
	IA	NY	VT	NC	
	KY	OH	VA	ND	
	LA	OK	WV	WI	
	ME	PA	WI	MO	
	MD		WY		

Adapted and updated from (Teaster et al. 2007)

^a Recently established

jumping-off point for commentary and resource generation. Some background about Massachusetts is needed to set the stage for the results of the inquiry that follows. In 2008, the Commonwealth of Massachusetts re-enacted its guardianship statute, closely following the model law, the Uniform Guardianship and Protective Proceedings Act. Subsequently, Massachusetts courts have worked to address other aspects of guardianship, such as guardianship monitoring. However, an area that Massachusetts has yet to address is the issue of public guardianship. In addition, Massachusetts is one of a handful of states that does not have a default surrogate consent law, potentially elevating the need to pursue guardianship appointments even when one does have family or friends if no advance directive was executed. Technically, Massachusetts has an “agency” model of “public guardianship” in that there is state funding for guardians for approximately 916 adults annually who meet specific criteria (e.g., victims of elder abuse) (Table 3). However, this is estimated to leave more than 3000 adults in need of state-funded guardians (Moye et al. 2016). When funding for these slots is exhausted or if individuals do not qualify for services, petitioners turn to an ad hoc custom of seeking unpaid persons to serve. Petitioners locate guardians, usually attorneys, who will serve in a *pro bono* capacity (Moye et al. 2016). Guardians may do so out of an earnest desire to provide some *pro bono* service and/or under an unspoken or explicit *quid pro quo* arrangement with an expectation of receiving paid work in the future. We use the term “unpaid” to distinguish this from explicitly designed *pro bono* guardianship programs that include structures and safeguards such as training, monitoring, evaluation, and quality control measures. While there are no data on the number of vulnerable adults with unpaid guardians, this approach is not unique to Massachusetts (Teaster et al. 2007).

The goals of this paper are to describe the results of qualitative interviews with relevant stakeholders with experience in working with adults who are incapacitated

Table 3 Adults under agency-provided public guardianship in Massachusetts as of 2016

Agency	Estimated number	Notes
Agency		
Executive office of elder affairs	170	These adults are drawn from 25,000 elder abuse reports each year.
Department of mental health	20	An estimated 2400 of DMH clients are under guardianship for the main purpose of antipsychotic monitoring; these are not public guardians.
Department of disability services	726	An estimated 12,000 of DDS clients are under guardianship for the main purpose of antipsychotic monitoring; these are not public guardians.
Total	916	
Other		
Grant/donation	Unknown	
Unpaid	Unknown	

and alone within hospital and long term care settings. We aim to add to the limited literature about this issue to describe how different constituencies encounter these adults, strategies used to resolve surrogate consent for these persons, problems that arise, and consequences for patients and the systems that intervene in their care. From this description, we offer suggestions for improving practice relevant to hospital ethics committees, clinicians, and other healthcare providers.

Methods

Participants

We interviewed three groups of participants (Table 4) knowledgeable about adults who are incapacitated and alone. The first group was comprised of senior officials ($n = 4$) within three relevant state agencies who serve adults at-risk for being incapacitated and alone to learn more about guardianship processes through their agencies: older adults with neurocognitive disorders, adults with severe and persistent mental disorders, and adults with significant developmental disabilities. These agencies were the Executive Office of Elder Affairs ($n = 1$), Department of Mental Health ($n = 1$), and Department of Disability Services ($n = 1$). We also interviewed an individual with the Disabled Persons Protection Commission ($n = 1$).

The second group was comprised of probate court personnel ($n = 4$) knowledgeable about adult guardianship proceedings. We approached 14 judges and the judicial case managers from probate courts, selecting those who hold “guardianship sessions,” as an indicator of a degree of attention to guardianship within the specific court. We also approached the Chief Justice of the Probate and Family Court.

The third group was comprised of clinicians and hospital counsel from acute and long-term care medical settings ($n = 12$). We approached four clinical social

Table 4 Participant characteristics

Setting	Targets	Completed n	Response rate (%)
Clinical	Hospitals long term care	12	85
	Clinical and legal staff		
Agencies/entities	Executive office of elder affairs	4	80
	Department of mental health		
	Department of disability services		
	Disabled persons protection commission		
	MA DD council		
Courts	Judges	4	27
	Judicial case managers		
	Mental health legal advisors commission		
Total		20	

workers from nursing homes serving older adults admitted for skilled nursing needs (e.g., not long term care facilities focused on adults with psychiatric illness or on adults with intellectual/developmental disability). Two were selected from the Boston metropolitan area and two from rural areas, both at random from the state data base of nursing home performance data. We also approached five clinical social workers and attorneys representing five acute care hospitals including urban, suburban, rural, and Veterans Administration (VA) settings. In selecting the clinical sample, our aim was not a comprehensive sample, but rather roughly to match the number of participants from government and court settings. Because the response rate was higher in the institutional group, there were more participants from these settings.

Procedures

The PI or research assistant contacted relevant individuals by letter (e-mail or paper) and then by telephone to explain the project and request permission to interview. Participants completed a structured telephone interview with at least two research investigators—a lead interviewer and a note taker. Notes for each interview were uploaded into a secure shared computer drive upon completion of each interview.

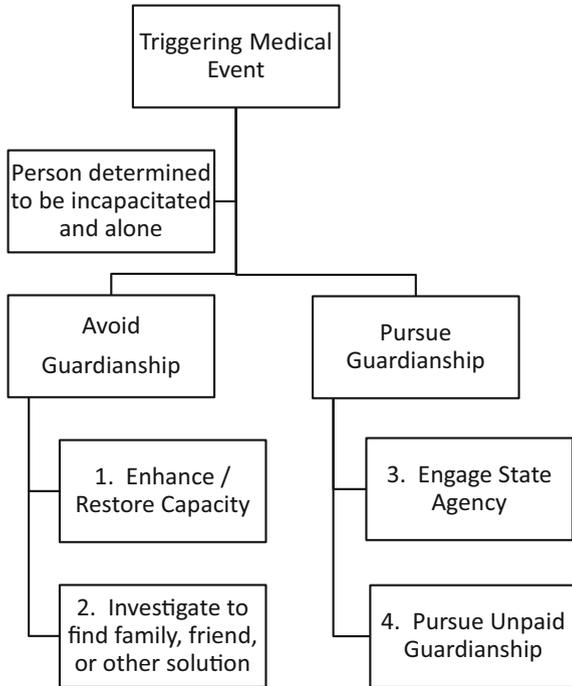
Measures

A separate measure was developed for each participant group. Interview questions were taken from those used in studies of public guardianship in other states, namely “Public guardianship and the elderly” (Schmidt et al. 1981) and “Wards of the state: A national study of public guardianship” (Teaster et al. 2007), which were adapted and refined by the research team for this project. Questions covered four content areas: (1) Do interviewees encounter adults who are incapacitated, alone, indigent, and in need of a surrogate decision maker; (2) Describe procedural paths and mechanisms for addressing the surrogate need; (3) Describe an example; (4) Describe the use of less restrictive alternatives to guardianship or other psychosocial interventions used to avoid guardianship. All were asked to share any other observations; clinicians in particular were prompted to describe problems or concerns. Minor modifications for flow and typographic errors were made after the initial interview. Interviewers had the flexibility to follow up on responses and pose additional questions for further clarification.

Analyses

Analyses of the completed interviews had three components. First, we determined the percentage of respondents who stated they encountered the problem described in their respective clinical, court, or agency setting. Then, we created an overall flowchart (Fig. 1) to summarize responses describing the current procedural paths for addressing the surrogate need. Finally, we coded narrative responses using an inductive approach. The principal investigator and project coordinator of this study (JM and CC) developed a list of content themes and exemplars. These themes were

Fig. 1 Pathways for resolving decision-making needs. *Four* current approaches for addressing surrogate needs were discussed by interviewees. In each of these pathways, the triggering event is the admission or encounter with an adult who lacks decision-making capacity, has no known advance directive document executed, and is without family or friends to make decisions



then reviewed by two legal and policy experts in adult guardianship (EW and PT) and a third reviewer (JK) for clarity.

Results

Pathways for Resolving Decision-Making Needs for Adults Who are Incapacitated and Alone

All interviewees (100%) stated that they “encounter adults who need a guardian (for healthcare or financial decisions) who have neither appropriate or available family/ friends, nor the financial means to pay a professional to serve in that role.” Interviewees described a variety of outcomes for such vulnerable adults, including pathways generated to avoid guardianship (Fig. 1). In each of these, the triggering event is the admission or encounter with an adult who lacks decision-making capacity, who has no known advance directive document executed, and who is without family or friends to make decisions.

Pathway 1: Team Works to Restore Capacity; No Guardianship Needed

In some cases, as care progresses, the patient’s capacity improves, and the patient regains the ability to make healthcare decisions by him or herself. Interviewees

noted it was important to assess decisional capacity and move forward with surrogate solutions so as not to delay care, while at the same time to work to enhance and restore capacity. It is important to acknowledge this pathway, as it illustrates the practice of strong attention to enhancing and restoring capacity, which may lead to the most desirable outcome of avoiding surrogate decision making altogether. Of course, this still leaves the issue of making decisions, typically on behalf of the patient, while awaiting restoration of capacity.

Pathway 2: Team Launches Investigation to Find Family, Friends, and Less Restrictive Alternative to Guardianship

Interviewees described examples of exhaustive and often ultimately successful searches for family and/or friends who agreed to serve in the surrogate role. In some cases, the patient was unable to make a healthcare decision but had the capacity to execute an advance directive and did so. In other cases, the impressive search for family led to the discovery of a previously executed advance directive. Within the VA, default surrogate consent was exercised (an option in many states, but not in Massachusetts, unless the patient is being treated in a VA medical center). Some clinicians had developed impressive and resourceful ways to find family members to serve. For example, clinicians within hospitals maintain relationships with staff across programs that serve indigent adults (e.g., homelessness programs) and reach out to these staff to learn more about the person in need. Interviewees also reported using social media and internet searches to identify family and friends and learn more about the individual in need. Table 6 summarizes information from interviewees about their search methods.

Interviewees also noted that family, once found, may need support to serve as surrogates, or—if needed—as guardians. For example, one probate court developed a family clinic in which professionals provide assistance to family members in completing petitions, care plans, annual accounting, and other paperwork required by the courts. The court recognizes that being a guardian is a serious, sometimes overwhelming, and often life-long commitment. The paperwork requirements and complexities sometimes exceed the abilities and resources of family members.

Pathway 3: Team Engages an Agency that Petitions for Guardianship

Interviewees also provided examples of appropriate and successful engagement of an agency serving at-risk adults. In one example of state-funded guardianship services managed by the Executive Office of Elder Affairs, an adult protective report was made for an adult found living in squalor in the family basement. The adult had lived with parents, but after the parents died, was increasingly less able to function. When the adult was placed under guardianship, the guardian was able to initiate appropriate healthcare and housing. After receiving these services, the adult's capacity improved, the guardianship was terminated, and rights were restored. The guardian continued as the agent under power of attorney, as requested by the adult. This example illustrates the role guardians can take in arranging appropriate care, maximizing functioning, and efficiently using resources when

funded to follow a person over an appropriate time period. In Massachusetts, agencies that may become involved with at-risk adults include the Executive Office of Elder Affairs, Department of Mental Health, and the Department of Disability Services.

Pathway 4: Team Asks Hospital Counsel to Petition for Guardianship

All those interviewed also spoke of a common pathway, in which no family or friends can be located, a guardian is needed, and agency funding is not available/appropriate. When no other options remain, the hospital may then seek to have a guardian through the state's unpaid approach. As previously noted, Massachusetts does not have a public guardianship system *per se*, and so this often means the hospital counsel petitions for guardianship and is responsible to find a person to serve in an unpaid capacity.

Procedural Challenges and Ethical Concerns When Using the Unpaid Approach

In using the state's unpaid approach to guardianship for those who are incapacitated and alone, interviewees described procedural challenges and ethical concerns.

Procedural Challenges

Interviewees across agencies, courts, and healthcare institutions raised concerns about problems created by the lack of a sufficient public guardianship system.

Identifying Guardians to Serve. Petitioners and courts reported significant difficulty identifying guardians. Interviewees spoke of time invested, inefficient use of funds, and the crisis created.

Everyone will scramble. Oftentimes, it comes from a hospital—they want to transfer to a rehab facility, and no one is identified who can consent. So some of the hospitals have some attorney; they have created their own list of people they would recommend. The same hospital attorneys understand we have what we call “The List.” We no longer can print these lists out. Those on the list have to be attorneys who are willing to take guardianship for no fee to be a fiduciary. The list is pretty short. A lot of attorneys—this is not what they are looking to do—you have to be an attorney to be on that list (\$10).

Engaging and Sustaining Guardians Once Appointed. Interviewees in clinical and court settings discussed concerns related to maintaining appropriate guardianship that meet the patient's ongoing needs. They stated that a guardian may be appointed but only as a temporary guardian without incentive within the system to determine whether a longer-term guardian might be able to advocate for care for the individual. For example, a judicial case manager reported:

It happens frequently with homeless people. We had a homeless guy with no one, and they needed a guardian and couldn't find anyone, so they came to

court and asked what to do. Unless there's a Rogers¹ component, there won't be someone to take that case. We took him to our list and eventually found someone to do the case. Sometimes, the person who says they'll do the case will only do it temporarily, with temporary guardianship and get the person through what they need (S06).

Further and in particular, clinicians bemoaned the consequences of working with over-worked and under- or unpaid guardians, explaining that the overall quality, and, especially, the responsiveness of guardians for making decisions, was uneven. One respondent stated:

Some guardians are completely invested, and they are such a pleasure to work with, they are really looking out for and trying to understand this person. With others, they are spread so thin and their time is so limited, it's a struggle to reach out to them (S08).

When asked about the qualities of a "good guardian," one respondent replied with a remarkably low standard: *Someone who answers the phone and visits once per quarter* (S14). In addition to difficulties in getting telephone calls returned, clinicians spoke of guardians who return calls but who are reluctant to expend time on the case. Agencies also identified difficulty replacing guardians who wished to retire or who had died. Other respondents noted that guardians might not have training or expertise relevant to the individual's needs. For example, the present system relies almost exclusively on attorneys. Most attorneys have the legal and financial skills to serve as guardians, but not all attorneys have the social services, healthcare, gerontological, or disability background to make appropriate surrogate decisions. A clinician stated, *We don't have the luxury of finding the perfect person for the patient* (S11).

Meeting the Needs of Special Populations. As difficult as the situation is on a day-to-day basis, interviewees identified particular populations that were nearly impossible to serve. These populations include: adults who have multiple problems that span multiple agencies (e.g., dementia and psychosis); those who are involved with the Department of Corrections; those whose paranoid disorder causes them to be hostile to guardians; and those with specific psychiatric disorders. For example, a participant noted:

The hardest to find is people who are willing to take eating disordered patients; they are hardest to deal with. Verbal, smart patients who can manipulate the system and people. They don't have capacity or understand their disease. Need someone to make hard decisions for them. Even if they have family, we'll get an independent guardian (S11).

¹ Massachusetts offers limited payment to guardians who are appointed with authority to monitor antipsychotic medication use, colloquially referred to as 'Rogers,' after the case which led to the practice. *Rogers v. Commissioner of the Department of Mental Health*, 390 Mass. 489, 458 N.E.2d 308 (1983).

Ethical Concerns

In addition to speaking about their frustrations with simply finding guardians to be appointed or getting responses from guardians once appointed, many persons whom we interviewed raised concerns about negative consequences for patients or simply more general ethical discomfort.

Delays in Care. In particular, clinicians noted adverse outcomes for individuals associated with the difficulty of locating appointed guardians. They expressed concern about delays in discharge leading to risks for the patient—for instance, the patient ends up in an environment too restrictive for him or her and without appropriate care (e.g., rehabilitation) while being exposed to hospital-related risks, for example:

I've gotten on the phone and begged someone to take someone. We had a 19-year-old with a head injury after a motor vehicle accident. Every day they stay here they are losing their rehab ability. And really it is because they don't have a legal guardian, not because [of] insurance. Really awful (S16).

There are patients who stay longer than they need to, at higher risk of infection and fall, less autonomous, worse for family and staff members, only here because of delay in guardianship, and that is extended when you don't have an involved family member (S11).

Short Term Gains for Long Term Costs. When guardians are not paid and therefore unable to follow the person over time, the guardian may not be able to advocate to achieve long term outcomes consistent with the individual's needs and preferences. In some cases, guardians may be appointed for “discharge purposes only,” as illustrated by this example:

The person gets discharged by the rehab into the community. They say, “We can't continue the guardianship because we don't have someone to continue the guardianship.” They (the patient) gets lost and then shows up again, and we start again (S12).

Inability to Meet the Person's Values and Preferences. Clinicians expressed real concerns about the impact of the current system on their ability to meet the patient's needs, preferences, and values on a more basic level. For example:

We had a challenging patient—waiting for years to get into a specialty nursing home all male unit—usually a 1–2 year wait list. We are about ready to discharge him—then I found out the guardian has gone to Florida. We've tried to contact him several times. One of the ongoing issues is the patient wants to have Cheetos, and he is at a high aspiration risk—but it is a quality of life issue. The patient himself is willing to say DNR/DNI, but I want Cheetos. The guardian, because he is in Florida, has not made a decision. He says, “I'll get back to you later, I'll address that when I get back.” He is not going to get back until after Thanksgiving. For months on end the guardian has been putting us off (S18).

When possible, clinicians worked to get information about the patient's values to support the guardian in his or her role.

An independent guardian has no prior relationship with this patient so it's a complete stranger coming in, making very challenging decisions, sometimes life or death. What we try to do is explore as much about a patient's past as possible. So that when the guardian comes in, we can give history—social history beyond just medical history—so that the guardian has at least some background based on not just what the medical team is recommending but what the patient would want. Quite often we don't have that background information so the guardian works with the medical team and the patient doesn't have a voice in that (S08).

Conflicts of Interest. The current practice of appointing guardians working on an unpaid status as requested by the hospital may create a potential conflict of interest. By law, guardians should be exercising substitute judgment, representing the individual, but perhaps might feel pressure to consider the hospital's preferences. One interviewee's comments seemed to focus more on the hospital's needs rather than the incapacitated person's wishes:

Some guardians really don't get their role. Their biggest mistake is taking too much guidance from the incapacitated person. That is not what you are supposed to do. A guardian may say "I have been named the guardian, and the patient doesn't want to go, so I'm not going to force." This happens more often with family guardians than corporate. Family has a harder time shifting their thought process to being independent of the incapacitated person (S12).

Discomfort with the Structure of the Current System. Interviewees spoke of their appreciation for those guardians trying to do their best but raised concerns about the viability of an ad hoc unpaid approach:

A problem is how few people there are who can do this. Often, the people who do it take on have too many cases, and then they're not doing as good a job as we wish they would in being this person's guardian. Both locating people willing and those people may be overloaded. We can't keep going to the well (S12).

We are finding fewer people willing to be guardian, and those there aren't doing a great job. We need data on whether there's follow up, are they really doing their job? A lot of them aren't, and a lot are, because they aren't being paid (S11).

Others were more succinct in capturing their disregard for the current system.

I don't think that individuals are well served by a system that considers the medical and other life decisions as a "freebie" for poorly paid Rogers Monitors (S17).

To say that the current system is working is like saying our democracy is working because there's no civil war (S11).

Discussion

Our interviews with professionals in clinical, court, and government agency settings throughout Massachusetts revealed a complex, unofficial, and inadequate system to serve the “unbefriended” in need of surrogates. While the exact prevalence is unknown, in this study, the occurrence of working with patients who are incapacitated and alone is frequent enough that every person interviewed had encountered it. Because there is no formal system of public guardianship in place in Massachusetts, indigent “unbefriended” adults are served by unpaid guardians, some of whom can be difficult to both recruit and engage. While many have good intentions, they may easily become overwhelmed and ill equipped to meet the emerging and complex needs of special populations. The interviewees noted that these difficulties often result in patients whose individual needs are not met.

These procedural challenges and ethical concerns demonstrate how vulnerable these adults are. Such patients have no advocate at the individual level to guide their care and no advocate at the macro level to advocate for policy change. While, in theory, public guardianship is designed to provide surrogate decision-making for these vulnerable individuals, if the public guardianship system is not adequately structured or funded, healthcare providers and hospital ethics committees are likely to be involved certainly before and sometimes after guardianship appointment.

There are a variety of potential surrogate mechanisms for adults who are incapacitated and alone (Table 5). We have little information on what those who are incapacitated and alone would want. A recent study of homeless persons who lacked

Table 5 Strategies to provide surrogates for the adult who is incapacitated and alone

Mechanism	Limitations
Public guardianship	<ul style="list-style-type: none"> • Not equipped to handle growing number of unbefriended • Quality, sophistication, and involvement of public guardians vary
Physicians as surrogates (may have ethics committee involvement)	<ul style="list-style-type: none"> • Potential for bias and conflicts of interest when only members of a particular institution make decisions for their patients
Trained volunteers as surrogates	<ul style="list-style-type: none"> • Typically focused on those with developmental disabilities and psychiatric disease rather than on older adults with neurocognitive illness • Requires resources for training
Detailed institutional decisional pathway	<ul style="list-style-type: none"> • e.g., Department of Veterans Affairs: degree of review increases as risk and invasiveness of the proposed treatment increases • Potential for bias and conflict of interest since decisions are made internally (somewhat mitigated by multiple levels of review) • Only suitable for internal medical decisions (i.e., cannot be used to allow long-term placement in a community facility)

Adapted from (Connor et al. 2016)

family revealed that half would want decisions regarding life-sustaining treatment to be made by their physician if they were incapacitated, and 80% would prefer a physician rather than a court-appointed guardian to make these decisions (Norris et al. 2005). Similarly, some suggest that the treating physician in consultation with the hospital ethics committee is the most appropriate surrogate mechanism (Courtwright and Rubin 2016). However, others note the potential for conflicts of interest and advocate for trained volunteer programs (Bandy et al. 2014). Detailed institutional pathways that outline these and other approaches may be useful (Table 5).

Each pathway presents ethical dilemmas. Ideally, surrogates who know the individual longitudinally make decisions for an individual with diminished capacity using substitute judgment informed by the individual's values and goals. In the case of an unbefriended adult, the key problem is the lack of an individual who knows the patient and the patient's values and goals. The attending physician, knowledgeable of the patient's medical condition and charged with an ethical obligation to act in the patient's best interests may be in the best position to do so. However—there may be several constraints for the attending physician. For example, depending on the jurisdiction, the physician, even with the oversight of the ethics committee, may be limited in their ability to make decisions involving extraordinary measures (e.g., withdrawal of life sustaining treatment). Further, some decisions may require longitudinal involvement and authorities beyond the physician's role. For example, if it is in the incapacitated patient's best interests to transfer to a long-term care facility—the physician could face pressures to make this decision efficiently to avoid hospital costs. However, the receiving institution may not accept the patient without a legally appointed surrogate who can continue to manage the patient's care and complete associated documentation such as a Medicaid application. The ethical obligations of the clinician to act in the patient's best interest may be at odds with the institutional ethics to provide as much care as possible for patients with limited means and with an outside facility's obligations to accept patients for whom they can provide adequate care. One could argue that a neutral surrogate such as a public guardian may be in the best position to navigate these multiple relationships—but the neutral person is also restricted by her lack of knowledge of the patient, potentially limited medical knowledge, and limits of their ability to act in an unpaid manner if that is being required. Within these complex and conflicting pathways, hospital ethics committees can serve as a safeguard to weigh the advantages and disadvantages of various solutions, ensuring that decisions are well vetted and include diverse viewpoints. Involving multiple perspectives and disciplines to resolve the ethical dilemmas that can arise when treating “unbefriended” individuals will hopefully best align care with the patient's values and goals.

While our interviews raised concerns about what isn't working in the system, we were also impressed with the positive practices that our interviewees have crafted. *Many* steps can be taken to avoid guardianship altogether in resolving surrogate needs. First, our interviewees reported that they were also sometimes able to locate family or friends, even when an individual was thought to be “unbefriended,” thus removing the need for an unpaid guardian and providing invaluable information

about the patient's history and preferences. Techniques used for identifying family and friends described by our interviewees are provided in Table 6. Of course, the search for potential surrogates or information about the patient's previous care preferences requires knowledge of these options and resources (time) to pursue them. Second, it is essential for healthcare providers to recognize that capacity may fluctuate and can be restored, thereby eliminating the need for a surrogate. A list of conditions and possible interventions to restore capacity is provided in Table 7. Third, advance care planning should be encouraged, through hospital and community based programs such as "The Conversation Project" (<http://theconversationproject.org>). Finally, and perhaps most importantly, it is critical for healthcare providers, ethics committees, and legally appointed surrogates to be knowledgeable about the patient's values and goals. Even patients with diminished capacity may be able to describe these. Structured "values interviews" may assist clinicians, committees, and surrogates in eliciting such values (Doukas and McCullough 1991; Naik et al. 2016; Karel et al. 2004).

Limitations

There are a number of limitations to this study. First, the sample size in this qualitative study was small. A larger survey would be necessary to determine if the views expressed herein represent those of the larger community. Second, we interviewed social workers, hospital counsel, and agency officials, but did not interview physicians, guardians, or members of healthcare ethics committees. Future work will need to explore the viewpoints of these constituent groups to fully describe the problem. Third, the study focused on the state of Massachusetts only, which has unique characteristics to its laws (e.g., no default surrogate consent law). The practices in Massachusetts do not reflect those of other states in the United States or of other countries. Fourth, some of the appendices provided herein are drawn from other sources, not from the present study. We did so to provide resources within this manuscript, but some were not generated from the current work.

Conclusion

Solutions to the problems raised herein reside at the intersections of healthcare, law, and ethics. On a macro level, we need robust and long-term problem solving that involves clinical—legal partnerships. For the times when public guardianship cannot be avoided, adequately funded and monitored solutions are needed that may require changes in laws and funding. But, legal solutions alone are inadequate to guide care in dynamic, complex healthcare environments. A multidisciplinary approach is necessary to provide a menu of options—involving clinicians, healthcare ethics committees, and the guardianship system—that fits different and evolving situations in addressing surrogate needs. Adults who are incapacitated and alone are some of society's most vulnerable and invisible individuals, and their

numbers are growing as the population ages. Collaboration is key to illuminate their needs and rights. Hospital ethics committee members, healthcare providers, attorneys, and other advocates have an ethical imperative and an opportunity to provide a voice for those without one.

Acknowledgements This project was funded by the Guardianship Community Trust. In addition, this material is the result of work supported with resources and the use of facilities at the Boston Veterans Administration Healthcare System. We thank the individuals who participated in our research interviews and who each gave generously of their time to speak with us about this important issue. Their commitment to the clients they serve was palpable and sincere.

Appendix

See Tables 6 and 7.

Table 6 Strategies for finding families and friends

Target	Approach
Police	In cases where the individual was carrying no identification and was unable to communicate, work with police to get fingerprints and identification.
Belongings	In cases where the individual is carrying personal belongings, go through anything the patient comes in with in order to find clues about the person's identity, residence, history, finances, and any friends or family.
Social media	Search on social media websites to identify family and friends. This method may be fruitful in learning about the individual's background, interests, and social network.
Collateral agencies	Reach out to area homeless shelters, hospitals, or nursing homes where the individual may have received care. Maintain relationships with other institutions to help facilitate this process.
Locate evidence of previous decisions	Communicate with other healthcare providers who had previously served the individual, which may provide useful information about the individual's preferences. Because many hospitals encourage or require patients to complete healthcare proxy or Do Not Resuscitate/Do Not Intubate (DNR/DNI) paperwork, these may be on file at another institution. The individual may also have refused or accepted certain treatments, or discussed healthcare preferences more broadly with the providers. Even after guardianship is obtained (either through the identified family/friend or through a professional guardian), these dedicated clinicians' work was not over. Interviewees stated that they made an effort to communicate what they had learned about the individual to help the guardian make decisions that would best reflect the individual's wishes.

Table 7 Means to enhance capacity

Cause of confusion	Possible intervention
Alcohol or other substances intoxication	Detoxification; supplement diet or other intake needs
Altered blood pressure	Treat underlying cause of blood pressure anomaly with medication or other treatment
Altered low blood sugar	Management of blood sugar through diet or medication
Anxiety	Treatment with medications and/or psychotherapy; support groups
Bereavement; Recent death of a spouse or loved one	Support; counseling by therapist or clergy; support group; medications to assist in short term problems (e.g., sleep, depression)
Bipolar disorder	Treatment with medications and/or psychotherapy; support groups
Brain tumor	Surgery and medication
Delirium	Obtain standard labs; obtain brain scan if indicated; assess vitals; treat underlying cause; monitor and reassess over time
Dementia	Treatment with medications for dementia; simplify environment; provide multiple clues within environment; use step-by-step communication
Depression	Treatment with medications and/or psychotherapy; add pleasurable activities to day; ECT if indicated; support groups
Developmental disability	Education and training
Difficulty hearing	Use hearing amplifiers; have hearing evaluated; provide hearing aids; write information down; repeat information; slow down speech; speak clearly and distinctly
Difficulty seeing	Use magnifying glass; have sight evaluated; provide glasses; provide spoken information; repeat information; ensure sufficient lighting; use large print; have access to Braille materials
Difficulty understanding English	Use translator
Head injury	Treatments for acute effects (e.g., bleed, pressure, swelling) as necessary; monitoring over time; rehabilitative speech, physical, occupational therapies
Infection (e.g., urinary, influenza, pneumonia, meningitis)	Treat underlying infection with antibiotic or other treatment
Insomnia	Sleep hygiene practices (e.g., limit caffeine, light exercise, limit naps); medications
Liver or kidney disease	Treatment of underlying illness with medication, dialysis, surgery
Loneliness	Social and recreational activities; support groups
Low educational or reading level; illiterate	Provide information in simple language without “talking down”; provide information in multiple formats
Malnutrition or dehydration	IV fluids; fluid/food by mouth; food supplements; food by feeding tube
Mania	Treatment with medications and/or psychotherapy; support groups

Table 7 continued

Cause of confusion	Possible intervention
Medications and sudden medication withdrawal	Review of medications by clinical pharmacist or specialist; slow one-by-one tapers or changes of medications
Poor heart or lung function (e.g., hypoxia)	Treatment of underlying condition with medication, surgery, supplemental oxygen
Post surgical confusion (usually related to anesthesia or pain medicines)	Monitoring and reassessment over time; try alternative medications and treatments for pain management
Recent stressful event; depression and anxiety	Support, counseling by therapist or clergy; support group; medications to treat symptoms
Religious, cultural, or ethnic background	Sensitivity to religious, cultural, and ethnic traditions; inquire about views and needs; involve professional from similar background
Schizophrenia; hallucinations or delusions	Treatment with medications for schizophrenia; simplify environment; provide support
Transfer trauma (a recent move that has the individual disoriented)	Monitoring over time; re-orientation to environment
Transient ischemic attacks (TIA)	Treatment of risk factors to prevent future recurrence
Urinary or fecal retention	Treat underlying cause of retention through medication or surgery
Vitamin deficiency; Imbalances in electrolytes and blood levels	Vitamin or electrolyte supplement; balanced diet; diet supplements

American Bar Association/American Psychological Association Assessment of Capacity in Older Adults Project Working Group. (2008). *Assessment of older adults with diminished capacity: A handbook for psychologists*. Washington DC: American Bar Association and American Psychological Association. Reprinted with permission

References

- American Bar Association/American Psychological Association Assessment of Capacity in Older Adults Project Working Group. (2008). *Assessment of older adults with diminished capacity: A handbook for psychologists*. Washington, DC: American Bar Association and American Psychological Association.
- Bandy, R. J., Helft, P. R., Bandy, R. W., & Torke, A. M. (2010). Medical decision-making during the guardianship process for incapacitated, hospitalized adults: A descriptive cohort study. *Journal of General Internal Medicine*, *25*, 1003–1008.
- Bandy, R., Sachs, G. A., Montz, K., Inger, L., Bandy, R. W., & Torke, A. M. (2014). Wishard Volunteer Advocates Program: An intervention for at-risk, incapacitated, unbefriended adults. *Journal of the American Geriatrics Society*, *62*, 2171–2179.
- Castillo, L. S., Williams, B. A., Hooper, S. M., Sabatino, C. P., Weithorn, L. A., & Sudore, R. L. (2011). Lost in translation: The unintended consequences of advance directive law on clinical care. *Annals of Internal Medicine*, *154*, 121–128.
- 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*, 128–132.
- Courtwright, A., & Rubin, E. (2016). Who should decide for the unrepresented? *Bioethics*, *30*, 173–180.
- Doukas, D. J., & McCullough, L. B. (1991). The values history: The evaluation of the patient's values and advance directives. *The Journal of Family Practice*, *32*, 145–153.
- Isaacs, E. D., & Brody, R. V. (2010). The unbefriended adult patient: The San Francisco General Hospital approach to ethical dilemmas. *San Francisco Medical Journal*, *83*, 25–26.
- Karel, M. J., Powell, J., & Cantor, M. (2004). Using a values discussion guide to facilitate communication in advance care planning. *Patient Education and Counseling*, *55*, 22–31.

- Karp, N., & Wood, E. (2003). *Incapacitated and alone: Medical decision-making for the unbefriended elderly*. Washington DC: American Bar Association Commission on Law and Aging.
- Moye, J., Wood, E., Teaster, P., Catlin, C., & Kwak, J. (2016). *Examining the need for a public guardian in Massachusetts: Phase 1*. Andover: Massachusetts Guardianship Policy Institute.
- Naik, A. D., Martin, L. A., Moye, J., & Karel, M. J. (2016). Health values and treatment goals among older, multimorbid adults facing life-threatening illness. *Journal of the American Geriatrics Society*, *64*, 625–631.
- Norris, W. M., Nielsen, E. L., Engelberg, R. A., & Curtis, J. R. (2005). Treatment preferences for resuscitation and critical care among homeless persons. *Chest*, *127*, 2180–2187.
- Pope, T. M., & Sellers, T. (2012). Legal briefing. The unbefriended: Making healthcare decisions for patients without surrogates (Part 2). *The Journal of Clinical Ethics*, *23*, 177–192.
- Sabatino, C. P. (1991/1992). Death in the legislature: Inventing legal tools for autonomy. *NYU Review of Law and Social Change*, *19*, 309–399.
- Schmidt, W. C., Miller, K. S., Bell, W. G., & New, B. E. (1981). *Public guardianship and the elderly*. Cambridge: Balinger.
- Teaster, P. B. (2002). The wards of public guardians: Voices of the unbefriended. *Family Relations*, *51*, 344–351.
- Teaster, P. B., Wood, E., Schmidt, W. C., Lawrence, S. A., & Mendionodo, M. (2010). *Public guardianship after 25 years: In the best interest of incapacitated people?* Santa Barbara, CA: Praeger Publishing Company.
- Teaster, P. B., Wood, E. F., Lawrence, W. F., & Schmidt, W. C. (2007). Wards of the state: A national study of public guardianship. *Stetson Law Review*, *37*, 193–201.
- Torke, A. M., Alexander, G. C., Lantos, J., & Siegler, M. (2007). The physician-surrogate relationship. *Archives of Internal Medicine*, *167*, 1117–1121.
- 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*, 2053–2059.
- White, D. B., Curtis, J. R., Wolf, L. E., Prendergast, T. J., Taichman, D. B., Kuniyoshi, G., et al. (2007). Life support for patients without a surrogate decision maker: Who decides? *Annals of Internal Medicine*, *147*, 34–40.