

# UCSF

## UC San Francisco Previously Published Works

### Title

Ethical Challenges in Caring for Unrepresented Adults: A Qualitative Study of Key Stakeholders.

### Permalink

<https://escholarship.org/uc/item/4kz782dx>

### Journal

Journal of the American Geriatrics Society, 67(8)

### ISSN

0002-8614

### Authors

Verma, Aradhana  
Smith, Alexander K  
Harrison, Krista L  
[et al.](#)

### Publication Date

2019-08-01

### DOI

10.1111/jgs.15957

Peer reviewed



Published in final edited form as:

*J Am Geriatr Soc.* 2019 August ; 67(8): 1724–1729. doi:10.1111/jgs.15957.

## Ethical Challenges in Caring for Unrepresented Adults: A Qualitative Study of Key Stakeholders

Aradhana Verma, MTM<sup>1</sup>, Alexander K. Smith, MD<sup>2</sup>, Krista L. Harrison, PhD<sup>2</sup>, Anna H. Chodos, MD<sup>2,3</sup>

<sup>1</sup>College of Medicine, California Northstate University, Elk Grove, California.

<sup>2</sup>Division of Geriatrics, University of California, San Francisco, San Francisco, California.

<sup>3</sup>Division of General Internal Medicine, University of California, San Francisco/San Francisco General Hospital and Trauma Center, San Francisco, California.

### Abstract

The decision-making process on behalf of unrepresented adults (i.e. those who lack capacity to make medical decisions and have no identifiable surrogate) is at risk for not incorporating their interests, raising ethical concerns. We performed semi-structured interviews with key stakeholders across multiple sectors in an urban county who participate in the care of or decision-making process for unrepresented adults. This included a safety net health care system, social services, and legal services. Participants were health care, social service and legal professionals who worked with unrepresented adults, n=25. Our interview questions explored the current process for proxy decision-making in cases of unrepresented adults and potential alternatives. We recorded, transcribed, and analyzed interviews using the constant comparative method to identify major themes related to ethical challenges if they were raised. Participants grappled with multiple ethical challenges around the care of unrepresented adults. Themes described by participants were: (1) prioritizing autonomy; (2) varying safety thresholds (3) distributing resources fairly; and (4) taking a moral toll on stakeholders. In conclusion, all stakeholders identified ethical challenges in caring for unrepresented adults. An applied ethical framework that takes these dilemmas into account could improve ethical practice for unrepresented adults and lessen the emotional toll on stakeholders.

### Keywords

unrepresented; unbefriended; ethical dilemmas; safety; autonomy; vulnerable populations

---

**Corresponding Author:** Anna H. Chodos, MD, 1001 Potrero Avenue, Box 1364, San Francisco, CA 94143, 415-206-4852, [anna.chodos@ucsf.edu](mailto:anna.chodos@ucsf.edu), @annachodos.

Twitter handles for all co-authors. @AKSmith @klharrisonPhD

**Author Contributions:** Verma and Chodos: study concept and design, recruitment of subjects, acquisition of data, analysis and interpretation of data, preparation of manuscript, critical revisions for intellectual content. Smith and Harrison: analysis and interpretation of data, preparation of manuscript, critical revisions for intellectual content. All authors meet the criteria for authorship stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals.

**Conflict of Interest:** The authors have no relevant financial or personal conflicts.

## INTRODUCTION

Unrepresented adults are those who lack capacity for decision-making, do not have a surrogate decision maker, and have no advance directive guiding their care.<sup>1</sup> Within states, local counties, and individual institutions, approaches to finding or appointing a surrogate vary.<sup>2,3</sup> Often, however, this circumstance presents barriers to timely health care and hospital discharge.<sup>4</sup> There may be delay in care decisions as providers look for a surrogate or need to undergo a legal process to obtain one. For example, adults without a surrogate who await a court-appointed conservator have longer lengths of stay, increased costs, and experience medical harm.<sup>5</sup>

Caring for unrepresented adults is a common problem. In hospital and nursing home settings, 3–30% of older adults are unrepresented.<sup>4,6,7</sup> In the intensive care unit (ICU), studies have shown that 16% of patients lack capacity and a decision-maker upon admission, while an estimated 6%–27% of patients who die there do not have a surrogate.<sup>8,9</sup> The number of unrepresented adults is expected to increase with the aging population and rise in single, childless adults.<sup>10–13</sup>

In addition to legal and practical barriers, unrepresented adults are also at risk of care that is not consistent with their values and transgresses standard ethical practice.<sup>1,12,14,15</sup> Available decision-makers, such as physicians, may consult an ethics committee or use the best interest standard, but this does not ensure that decisions uphold the patient's values.<sup>3,12,16</sup> Studies in the ICU reveal that the decision to withdraw life support in most unrepresented patients (80–90%) are made without oversight.<sup>8,9</sup> When the physician is the decision-maker, evidence shows they make decisions based on their own professional and personal values, rather than considering the patient's values.<sup>4,17</sup> In 2016, the American Geriatrics Society highlighted the practical challenges of caring for these patients, including the potential for ethical transgressions.<sup>1</sup> A recent qualitative study highlighted the complexity of caring for unrepresented adults in Massachusetts in hospitals and long-term care, including the number of multisector stakeholders, such as healthcare and the courts, and related ethical concerns.<sup>14</sup>

To our knowledge, ethical challenges in caring for unrepresented adults in the safety net has not been described from the perspective of multiple stakeholders. We interviewed individuals across professions, including outside of healthcare, that care for unrepresented adults to learn about the process from different perspectives and then identified ethical challenges.

## METHODS

### Study Design

We qualitatively explored the experiences of stakeholders caring for unrepresented adults through semi-structured interviews conducted in June and July of 2017 as part of a larger quality improvement initiative at our institution to address the needs of our unrepresented patients. We purposively sampled professionals with significant roles in their care. Our project was considered quality improvement and therefore not subject to IRB review. (See section “Quality Assurance and Quality Improvement Activities -Clinical” at <https://>

[irb.ucsf.edu/quick-guide-activities-requiring-irb-review](http://irb.ucsf.edu/quick-guide-activities-requiring-irb-review).) All individuals consented to participate via email and again in person.

### Study Setting

We recruited participants who are nationally recognized in the field of ethics or geriatrics and outside of our home institution, or who work in our urban safety net health care system, court, or community services.

### Participants

Using a purposive sampling method, we first contacted people known to be part of caring for unrepresented adults in their institution, such as clinicians, social workers, ethics committee members, and then asked relevant community agencies and the courts about key individuals to interview. Those eligible for recruitment included clinicians, social workers, public guardians (county agents that can serve as a conservator for unrepresented adults), probate court investigators, and Adult Protective Services staff, as well as national experts in the fields of geriatrics and ethics. We asked everyone about other agencies or services known to participate in this process, and sought to interview at least one individual representing each element of the process of care of unrepresented adults. Participants were contacted by email.

### Data Collection

Two investigators (AV, AC) conducted semi-structured 60-minute face-to-face interviews at a location of the participant's choice. Questions explored the participant's roles in working with unrepresented adults, thoughts on the process for decision making for unrepresented adults, and potential alternatives to the current process. Of note, the questions did not directly ask about ethical issues because the initial goal of the study was to understand the process of care for unrepresented adults. However, all interviewees raised ethical concerns as a challenging part of this process, and we explored these challenges when they did.

### Analysis

All interviews were audio-recorded and transcribed verbatim. We analyzed the transcripts to create codes through qualitative coding. Two authors (AV, AC) read all transcripts independently. For this analysis, we focused on the ethical themes that emerged from the data, and then created codes based on themes. The themes included descriptions, challenges, and solutions regarding the decision-making process for unrepresented adults. All transcripts were then coded for themes and sub-themes. All coding was reviewed by the authors coding data (AV, AC) and any disagreements were resolved through discussion. Then, the codes were rearranged into tables that consisted of headings and subheadings that were generated during the development of the thematic framework. For example, the codes, "misuse of resources" and "inappropriate use of hospitalization" were sorted into the larger heading of justice with the subheading of distributive justice. The final step involved interpretation of the data as it was laid out in the chart by utilizing strategies, such as finding associations across the data set. For example, the codes under the headings of safety and autonomy were often mentioned together. Analysis of transcribed data was performed with Dedoose v7.7.18.

## RESULTS

A total of 25 individuals agreed to participate and none declined. Sample characteristics are in Table 1. All interviewees expressed ethical concerns and major themes around ethical challenges in the care for unrepresented adults were: (1) prioritizing autonomy; (2) varying safety thresholds (3) distributing resources fairly; (4) taking a moral toll on stakeholders. (See Table 2.)

### 1) Prioritizing Autonomy

In total, ten interviewees expressed how “autonomy” of unrepresented patients is prioritized above other considerations, particularly by the courts. Court interviewees, in particular, emphasized the gravity of taking away a person’s rights and how conservatorship, i.e. the legal process formally transferring someone’s autonomous rights to another person, is the last option to help someone.

“Everybody’s trying to do what is right for this person. And what is right for them is to provide them with the assistance and protection they need in the least legally restrictive manner. Once you have a conservatorship, it’s reviewed and it can be terminated, but you’ve lost a lot of your civil liberties. Where you live, how your money gets used, your choice of medical care. It’s a lot.” –Probate court investigator

When doing decision making with incapacitated patients, providers described how it was challenging to respect autonomy. This created an uncomfortable tension for care providers.

“How do you make decisions for folks and have their values represented when we just decide that they lack capacity and there’s nobody who can speak for them? I think that’s a challenge, because you don’t want to insert your own values in decision making, but you don’t have a lot to go with.” –Physician, Hospital ethics committee member

Some stakeholders described, as well, the challenge of respecting autonomy when patients refused recommended care or made poor decisions. Interviewees described an “all-or-nothing” tendency to remove all autonomy when a patient lacks capacity, effectively silencing them.

### 2) Varying Safety Thresholds

Interviewees explained that infringing on autonomy, when it happened, was to improve a patient’s safety related to a substantial risk of harm in the community from their lack of capacity and poor decision making, but the threshold for a safety risk varied between people and professions. An Adult Protective Services (APS) administrator described the organization’s approach when weighing the extent of harm from the status quo versus the harm of their intervention on that person’s rights.

“You have to be currently at substantial risk of harm for us not to abandon you and go away when you say just leave me alone... We don’t want to violate your rights, but we don’t want to abandon you if what we’ve heard and what we’re seeing clearly indicates substantial risk of harm”- Adult protective services administrator

Some questioned if a focus on safety was in alignment with the needs of the patient, because it often meant keeping a patient hospitalized against her preferences. A resident physician, said that “until you’ve proven to me that {the patient’s situation is} unsafe, I am a little bit inclined to kind of let things be”, and questioned if hospitalization for a safety concern helps the patient by saying “sometimes, but sometimes it doesn’t.” One interviewee, a social worker, referred to the hospital as the “bleeding heart” of the city, meaning that the culture of the hospital was to consider all needs, including non-medical needs of patients such as safety, before discharging them.

Stakeholders frequently described this challenge: hospitalizing unrepresented adults to protect safety and thereby infringing on their autonomy versus discharging them with a risk of harm in the community. Some interviewees described this as a thoughtful “risk-benefit analysis”. But others believed that it was a “crisis-driven” approach that underemphasizes safety, and one physician highlighted the importance of involving the appropriate resources before the patient is at overt risk and needs to be referred to the Public Guardian, i.e. the county agency that can serve as a conservator for unrepresented adults.

“When patients are sending you signals that things are going in the wrong direction, then [the Public Guardian] should get involved. Instead they wait until the very end. It’s all failed until we’re at our wits’ end, and then they say — ‘call us in’. And I get that, that’s the way to use that resource as carefully as possible, as parsimoniously as possible, but it puts people at risk.” – Hospital physician

### 3) Distributing Resources Fairly

Eight interviewees expressed concern about the implications of current practice for unrepresented adults on the fair distribution of health system resources.

“I think it’s just people stay in the hospital for longer than they need to as these issues are being evaluated and worked out, and that’s hard too. It’s an expense to society, it’s taking up a bed that maybe could be used by somebody who actually needs an acute care bed” –Physician, Hospital ethics committee member

Concerns such as the one above about inappropriate hospitalizations that took resources away from other patients were contextualized in a safety net health setting. One interviewee expressed that “we’re the safety net of the community, but if we do go bankrupt then we are not able to help the community.”

The tension between safety and autonomy was identified as a complex decision and therefore a driver of prolonged hospitalization. For some, this meant a concern for safety was too often invoked and conflicted with the core mission of the hospital.

“We had a few [scenarios] where we’re like we can’t discharge him, he doesn’t have a home. That’s not a reason. He has no medical needs... I understand. Socially it doesn’t feel good. However, it’s not a reason to keep a patient here.”- RN, Risk management

Interviewees also pointed out larger societal issues related to the fairness of the process. The individuals who required public guardianship and associated restrictive living conditions

were largely indigent. They worried that the process might therefore be inequitable between people who lack capacity and have means versus those who have none.

“If you have someone who is wealthy and is maybe quasi-bed bound or requires two people to assist them in transferring to the bed, a hospital bed maybe, to the wheelchair, then you have to hire two CNA’s [Certified Nursing Assistant], for example. Right? And then you have to have shifts. So if you have money to do all that, you can stay home... You have the same person who is poor, they’re not going to stay home, right?”– Adult protective services administrator

One interviewee succinctly summarized the disparity, “the people with more money have a lot more choice”.

Many interviewees expressed concern that the current process was opaque and ad hoc, adding to a lack of fairness. One interviewee added that a more standard process would address this.

“There’s something about setting up a process that shows that we’re showing that we’re trying to do a good job for these patients in the process, even if it doesn’t change the outcome most of the time. By designing that process, it demonstrates respect for the person.” - Health law expert and ethicist

#### 4) Taking a Moral Toll on Stakeholders

Eight interviewees highlighted that unrepresented patients as a population inherently present serious ethical challenges, and we should diligently ensure ethical practice as a result.

“We’re talking about people who had illegal drug use problems, people who are homeless. Why are they {unrepresented}? People who are ostracized from their family because of their criminal history, ostracized from their family because of their LGBT status, and so forth. If there’s ever a population of patients that is subject to potential discrimination or biases on the part of their treating clinicians, it’s this population. If you’re ever going to need a process to have checks and balances on the personal biases of the treating clinicians, this is the time.” –Health law expert and ethicist

Eight interviewees identified that these ethical challenges in the care of unrepresented adults was a source of tremendous moral and emotional burden.

“I think under the stress of what the stakes are and the trauma that we all experience as a result of bearing witness to these patients’ stories, I think that it provides an unhealthy atmosphere. So my hope is that we’re able to also think of the impact that making these sorts of decisions has on the individuals that have to make the decisions, and how we as a system can have a more trauma-informed approach around that. Because I do think that these decisions are incredibly difficult and are fraught with confusion and waiting and risk.” -Neuropsychologist

One interviewee, a hospital physician, described the current process as “unconscionable” as he felt that patients experienced harm from a crisis-driven system.

## DISCUSSION

Our interviews with key stakeholders in an urban health care system, court system, and social services revealed ethical challenges around decision-making and care planning for unrepresented adults. Interviewees discussed how safety and autonomy were important ethical guideposts and in tension with each other when engaging in decision making for unrepresented adults. Interviewees expressed concern about ignoring patients' preferences in the context of incapacity, the potentially inappropriate use of hospital resources because of prolonged hospitalization, and the importance of a consistent and fair process for this population. These ethical challenges exacted a large emotional toll on interviewees. Across the professions, interviewees identified similar challenges.

Ethical challenges that arise in the care of unrepresented adults have long been recognized and force us to solve tensions between foundational concepts in bioethics, such as autonomy and beneficence.<sup>18</sup> However, there remains a small literature on the prevalence of these challenges and addressing them or examining the relevance of other theoretical frameworks in bioethics, e.g. ethics of care.<sup>1,6,12-14,17,19-23</sup> Even the terminology is still evolving, from "adult orphan" or "unbefriended" to "unrepresented", which we use here.<sup>1,15,24</sup> The recent study by Moye et al. about the "institutional pathways" to provide surrogates for unrepresented adults concluded that all the pathways present ethical concerns and distress for stakeholders.<sup>14</sup> In our institution, leaders of the ethics committee wrote about these challenges creating "angst" almost 10 years ago<sup>25</sup>. Such distress could increase the risk of provider burnout, another reason to address these ethical issues.<sup>26</sup>

Our study adds further detail about ethical challenges encountered in the care of unrepresented adults in a safety net setting and across multiple professions. As noted by the AGS Position Statement, identifying ethical challenges is only one step; others include addressing ethical issues explicitly, promoting procedural fairness, and a team-based approach to incorporate unrepresented adults' preferences into treatment decisions.<sup>1</sup> Our participants made similar recommendations. Moye, et al in their conclusion advocated for multiple stakeholder involvement to ensure more perspectives in the decision-making process.<sup>14</sup> This study is in agreement with such calls for more guidance on decision-making for these patients and stakeholder collaboration.<sup>1,12,14,22</sup>

There are a number of limitations to this study. This qualitative study focuses specifically on the experience of one urban county. Given the wide variation in legal and hospital practices, the practices of other counties and states in the United States and other countries may vary from what our participants reported. Our sample includes only professionals and no unrepresented patients, who would be challenging to ethically consent for any study. As a result of our sampling, we had more representatives from the medical setting, though these were from multiple different professions. Lastly, this study did not explicitly include questions on ethical challenges as part of the questionnaire for participants. Rather, comments on these challenges emerged from a broader inquiry into the current process of decision making for unrepresented adults. The interviewees may not have provided comprehensive details on this topic. Conversely, this could be considered a strength of the study as our participants were not primed to think specifically about ethical issues.



Our findings suggest that stakeholders would benefit from an explicit process for openly and uniformly weighing different ethical priorities affecting each patient's situation; this uniform process could decrease uncertainty and distress. Developing and testing an applied ethical framework specific to the scenarios facing unrepresented adults might help with this. Future studies could explore ethical challenges among unrepresented adults in other settings, e.g. non-safety, community-dwelling, or institutionalized, or among different age groups, to test the generalizability of our findings. Future research should also focus on how adults at risk of becoming unrepresented weigh these ethical concerns themselves.<sup>27</sup> Improving how we address ethical challenges in caring for unrepresented adults is crucial for providing excellent, compassionate care for this population as well as supporting the providers who care for them.

## ACKNOWLEDGMENTS

**Financial Disclosure:** Aradhana Verma was funded by the NIH and NIA through the Lillian R. Gleitsman Medical Student Summer Research in Aging Program.

**Sponsor's Role:** The NIH and NIA had no role in the design, methods, subject recruitment, data collections, analysis or preparation of this paper.

## REFERENCES

1. Farrell TW, Widera E, Rosenberg L, et al. AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults. *J Am Geriatr Soc*. 2016.
2. DeMartino ES, Dudzinski DM, Doyle CK, et al. Who Decides When a Patient Can't? Statutes on Alternate Decision Makers. *N Engl J Med*. 2017;376(15):1478–1482. [PubMed: 28402767]
3. Pope TM, Sellers T. Legal briefing: The unbefriended: making healthcare decisions for patients without surrogates (Part 1). *J Clin Ethics*. 2012;23(1):84–96. [PubMed: 22462389]
4. Miller TE, Coleman CH, Cugliari AM. Treatment decisions for patients without surrogates: rethinking policies for a vulnerable population. *J Am Geriatr Soc*. 1997;45(3):369–374. [PubMed: 9063286]
5. Ricotta DN, Parris JJ, Parris RS, et al. The Burden of Guardianship: A Matched Cohort Study. *J Hosp Med*. 2018.
6. Gillick MR. Medical decision-making for the unbefriended nursing home resident. *J Ethics Law Aging*. 1995;1(2):87–92. [PubMed: 11654399]
7. Karp NWE. Incapacitated and Alone: Healthcare Decision Making for Unbefriended Older People. American Bar Association Commission on Law and Aging. 2004;31(2).
8. White DB, Curtis JR, Lo B, et al. Decisions to limit life-sustaining treatment for critically ill patients who lack both decision-making capacity and surrogate decision-makers. *Crit Care Med*. 2006;34(8):2053–2059. [PubMed: 16763515]
9. White DB, Curtis JR, Wolf LE, et al. Life support for patients without a surrogate decision maker: who decides? *Ann Intern Med*. 2007;147(1):34–40. [PubMed: 17606959]
10. Profile of Older Americans. U.S. Census Bureau, the National Center for Health Statistics, and the Bureau of Labor Statistics; 2011.
11. U.S. Census Bureau Projections Show a Slower Growing, Older, More Diverse Nation a Half Century from Now. In: U.S. Census Bureau; 2012.
12. Pope TM. Making medical decisions for patients without surrogates. *N Engl J Med*. 2013;369(21):1976–1978. [PubMed: 24256375]
13. Chamberlain S, Baik S, Estabrooks C. Going it Alone: A Scoping Review of Unbefriended Older Adults. *Can J Aging*. 2018;37(1):1–11. [PubMed: 29338799]

14. Moyer J, Catlin C, Kwak J, et al. Ethical Concerns and Procedural Pathways for Patients Who are Incapacitated and Alone: Implications from a Qualitative Study for Advancing Ethical Practice. *HEC Forum*. 2017;29(2):171–189. [PubMed: 28084575]
15. Kim H, Song MK. Medical Decision-Making for Adults Who Lack Decision-Making Capacity and a Surrogate: State of the Science. *Am J Hosp Palliat Care*. 2018;35(9):1227–1234. [PubMed: 29390870]
16. Pope TM. The Best Interest Standard for Health Care Decision Making: Definition and Defense. *Am J Bioeth*. 2018;18(8):36–38.
17. White DB, Jonsen A, Lo B. Ethical challenge: when clinicians act as surrogates for unrepresented patients. *Am J Crit Care*. 2012;21(3):202–207. [PubMed: 22549577]
18. Beauchamp TL, Childress JF. *Principles of biomedical ethics* (7th ed.). New York: Oxford University Press; 2013.
19. Connor DM, Elkin GD, Lee K, et al. The Unbefriended Patient: An Exercise in Ethical Clinical Reasoning. *J Gen Intern Med*. 2016;31(1):128–132. [PubMed: 26438516]
20. Cohen AB, Wright MS, Cooney L Jr., et al. Guardianship and End-of-Life Decision Making. *JAMA Intern Med*. 2015;175(10):1687–1691. [PubMed: 26258634]
21. Kopelman LM. The best interests standard for incompetent or incapacitated persons of all ages. *J Law Med Ethics*. 2007;35(1):187–196. [PubMed: 17341227]
22. Bandy R, Sachs GA, Montz K, et al. Wishard Volunteer Advocates Program: an intervention for at-risk, incapacitated, unbefriended adults. *J Am Geriatr Soc*. 2014;62(11):2171–2179. [PubMed: 25354983]
23. Jonsen ARSM, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. Seventh Edition ed. ed: McGraw-Hill; 2010.
24. Pope TM. Legal Briefing: Adult Orphans and the Unbefriended: Making Medical Decisions for Unrepresented Patients without Surrogates. *J Clin Ethics*. 2015;26(2):180–188. [PubMed: 26132070]
25. Isaacs ED, Brody RV. The unbefriended adult patient: The San Francisco General Hospital approach to ethical dilemmas. *San Francisco Medical Journal*. 2010;83:25–26.
26. Bodenheimer T, Sinsky C. From triple to quadruple aim: care of the patient requires care of the provider. *Ann Fam Med*. 2014;12(6):573–576. [PubMed: 25384822]
27. Teaster PB. The Wards of Public Guardians: Voices of the Unbefriended. *Family Relations*. 2002;51:344–350.

**Table 1.**

Stakeholders Interviewed (n=25)

<b>Discipline</b>	<b>Title</b>
Legal system	Probate court investigator
Healthcare	Primary care physician
	Inpatient physicians (4 people, Internal Medicine)
	Hospital ethics committee member (an MD)
	Social worker (Inpatient)
	Social worker (Outpatient)
	Psychiatrist
	Neuropsychologist PhD (3 people: 1 with dual role of outpatient and inpatient, 2 nursing home)
	Utilization management, RN
	Utilization management, MD
	Risk management, RN
City and Social Services	Adult protective services administrator
	Non-profit fiduciary
	Public guardian (3 people)
Outside experts (not directly in our system)	American Geriatric Society Ethics Committee Member
	Public guardian and conservator state association member
	Health law expert and ethicist
	Psychologist PhD (academic)

**Table 2.**

**Themes Identified**

<p><b>Prioritizing Autonomy</b></p> <ul style="list-style-type: none"> <li>- “So you want to take them, lock them in a facility, take away all their drugs, give them our drugs to hope they quiet all that down, but they may still get those thoughts, we’re going to lock you up and protect you. Is that the right thing? Is that good for the patient? What’s better? We feel good about it, but does the patient? And that’s where it gets a little hard.” – Risk management, RN</li> <li>- “I think I fall a little bit more on the patient autonomy side. Like until you’ve proven to me that... it’s unsafe, I am a little bit inclined to kind of let things be. And I think maybe that’s changed and maybe I was a little bit more kind of on the protection side previously.” – Inpatient physician</li> <li>- “Our general framework, our ethical framework is to assist clients to stay, we really want to maximize self-determination and we want to help our clients to live in the least restrictive setting possible. So the challenge that comes is that if someone is so functionally and cognitively impaired that they really need a nursing home, is nursing home placement a failure or a success?” -Public guardian</li> </ul>
<p><b>Varying Safety Thresholds</b></p> <ul style="list-style-type: none"> <li>- “You have to be currently at substantial risk of harm for us not to abandon you and go away when you say just leave me alone... We don’t want to violate your rights, but we don’t want to abandon you if what we’ve heard and what we’re seeing clearly indicates substantial risk of harm.” -Adult protective services administrator</li> <li>- “But we also see in the teams, the clinical teams are phenomenally democratic almost to a fault. So if anyone on the team raises the fact that I don’t think it’s safe to send the patient home now, it’s kind of like everything stops dead in their tracks, even if there’s three other people who think they do.” -Utilization management MD</li> <li>- “When patients are sending you signals that things are going in the wrong direction, then [the Public Guardian] should get involved. Instead they wait until the very end. It’s all failed until we’re at our wits’ end, and then they say — ‘call us in’. And I get that, that’s the way to use that resource as carefully as possible, as parsimoniously as possible, but it puts people at risk.” –Inpatient physician</li> </ul>
<p><b>Distributing Resources Fairly</b></p> <ul style="list-style-type: none"> <li>- “We’re the safety net of the community, but if we do go bankrupt then we are not able to help the community” –Utilization Management RN</li> <li>- “Then I think it’s just people stay in the hospital for longer than they need to as these issues are being evaluated and worked out, and that’s hard too. It’s an expense to society, it’s taking up a bed that maybe could be used by somebody who actually needs an acute care bed. So a lot of compromises happen.” -Hospital Ethics Committee Member MD</li> <li>- “I think there’s a lot of inefficiency. Public health... is a resource-limited system, and I think we need to do a better job of prioritizing and triaging and operationalizing and getting standard work around capacity, and getting all the stakeholders brought into what that standard work is.” -Neuropsychologist PhD</li> </ul>
<p><b>Taking a Moral Toll on Stakeholders</b></p> <ul style="list-style-type: none"> <li>- “We’re talking about people who had illegal drug use problems, people who are homeless. Why are they [unrepresented]? People who are ostracized from their family because of their criminal history, ostracized from their family because of their LGBT status, and so forth. If there’s ever a population of patients that is subject to potential discrimination or biases on the part of their treating clinicians, it’s this population. If you’re ever going to need a process to have checks and balances on the personal biases of the treating clinicians, this is the time.” –Health law expert and ethicist</li> <li>- “It’s demoralizing, I think, for the providers because you feel a weight, a sort of burden on your shoulders when you’re helping to make decisions for a patient where you don’t know if you have the right to do that.” -Hospital Ethics Committee Member MD</li> <li>- “We have to let them fail, which scares us to death. And that’s what we have the most trouble with.” -Social worker (Inpatient)</li> <li>- “A person that has an aphasia, are they always lacking capacity? They might come across like that, but maybe they’re not. In a fast world, they may fall apart, and we would look at them and say they can’t do a thing, but they can. So why would I want to take away their independence? Thank God there’s ethics committees and it doesn’t have to fall on me all the time” -Neuropsychologist PhD</li> </ul>

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript