

# Challenges Related to Safety and Independence



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## KEYWORDS

• Geriatrics • Older adults • Autonomy • Risk • Independence • Safety • Ethics

## KEY POINTS

- Perceptions of safety and risk vary widely, throughout society and among clinicians and patients.
- When safety and independence are in conflict, clinicians should consider several factors: the patient's perspective, the perspectives of other major stakeholders, the magnitude of patient risk and risk to others, clinician biases, and liability.
- The goal in general is not to find the right answer, but to find a fair, transparent way to choose among morally acceptable alternatives, fashioning a consensus agreement on a strategy that optimizes both safety and independence.
- When a patient's civil liberties might be abridged, involvement of the state may be necessary.

## CLINICAL CASES

### Case 1

Ms J is a 68-year-old who is seen in the office for routine primary care follow-up. Her medical conditions include rheumatoid arthritis and advanced chronic obstructive pulmonary disease. She has significant joint destruction in her hands and feet. She requires supplemental oxygen and is dyspneic with any exertion. She uses a wheelchair for mobility and requires assistance for most of her activities of daily living. She lives with her husband who is also her caregiver. Her husband works outside the home during the day, during which time Ms J is often alone. During the visit, her primary care physician notes poor personal hygiene and multiple pressure injuries and wounds. A recent note in her chart from the home-health registered nurse says the home is unfit for habitation and that Ms J is home alone in soiled clothing, with no way to call for help. Ms J's physician is concerned that her recurrent skin infections and wounds, which have led to several hospitalizations, are related to inadequate

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care. She was previously admitted to a skilled nursing facility after a hospitalization but left against medical advice because she felt frustrated with her care there. She adamantly refuses to return to any facility. She acknowledges that her current situation is not ideal and requests help finding additional caregiving resources and help with improving the home condition. Despite knowing that these services are not immediately available to her, Ms J wants to remain in her current home.

### **Case 2**

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You receive a call from the neighbor of your patient, Mr L, informing you that Mr L had another fall. The neighbor says that Mr L was walking toward Maple Avenue, a busy street, at 5 AM and not wearing a coat despite the freezing weather. The neighbor found him having fallen on an uneven lawn. Mr L says he was going to a fast food place to get dinner but did not realize the place was not yet open. He thought it was 5 PM rather than 5 AM. Mr L lives alone in the house where he was born 85 years ago. His neighbor checks in on him every day, brings over groceries, and does small errands. Mr L used to rely on his nephew, but the nephew formally resigned as his power of attorney out of frustration because Mr L refused to move, hire an aide, or modify his living situation. Mr L would call the nephew up to 15 times a night with repetitive questions. You do a house call for Mr L and see that belongings are piling up. There is a strong odor. It is clear that he is sleeping in his recliner rather than his bed upstairs. He takes none of the medications that you had prescribed for coronary artery disease. You gently engage him in a conversation about his care, and when you say assisted living facility he says “No! No! No!”

### **Case 3**

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Ms F is an avid bingo player. She is a widow and drives to the bingo hall each week to see her friends, an outing that is the center of her social life. She has been living with diabetes for many years. In the last few years, the neuropathy in her legs has worsened and is now also affecting her fingers. Over the past year, she has had 3 fender-benders in which she knocked over a neighbor’s mailbox, scraped her garage wall, and had a minor parking lot collision. For the past year, her 2 daughters have forbidden her grandchildren from riding in the car with her. On examination, she has diminished awareness of joint positioning and a loss of sensation to light touch in both her feet and ankles. When you bring up concern about her driving, she immediately gets defensive: “I only drive during the day, I go slowly, and I stay in my neighborhood on roads that I know like the back of my hand.” Despite her protest, you make a firm recommendation that she no longer drive and ask a community health worker to meet with Ms F to see whether there are other ways that she could still get to bingo.

## **INTRODUCTION**

Balancing safety and independence is a fundamental challenge for most humans. The balancing act can be seen in sharpest relief at the extremes of age: in childhood, adolescence, and old age. Need for substitute decision makers and the involvement of the state can affect how the balance is achieved. In 2015, the parents of a 6-year-old and a 10-year-old were charged with child neglect for allowing their children to walk home alone from neighborhood playgrounds in the suburbs of Washington, DC. The parents were ultimately cleared of charges, but the debate was furious.<sup>1</sup> Did the risk to which these parents exposed their children amount to criminal disregard for safety? On a larger scale, in 1919 the 18th Amendment ushering in prohibition was ratified in 46 of 48 states and became the law of the land for more than a decade. Although an element of moral judgment contributed to the amendment’s passage,

improved public health was a central argument. Rates of alcoholism, cirrhosis, and death from cirrhosis decreased sharply. Prohibition ended with the 21st Amendment, and "an excess of 13,665 infant deaths ... could be attributable to the repeal of federal prohibition in 1933."<sup>2</sup> Reestablishing prohibition now seems inconceivable.

Four factors ensure that these debates often defy a simple resolution. First, it is rarely possible to provide a precise quantitative assessment of risk. For example, what is the risk of staying home alone in squalid conditions, as in cases 1 and 2? Who defines what squalid means? Second, even if a precise quantitative statement of risk were possible, there is no societal agreement on what is too risky. Third, the ability to make a meaningful decision (in medical terms, capacity) about a known level of risk can vary over time. Fourth, American society, with its emphasis on individualism, is far from achieving a stable consensus on the role of the state or medical authority in regulating risks.

Decisions that balance maintenance of independence with promotion of safety frequently challenge older adults and their health care providers. These challenges commonly arise in decisions about living environment and driving and, as such, may include both social and medical factors. From physical rehabilitation to the installation of home modifications to a change of residence (with a change in level of care), many decisions about health care for vulnerable older adults focus on safety. Several factors combine to make the challenges particularly complex. As adults age, rates of frailty, medical illness, and disability increase, increasing the risk of everyday behaviors. Factors that help to mitigate risk, such as social networks and financial resources, may dwindle. Cognitive dysfunction may decrease an individual's ability to assess risk accurately and make sound decisions. Each of these factors may be progressive.

This article is intended to help clinicians working with older adults navigate challenges to safety and independence. It begins with a brief discussion of clinicians' ethical obligations toward patients and how these obligations ground their approach to negotiating safety and independence. It presents safety and risk as inherently subjective clinical assessments for which there is no gold standard measurement. It then considers several factors that may help clinicians when assessing safety challenges in the care of individual patients, including evaluation of decision-making capacity. It suggests some pragmatic strategies for addressing these challenges in commonly encountered clinical scenarios, such as the cases at the beginning of this article.

## DISCUSSION

### *Ethical Obligations to Patients*

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Clinicians have an ethical obligation to promote their patients' health and prevent harm. These duties arise from the principles of beneficence and nonmaleficence. However, clinicians' ethical obligations are not limited to these fundamental principles. Beauchamp and Childress's<sup>3</sup> now-classic formulation of bioethics puts equal or greater weight on patient autonomy. In some situations, such as cases 1 and 2, in which a patient desires to live at home despite high risk and even actual harms, these ethical obligations, to promote health and prevent harm on one hand and to respect the patient's self-determination on the other, may be at odds.<sup>4</sup> Clinicians are also constrained by the requirement of nonabandonment, the commitment that clinicians make to remain with the patients, to continue to work with them, and to face an uncertain future together without necessarily agreeing with the patients' decisions.<sup>5</sup>

### *Safety and Risk*

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In most clinical scenarios, clinicians cannot objectively measure risk, but must instead estimate it based on experience, published data, or both. Validated tools exist to

estimate certain risks. In other cases, individuals must rely on their life experience and the professional judgment of physicians, physical therapists, or other health care providers. A patient may have an increased risk of falling based on a validated tool and clinical assessment, but whether moving from home to an assisted living facility will reduce the risk of a complex multifactorial outcome such as a hip fracture is not knowable.

Patients may engage in high-risk activities, such as continuing to drive or to live alone, because they assume that their doctors would have told them if their behaviors were unsafe.<sup>6</sup> Although clinicians often primarily consider physical safety, this is only 1 aspect of what may be important to a patient or caregiver. Patients with full knowledge and full capacity may choose to accept high levels of physical risk for a host of factors, including emotional safety, financial safety, integrity, dignity, privacy, and personal relationships. Clinician and patient should work together to identify and clarify the patient's values and priorities in order to facilitate sound decision making. If a given high-risk behavior aligns with a patient's stated values, the decision to accept this risk is more clearly justified. For example, if a patient places high value on remaining (and dying) in the patient's lifelong home, a place that is associated with familial relationships and safety, then the patient may accept substantial risks in order to achieve that goal. Furthermore, a patient in this scenario may not be as concerned with the risk of death and instead may be focused on the risks of pain or discomfort. Understanding motivation helps clinicians support people to make authentic personal choices rather than choices that optimize only physical safety from a medical standpoint.

### ***Clinical Approach***

**Box 1** lists several of the factors that should be made as transparent as possible to all who are part of the decision-making process when facing a situation in which there is a challenge to safety and independence.

### ***Magnitude of risk***

Estimating risk requires making predictions about the future. For many patients and their loved ones, probability and the quickly branching chains of various hypothetical outcomes are extremely difficult tools to use in decision making. Online tools provide visual aids that may help in conceptualizing risk of mortality or other adverse outcomes in some situations.<sup>7</sup> Providing written material to the patients can be helpful for both the patients and their companions, who may not retain all a clinician says, and for loved ones who were not at the meeting.

#### **Box 1**

#### **Recommended factors for clinicians to consider when assessing potentially unsafe choices**

- Magnitude of risk: what are the likelihood and severity of potential adverse outcomes? Is there risk to others? Do I understand what risks most concern this patient?
- Decision-making capacity: does this patient understand relevant details, benefits, burdens, and alternatives?
- Collateral information: with the patient's permission, have I elicited the perspectives of friends and family?
- Clinician bias: how do my values and life experiences shape and bias my assessment of safety?
- Alternatives: what compromises or risk-mitigating strategies are available?
- Liability: are there legal or professional requirements that I must fulfill?

Risk to others is a separate consideration, distinct from risk to self. For example, continuing to drive despite demonstrably increased risk of doing so (for various reasons, including declining vision, reflexes, judgment, substance abuse, peripheral neuropathy, or epilepsy) endangers not only the driver but also the public, as in case 3. In most jurisdictions, risk to others at certain thresholds supersedes autonomy of a competent individual. Some states (eg, California, Pennsylvania, and New Jersey) require that providers report their medically or cognitively impaired patients to the Department of Motor Vehicles. Analogously, reporting to the Department of Health is mandatory for infectious diseases such as tuberculosis or syphilis. Sometimes, if a clinician detects credible risk of harm to others, the clinician must override a person's autonomy, compromise privacy, and hospitalize the person involuntarily through the courts and law enforcement. Reporting patients who are immediate threats to others is widely permitted in some circumstances, such as imminent threats of violence to others. However, there is considerable gray area in between what constitutes an obvious danger and a low level of risk.

### ***Decision-making capacity***

A patient's capacity to make a meaningful decision significantly changes the appropriate course of action. The threshold for capacity changes relative to the risk. For situations where risk is high, the scrutiny of an individual's capacity is greater. Although clinician judgments about capacity may vary along this spectrum, clinicians are often asked to make a yes-or-no judgment. No formulaic test can prove presence or absence of capacity; the assessment of capacity requires a discussion with the patient. **Box 2** lists several questions that may be useful to clinicians during such a discussion. These questions also help clinicians understand how patients' values are informing their choices and their risk tolerance.

When a clinician determines that a patient lacks capacity, there should still be an attempt made to incorporate the patient's current or previously stated preferences and show respect for the person into decisions made on the person's behalf. When accepting risk for patients who lack capacity, clinicians and caregivers should try to mitigate any potential harms that may accompany the patient's wishes. Respect for current and previously expressed preferences is important but may not be decisive and may not always be possible.

If a substitute decision maker is needed for a specific decision, the patient may retain the ability to make other decisions. For example, because of safety concerns, a person may be required to move from independent living to assisted living despite wishing to remain at home. That person might still participate in choosing the facility that will become home.

For a patient with diminished capacity, decisions that focus only on decreasing risk and increasing safety may undermine the patient's dignity. This concept, the dignity of risk, was introduced in 1972 by Robert Perske,<sup>8</sup> an advocate for people with

#### **Box 2**

##### **Example questions to use in discussions assessing capacity**

Tell me in your own words what decision you are considering.

What are some possible upsides and downsides of that choice?

What other options might you have?

Why are you choosing option A instead of option B?

intellectual and developmental disabilities (IDDs). He noted that, among people with IDDs, denying any risk “tends to have a deleterious effect on both their sense of human dignity and their personal development. In addition, the removal of all risk diminishes the retarded [sic] in the eyes of others.”<sup>8</sup> The same is likely true for the elderly.<sup>9</sup> Despite clinicians’ best intentions, they may cause harm when they focus too narrowly on physical safety.

When a patient has diminished capacity, risk levels are extremely high, and no compromise strategy can be found, outside intervention may be required. This major escalation can generate great burden for all concerned, but due-process safeguards are necessary when a person may lose fundamental civil liberties. The legal steps vary from state to state and may involve Adult Protective Services, emergency petition, and guardianship. Alternatives to guardianship, which seek ways to balance independence and safety with nonadversarial approaches that still provide due process of law, are under study.<sup>10</sup> It is rare, but possible, for individuals to argue that they have regained capacity and formally regain independence and an end to guardianship.

Laws and nomenclature about substitute decision makers (SDMs) vary widely by jurisdiction, creating potential confusion for clinicians, patients, families, and support systems. A person could be acting as an SDM because the patient assigned this role, or by default as next of kin. Although designated and default SDMs hold comparable levels of authority in some jurisdictions, in others the designated SDM has significantly more authority than the default SDM. The terminology for designated and default SDMs varies widely by jurisdiction. Many states refer to designated SDMs as health care agents or durable powers of attorney. Some states use the terms proxy or surrogate to refer to default decision makers, but the same terms may refer to the designated SDM or simply any SDM in another state. In sum, the authority of an SDM to guide the treatment of a patient depends heavily on the regulations of the local jurisdiction.

### ***Perspective of family and friends***

Involvement of a patient’s family or support network is often critical and, when possible, should only be done with the patient’s permission. It is helpful to ask a patient, “Is there anyone else who may be affected by this decision with whom we should talk?” The ultimate decision remains that of the patient or, when decision capacity is lacking, a surrogate decision maker (or makers).

Inviting the perspective of the family and support network helps put an individual’s decisions into context, can be helpful in capacity determination, and can generate a more durable solution because it is supported by friends and family. Impact on others may drive an individual’s motivation for one choice or another. Older adults often fear being a burden on others.<sup>11</sup> Having the support network engaged in the conversation can thus help patients clarify assumptions about their impact on their caregivers and loved ones, whose perspectives may differ greatly from what the patient anticipates. Consider what hypothetical adult children might think if they perceive their loved ones to be in a high-risk situation (**Box 3**). In some situations, the clinician may have to explain to the loved ones that the patient is able to make decisions that caregivers would consider unsafe, whereas, in other cases, collateral information from caregivers makes it evident that a person lacks decision-making capacity. Adult children face very difficult choices when their frail parents insist on choosing risky options. The caregivers may wish to ally with the clinician to tell their loved one what to do (eg, “Doc, you have to tell Mom to stop doing...”). In these cases, clinicians need to be sure to make an independent assessment of the situation.

**Box 3****What the adult child might be thinking**

I can't bear the thought of my mom with a new serious injury.

I couldn't live with it if she is badly harmed and I said "OK."

What will my siblings/partner/neighbors say?

I can't let this happen.

I can't keep doing this for much longer.

***Clinician bias***

Clinicians' ability to accurately assess risk and judge capacity is subject to bias. Awareness of personal biases is therefore critical for reducing their impact. Biases can include notions about what is appropriate for persons based on their age, gender, race, socioeconomic status, cognitive and physical ability, and somatic and psychiatric health conditions. Ageism and ableism may lead clinicians to overestimate risk. Clinicians' cultural expectations, lived experience, and values shape perceptions of risk. For example, poor hygiene is a commonly cited risk factor for development of skin and wound infections. Poor hygiene is a subjective determination and the evidence supporting this belief is equivocal and limited.<sup>12</sup> An older adult initiating a new sexual relationship is another example. This relationship can be profoundly disturbing to relatives, who may couch their objection as a safety issue.

Deviation from dominant cultural norms of dressing, hygiene, or social behavior may serve as triggers for clinicians and social workers to assess the safety of individuals in their current situations. The authors suggest that clinicians carefully scrutinize such concerns before taking action. Is there truly a safety issue at heart? Changes in personal hygiene or housekeeping may alert clinicians to a developing medical disorder such as dementia or depression, but deviations from social norms may also simply reflect personal and social variation or an accommodation to difficult circumstances. Distinguishing among these requires clinician self-awareness. Collateral information from loved ones can be particularly informative in these situations. It is not the job of clinicians, nor is it ethical, to enforce a bourgeois lifestyle or impose their personal standard of living on their patients.

Considering questions such as those in **Box 4** may help clinicians reflect on their own values and views informing safety and risk. Importantly, awareness of personal biases is lifelong work. The authors encourage clinicians to revisit this topic periodically. The goals and values of an 80-year-old, or of a caregiving 45-year-old adult child, may not be intuitively obvious to a 35-year-old medical professional.

***Alternatives: making the best of it***

If a person chooses to remain in a risky situation at home, harm reduction strategies include home safety upgrades, home monitoring devices, and increased frequency of

**Box 4****Empathy in difficult situations: the do-unto-others test**

What are some choices that I have made that put myself or others at risk?

How much personal surveillance would I be OK with?

What would I consider an acceptable standard of living?

How much risk, inconvenience, and reduced hygiene would I accept in order to stay at home rather than entering a nursing home?

check-ins by family members or professional caregivers. Widely available community resources include meal delivery services, paid caregiver services, and mobility services such as senior rides. Other supports may be available. All states have Medicaid waiver programs of various forms and availabilities to help provide low-income patients with in-home support.

These risk mitigation strategies may themselves be unacceptable to patients. Patients may perceive home monitoring devices such as cameras or fall detection systems as intrusive.<sup>13</sup> Older adults may not see the value of spending the money, or have the money available, to afford in-home aides, who may seem intrusive to patients. Clinicians should revisit these strategies periodically with patients and their loved ones, because changes in conditions may lead to reconsideration of priorities.

### ***Considering liability***

Clinicians may be concerned about liability if a patient makes an unsafe choice. In certain situations, clinicians are legally required to report concerns for abuse, financial exploitation, neglect, or self-neglect perpetrated against vulnerable adults, especially those who have significant cognitive impairment. It is important to be aware of the laws of the local jurisdiction. Documentation in the medical record is important both for potential liability issues and to clarify for other clinicians the process by which the current circumstances were fashioned. This record-keeping avoids the unnecessary repetition of conversations that are often burdensome to all concerned.

The practices of dismissing patients from a clinic practice, ending the doctor-patient relationship, and of discharging patients from a hospital or other care facility against medical advice may sometimes be considered when caring for patients whose disregard for the safety of self or others exceeds some important threshold. These complex topics are not considered here, in part because there are considerable legal and policy dimensions to each of these practices.

## **SUMMARY**

The cases presented at the beginning of this article feature patients who choose to live at home and to drive, despite health care providers' concerns about the significant risks of doing so. These cases are examples in which older adults, their families, and their clinicians must balance risk reduction with autonomy and respect for person. To further complicate such decisions, there is significant ambiguity regarding risk, both in how much risk a decision entails and in how much risk is too much. Capacity to make a given decision may vary over time, and the authority of surrogate decision makers varies between jurisdictions. Clinicians should seek to understand the patient's (and, with permission, other relevant parties') perspectives, and should be mindful of how their own biases may affect their assessment of a situation. In cases where there is significant risk to others, or when a vulnerable patient is in a high-risk situation, outside intervention may be needed. In other situations, clinicians should partner with patients and their families to be transparent about the decision-making process and to find ways to reduce risk that all parties deem acceptable. In all cases, the goal is to support the patient in making choices that are authentic to their values and preferences.

## **CLINICAL CARE POINTS**

- Risk is often difficult to quantify; communicating it clearly and accurately to patients is often even more difficult. Written and visual materials can be helpful to complement verbal communication.



- Evaluation of capacity to make a decision requires a discussion with the patient, rather than reliance on tools or formulaic tests. Capacity may vary continuously and fluctuate over time.
- Risk mitigation strategies include using community resources, paid caregivers, and technology such as surveillance devices. These strategies are not accessible or acceptable to all patients, and some may find them intrusive.
- Situations in which there is significant risk to others, or in which a vulnerable patient is in a high-risk situation, generally require outside intervention, such as involvement of Adult Protective Services or emergency petition via law enforcement. Specifics of these interventions vary by jurisdiction.

## DISCLOSURE

The authors have nothing to disclose.

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