

Who Gets to Determine Whether Home Is “Unsafe” at the End of Life?

Jessica X. Zuo, MD^{a,b}; Andrea Ruskin, MD^c; Margaret R. Bauer, PhD^c

Background: At the end of life, some patients wish to be discharged directly home from the hospital, but health care teams may consider this unsafe, raising concerns for capacity and risk. However, defining risk is subjective and impacted by values, preferences, and clinical status. Accommodating patient preferences in discharge destinations can promote autonomy, dignity, and quality of life at the end of life.

Observations: We developed a risk assessment framework to help clinicians objectively identify risk factors and protective

factors and develop a comprehensive discharge plan. We applied this framework to a veteran nearing the end of life and he was able to successfully return home from the hospital.

Conclusions: Approaching end-of-life discharges with a framework can inform discharge planning and lessen the risk of adverse events. Importantly, this framework can help clinicians communicate better and partner with patients and their loved ones in prioritizing patient values and preferences.

Author affiliations can be found at the end of this article.

Correspondence:

Jessica Zuo
(jessica.zuo@va.gov)

Fed Pract. 2023;40(11).
Published online November 9.
doi:10.12788/fp.0434

Sometimes a patient at the end of life (EOL) just wants to go home. We recently treated such a patient, “Joe,” a 66-year-old veteran with end-stage chronic obstructive pulmonary disorder (COPD), severe hearing loss, and heavy alcohol use. A neighbor brought Joe to the hospital when he developed a urinary tract infection. Before hospitalization, Joe spent his days in bed. His neighbor was his designated health care agent (HCA) and caregiver, dropping off meals and bringing Joe to medical appointments. Joe had no other social support. In the hospital, Joe could not participate in physical therapy (PT) evaluations due to severe dyspnea on exertion. He was recommended for home PT, a home health aide, and home nursing, but Joe declined these services out of concern for encroachment on his independence. Given his heavy alcohol use, limited support, and functional limitations, the hospitalist team felt that Joe would be best served in a skilled nursing facility. As the palliative care team, we were consulted and felt that he was eligible for hospice. Joe simply wanted to go home.

Many patients like Joe experience functional decline at EOL, leading to increased care needs and transitions between sites of care.¹ Some hospitalized patients at EOL want to transition directly to home, but due to their limited functioning and social support, discharge home may be deemed unsafe by health

care professionals (HCPs). Clinicians then face the difficult balancing act of honoring patient wishes and avoiding a bad outcome. For patients at EOL, issues of capacity and risk become particularly salient. Furthermore, the unique structure of the US Department of Veterans Affairs (VA) health system and the psychosocial needs of some veterans add additional considerations for complex EOL discharges.²

END-OF-LIFE DECISION MAKING

While patients may express strong preferences regarding their health care, their decision-making ability may worsen as they approach EOL. Contributing factors include older age, effects of hospitalization, treatment adverse effects, and comorbidities, including cognitive impairment. Studies of terminally ill patients show high rates of impaired decisional capacity.^{3,4} It is critical to assess capacity as part of discharge planning. Even when patients have the capacity, families and caregivers have an important voice, since they are often instrumental in maintaining patients at home.

Defining Risk

Determining whether a discharge is risky or unsafe is highly subjective, with differing opinions among clinicians and between patients and clinicians.⁵⁻⁷ In a qualitative study by Coombs and colleagues, HCPs tended toward a risk-averse

TABLE 1 Risk Factors and Protective Factors

Risk factors	Protective factors
<ul style="list-style-type: none"> • Poor performance status, sensory impairments, functional dependence in activities of daily living, frailty • Limited insight into current condition • Lack of an involved health care agent • Lack of connection with the health care system • Difficulty reaching patient in outpatient setting • Home skilled services or home health aides refusal • Inadequate instrumental support from friends or family • Frequent falls or mobility issues • Cognitive issues, including delirium or dementia • Undertreated mental health or substance use disorders 	<ul style="list-style-type: none"> • Good functional status • Good understanding of illness and functional status • Presence of an actively involved health care agent • Consistent connection to the health care system, such as primary care professional or other important subspecialists • Reliable communication between patient/family and health care professionals • Willingness to accept home skilled services or home health aides • Willingness to come to the emergency department for acute medical issues

approach to discharge decisions, sometimes favoring discharge to care facilities despite patient preferences.⁶ This approach also reflects pressures from the health care system to decrease the length of stay and reduce readmissions, important metrics for patient care and cost containment. However, keeping patients hospitalized or in nursing facilities does not completely mitigate risks (eg, falls) and carries other hazards (eg, nosocomial infections), as highlighted during the COVID-19 pandemic.^{7,8} The prospect of malpractice lawsuits and HCP moral distress about perceived risky home situations can also understandably affect decision making.

At the same time, risk calculation changes depending on the patient's clinical status and priorities. Coombs and colleagues found that in contrast to clinicians, patients nearing EOL are willing to accept increasing risks and suboptimal living conditions to remain at home.⁶ What may be intolerable for a younger, healthier patient with a long life expectancy may be acceptable for someone who is approaching EOL. In our framework, a risky home discharge at EOL is considered one in which other adverse events, such as falls or inadequate symptom management, are likely.

Ethical Considerations

Unsafe discharges are challenging in part because some of the pillars of medical ethics can conflict. Prior articles have analyzed the ethical concerns of unsafe discharges in detail.⁹⁻¹¹ Briefly, when pa-

tients wish to return home against initial medical recommendations, treatment teams may focus on the principles of beneficence and nonmaleficence, as exemplified by the desire to minimize harm, and justice, in which clinicians consider resource allocation and risks that a home discharge poses to family members, caregivers, and home health professionals. However, autonomy is important to consider as well. The concept of dignity of risk highlights the imperative to respect others' decisions even when they increase the chance of harm, particularly given the overall shift in medicine from paternalism to shared decision making.¹² Accommodating patient choice in how and where health care is received allows patients to regain some control over their lives, thereby enhancing their quality of life and promoting patient dignity, especially in their remaining days.¹³

DISCHARGE RISK FRAMEWORK

Our risk assessment framework helps clinicians more objectively identify factors that increase or decrease risk, inform discharge planning, partner with patients and families, give patients a prominent role in EOL decisions, and mitigate the risk of a bad outcome. This concept has been used in psychiatry, in which formal suicide assessment includes identifying risk factors and protective factors to estimate suicide risk and determine interventions.¹⁴ Similar to suicide risk estimation, this framework is based on clinical judgment rather than a specific calculation.

TABLE 2 Determination of Risk Level at Discharge

	Low risk	Moderate risk	High risk
Required factors	Adequate but declining functional status with good insight	Inadequate instrumental support, poor functional status but with insight or adequate instrumental support but with poor insight	Inadequate instrumental support, poor functional status, and poor insight
Protective factors that reduce risk	Maintains low risk status: adequate instrumental support, willingness to come to ED, consistent communication with HCP, connection to health care system, involved HCA	Willingness to come to ED, involved HCA, connection to health care system	Will not likely modify this risk
Risk factors that could increase risk	Inadequate instrumental support, active substance use disorder, sub-optimally treated mental health disorder, uninvolved or no HCA	Unwillingness to come to ED, suboptimally treated mental health disorder, active substance use disorder, uninvolved or no HCA, poor communication with HCPs	
Risk factors that automatically raise to moderate risk	Unwillingness to come to ED, poor communication with HCPs, rapidly progressive disease		

Abbreviations: ED, emergency department; HCA, health care agent; HCP, health care professional.

While this framework serves as a guide for determining and mitigating risk, we encourage teams to consider legal or ethical consultations in challenging cases, such as those in which patients lack both capacity and an involved HCA.

Step 1: Determine the patient's capacity regarding disposition planning. Patients at EOL are at a higher risk of impaired decision-making capabilities; therefore, capacity evaluation is a critical step.

Step 2: Identify risk factors and protective factors for discharge home. Risk factors are intrinsic and extrinsic factors that increase risk such as functional or sensory impairments. Protective factors are intrinsic and extrinsic factors that decrease risk, including a good understanding of illness and consistent connection with the health care system (Table 1).

Step 3: Determine discharge to home risk level based on identified risk factors and protective factors. Patients may be at low, moderate, or high risk of having an adverse event, such as a fall or inadequate symptom control (Table 2).

Step 4: Identify risk mitigation strategies. These should be tailored to the patient based on the factors identified in Step 2. Examples include home nursing and therapy, mental health treatment, a medical alert system, and frequent contact between the patient and health care team.

Step 5: Meet with inpatient and outpatient HCP teams. Meetings should include the

primary care professional (PCP) or relevant subspecialist, such as an oncologist for patients with cancer. For veterans receiving care solely at a local VA medical center, this can be easier to facilitate, but for veterans who receive care through both VA and non-VA systems, this step may require additional coordination. We also recommend including interdisciplinary team members, such as social workers, case managers, and the relevant home care or hospice agency. Certain agencies may decline admission if they perceive increased risk, such as no 24-hour care, perceived self-neglect, and limited instrumental support. During this meeting, HCPs discuss risk mitigation strategies identified in Step 4 and create a plan to propose to patients and families.

Step 6: Meet with patient, HCA, and family members. In addition to sharing information about prognosis, assessing caregiver capabilities and burden can guide conversations about discharge. The discharge plan should be determined through shared decision making.¹¹ If the patient lacks capacity regarding disposition planning, this should be shared with the HCA. However, even when patients lack capacity, it is important to continue to engage them to understand their goals and preferences.

Step 7: Maximize risk mitigation strategies. If a moderate- or high-risk discharge is requested, the health care team

should maximize risk mitigation strategies. For low-risk discharges, risk mitigation strategies can still promote safety, especially since risk increases as patients progress toward EOL. In some instances, patients, their HCAs, or caregivers may decline all risk mitigation strategies despite best efforts to communicate and negotiate options. In such circumstances, we recommend discussing the case with the outpatient team for a warm handoff. HCPs should also document all efforts (helpful from a legal standpoint as well as for the patient's future treatment teams) and respect the decision to discharge home.

Applying the Framework

Our patient Joe provides a good illustration of how to implement this EOL framework. He was deemed to have the capacity to make decisions regarding discharge (Step 1). We determined his risk factors and protective factors for discharge (Step 2). His poor functional status, limited instrumental support, heavy alcohol use, rejection of home services, and communication barriers due to severe hearing impairment all increased his risk. Protective factors included an appreciation of functional limitations, intact cognition, and an involved HCA. Based on his limited instrumental support and poor function but good insight into limitations, discharge home was deemed to be of moderate risk (Step 3). Although risk factors such as alcohol use and severe hearing impairment could have raised his level to high risk, we felt that his involved HCA maintained him in the moderate-risk category.

We worked with the hospitalist team, PT, and audiology to identify multiple risk mitigation strategies: frequent phone calls between the HCA and outpatient palliative care team, home PT to improve transfers from bed to bedside commode, home nursing services either through a routine agency or hospice, and hearing aids for better communication (Steps 4 and 5). We then proposed these strategies to Joe and his HCA (Step 6). Due to concerns about infringement on his independence, Joe declined all home services but agreed to twice-daily check-ins by his HCA, frequent communication between his HCA and our team, and new hearing aids.

Joe returned home with the agreed-upon risk mitigation strategies in place (Step 7). Despite clinicians' original reservations about sending Joe home without formal services, his HCA maintained close contact with our team, noting that Joe remained stable and happy to be at home in the months following discharge.

CONCLUSIONS

Fortunately, VA HCPs operate in an integrated health care system with access to psychological, social, and at-home medical support that can help mitigate risks. Still, we have benefitted from having a tool to help us evaluate risk systematically. Even if patients, families, and HCPs disagree on ideal discharge plans, this tool helps clinicians approach discharges methodically while maintaining open communication and partnership with patients. In doing so, our framework reflects the shift in medical culture from a patriarchal approach to shared decision-making practices regarding all aspects of medical care. Furthermore, we hope that this can help reduce clinician moral distress stemming from these challenging cases.

Future research on best practices for discharge risk assessment and optimizing home safety are needed. We also hope to evaluate the impact and effectiveness of our framework through interviews with key stakeholders. For Joe and other veterans like him, where to spend their final days may be the last important decision they make in life, and our framework allows for their voices to be better heard throughout the decision-making process.

Acknowledgments

We thank Brooke Liffand, MD, for her theoretical contributions to the concept behind this paper.

Author affiliations

^aUniversity of Pennsylvania, Philadelphia

^bCorporal Michael J. Crescenz Veterans Affairs Medical Center, Philadelphia, Pennsylvania

^cVeterans Affairs Connecticut Healthcare System, West Haven

Author disclosures

At the time of this work, Jessica Zuo was funded as a Geriatric Medicine Education Fellow by the Connecticut Older Adult Collaboration for Health 4M (COACH 4M) grant, a Geriatric Workforce Enhancement Program funded by the Health Resources and Services Administration (HRSA). The COACH 4M grant and HRSA had no role in the development of this work or the preparation of this manuscript. The authors report no actual or potential conflicts of interest with regard to this article.

Disclaimer

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Ethics and consent

Verbal consent was obtained from the veteran reported.

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