



Shared Disposition Decision-Making in the Emergency Department for Persons Living with Dementia

Justine Seidenfeld, MD, Fernanda Bellolio, MD, MS, Anita Vashi, MD, MPH, MHs, Courtney Van Houtven, PhD, Susan Hastings, MD, MHs

INTRODUCTION

Case Study: Mr. S is 81 years old, was diagnosed with dementia three years prior, and lives alone in a two-story house. His daughter lives 45 minutes away and visits him at home a couple times per week after work to check in and drop off prepared dinners. Mr. S was well upon waking early this morning, but gradually felt more fatigued and decided to take a nap mid-morning. Later, he was too tired to go from his 2nd floor bedroom down to the kitchen to make his usual lunch. When his daughter arrived late afternoon, she found him still in bed. She had to assist him to walk downstairs and decided to bring him to the emergency department (ED) because he was feeling unusually weak and tired. In the ED, Mr. S's vitals are normal, and he denies any chest pain, shortness of breath, or abdominal pain, and reports having no recent falls or injuries. His workup, including infectious sources, electrolytes, and ECG are all normal. However, Mr. S still reports feeling unwell and while he can get out of bed, he doesn't want to get up or walk even 20 feet outside of his room. His daughter is concerned because this is unusual for him. The ED physician, Dr. F, is conflicted on whether to admit the patient for further monitoring and evaluation. Mr. S does not have any evidence of a serious illness that clearly requires treatment in the hospital, but Dr. F knows that older patients with weakness can have poor outcomes even with nonspecific presentations.

For persons living with dementia (PLWDs), one of the most impactful and costly elements of emergency department (ED) care is the decision to discharge or admit them to the hospital- the “disposition” decision. For those requiring urgent treatment in the hospital, the decision to admit is straightforward; but in many cases, this decision is not so simple.¹ In these cases, ED health care providers (including emergency physicians, nurse practitioners, and physician assistants) must balance the risks of hospital admissions, such as delirium and functional decline, against the risks of discharge, which include return ED visits and hospitalizations, falls, worsening morbidity, mortality, and poor patient experience.² Disposition decisions are especially complex for PLWDs, as they often have a higher number of comorbidities, take more medications, and are at higher risk of adverse events compared to their counterparts without dementia.^{3,4} Additionally, they may have a care partner to consider in decision making. When equipoise exists regarding a health care decision, such as the decision to admit or not, shared decision making (SDM) can be a strategy to facilitate conversations between patients, care partners, and health care providers, and increase patient engagement and understanding of their options.^{5,6}

Patient involvement in SDM can take a variety of forms, with varied degrees of “sharing” in the final decision. It is increasingly recognized that health care providers underestimate the degree to which patients want and are able to be involved.⁷ A scoping review focused on ED communication strategies among patients with dementia demonstrated that SDM is feasible in several scenarios, although none of the included studies evaluated it at the time of the disposition decision.⁸ Barriers to SDM included

symptom severity, inadequate decisional capacity, and care partner preparedness to serve as a surrogate decision-maker.

Given these complexities, shared disposition decision making requires deliberate effort from all involved parties to understand PLWD preferences. While high quality decisions will be aligned with the patient and care partners' values, the health care provider is directly responsible for the admission or discharge process and should lead the conversation. Below, we outline several steps involved in SDM and important considerations when discussing ED dispositions with patients and care partners. Specific health care team recommendations are provided in Table 1. These are based on the literature on communication and patient centered care, and the consensus of the authors as experts in geriatrics, emergency medicine, SDM, and healthcare for PLWDs and their care partners.

Table 1: SDM Principles and Recommendations	
SDM Principle	Recommendations
<p>Decisional roles Who should be involved in making the disposition decision?</p>	<ul style="list-style-type: none"> • Is there a surrogate decision-maker or legally authorized representative that needs to be involved? May need to check the electronic medical record (EMR) for documentation. • Always involve the PLWD in the decision in some way. Even if they do not have decisional capacity, seek their <i>assent</i> to have an SDM conversation to respect their personhood and dignity. • Communication with the patient should be based on their status at the time of the ED visit. Tailor the conversation based on their cognitive status and preferences at the time you see them. • Consider the care partner. Check if the care partner can meet the needs that would be in the best interest of the patient at that time.
<p>Establish rapport How to create trust and a sense of empathy?</p>	<ul style="list-style-type: none"> • Make sure they know there is a choice to be made. The PLWD and care partner should know that they can contribute to the extent that they feel comfortable. • Use understandable language. This can include visual or written aids if that would be helpful. • Think about non-verbal elements of communication. For example, not standing over the patient. Sit, try to speak at eye level, and make eye contact.
<p>Provide information Do the patient and care partner have all the information they need to decide?</p>	<ul style="list-style-type: none"> • List and explain options. • Check understanding of essential facts. Ask them to summarize their understanding of their options. • Fill in any gaps. Ask them what else they would need to know in order to make a decision. • Take your time. Make sure they have time if needed to process new information at this point.

<p>Clarify personal values and preferences</p> <p>What are the goals of their ED visit?</p>	<ul style="list-style-type: none"> • Directly invite the patient and care partner to share their views. With multiple or competing values, frame them in terms of the decision (e.g. “If [A] matters most to you, option 1 might be best; if [B] matters most, option 2 might be best.”¹⁴)
<p>Support the discussion</p> <p>How to reach an agreement about the preferred option?</p>	<ul style="list-style-type: none"> • Focus on preferences. • Use open ended questions. This may be needed to move the discussion through stages. • Take more time. This may be another point at which the patient and/or care partner need additional time to decide, and the discussion can be broken up into multiple shorter sessions. • Clarify any remaining questions.

DISCUSSION

Decisional Roles

One of the first steps is determining who will be involved in making the disposition decision.

- PLWDs can reliably communicate their values and choices, even as cognition declines.⁸ However, their decision making capacity is often overlooked by both health care and family members.⁹ Patients wish to be involved and make their own decisions, and will have different levels of dementia severity and decisional capacity.
- Additionally, the care partner present at the ED visit with them may not be the documented legally authorized representative. In these cases, ideally both the bedside care partner and the legally authorized representative would be involved in the decision making in addition to the patient. If there is no care partner at the bedside, do your best to work with the PLWD to identify and reach out to the most appropriate party.
- PLWDs will experience a range of “good days and bad days”. Patients with low levels of dementia severity and high decisional capacity when at their baseline may be having more severe cognitive symptoms at the time of the ED visit. Likewise, a patient with high severity dementia may be having a “good day” during the ED visit, and should not be excluded from the decision making conversation.
- The type of activities and amount of time involved in caregiving for PLWDs can vary considerably throughout the disease trajectory. Care partners often can relay the patient preferences if needed, act as the primary source of care coordination, and must navigate increasingly complex health care systems as the severity of dementia increases.¹⁰ This is a difficult and often underappreciated role, and it is important to recognize that acting in the best interests of the patient should include considering the capacity of the care partner.

Establish Rapport

The ED encounter represents a very stressful situation, as it is an unfamiliar environment requiring interactions with multiple staff members. Consequently, trust and a sense of empathy from the health care provider are needed to facilitate interactive communication and to ensure that PLWDs and care partners feel comfortable expressing their own values and preferences.

- Health literacy is an important communication barrier to recognize when having a complex conversation around the disposition decision, even if there is no formal assessment of literacy level.¹¹ This is especially important for PLWDs as health literacy changes with dementia severity.

- Nonverbal communication is also important to establish rapport and invite participation. This can include taking the time to sit or otherwise position yourself at eye-level and avoid multi-tasking (including use of screens) during the discussion.

Provide Information and Assess Decisional Needs

One of the health care provider's roles is to give information about the options available to the patient in a neutral and balanced manner.¹²

- Discussing the possible risks and benefits of both admission and discharge will always have to be tailored to the PLWD and care partner's particular situation and the reason for their ED visit. While it is not often going to be possible, or even recommended, to convey risks in statistical forms of likelihood, it is important to ensure that the patient and care partner have the relevant facts to participate in decision making.
- Give the patient and care partner sufficient time to process new information. This may require breaking up the discussion into two or more sessions, leaving them time to consider their options before being asked for their opinions or preferences.

Clarifying Personal Values and Preferences

It is also important to give the PLWD and care partner the opportunity to share any relevant information with you. This will in turn improve the decision-making process.

- The patient and the care partner may have different goals or levels of risk tolerance or aversion that need to be balanced.
- Clarify any goals that might have prompted the ED visit and get a sense of "what matters most" to them. This will allow all parties to consider the disposition decision in terms of those goals.
- Personal or situational circumstances for the patient and care partner might impact the decision (for example, the primary care partner lives 45 minutes away and cannot help every day with activities like dressing or bathing at home.)

Supporting Deliberations

This final step combines the knowledge of risks and benefits of the options along with the goals of the patient and care partner, to work together to reach agreement about the preferred option.

- Decision making can happen in stages, and the health care provider's role is to facilitate progress throughout the discussion.
- This part of the discussion may reveal additional psychosocial or resource related issues that may influence the decision. It is often difficult for the ED health care provider to directly access, and coordinate services given multiple demands in the busy ED environment, so they may benefit from engaging an interdisciplinary care team. These teams are increasingly used as part of widespread efforts towards improving geriatric ED care,¹³ and can address home help needs or outpatient care follow up that would support a safe discharge home- if aligned with PLWD and care partner preferences. If there are options to address these (i.e., arranging for home physical therapy), be sure to communicate that to the patient and care partner.

CONCLUSION

Case Study Conclusion: Dr. F, Mr. S, and Mr. S's daughter review the test results. Although they are both relieved that there is no sign of a serious problem, they are still concerned that they don't know what is making him so tired today. Dr. F asks Mr. S's nurse to teach him to use a walker, which he can use at home until he feels stronger. Dr. F describes the options to either 1) go home and wait to see what happens- knowing that they can return if it gets worse or doesn't go away, or 2) Mr. S could be admitted to the hospital to be watched overnight. Mr. S expresses that he prioritizes having control of his own schedule, and he would rather see if he feels improved with a good night's sleep at home. He says he will use the walker at home until he feels stronger. His daughter expresses that she is worried about him being alone because she cannot stay with him overnight. What if he forgets to use the walker and falls because he is so weak, and no one is there? Dr. F asks the ED social worker to talk to Mr. S and his daughter about possible resources they could have at home to help. The social worker arranges for a home safety evaluation, although it may take a week or more before it can be completed. In the meantime, the social worker helps them develop a plan to have Mr. S's nephew come to stay with him for the next night or two, as the nephew can work from Mr. S's spare room. Dr. F also sends an EMR message to Mr. S's primary care provider to notify him about the ED visit. Both Mr. S and his daughter are satisfied with this decision, and Dr. F discharges them after a discussion about return precautions. The following week, Dr. F checks the EMR and sees that a nurse practitioner from the PCP's office called Mr. S a few days after the ED visit. Per documentation, Mr. S felt significantly improved by the time of the call and had resumed his normal activities.

PLWDs are a vulnerable and heterogeneous population, and the ED disposition decision requires weighing many downstream possibilities that are often difficult to quantify. Given these additive complexities, this is an important circumstance in which SDM can be used to support ED care that is consistent with what matters most to patients and care partners. Involving patients in their health care decision and disposition decisions both empowers and respects them. SDM is a relatively new tool in the ED setting, but there are many scenarios where its use is both feasible and appropriate.¹⁵ Current ED-based SDM tools cover a broad scope of patient populations and health care decisions, including tools for dispositions for chest pain¹⁶ and syncope¹⁷, imaging for kidney stones¹⁸, and to facilitate conversations about goals of care in older adults.¹⁹ Many of these tools have been evaluated with randomized controlled trials and pilot studies, and have demonstrated increased patient knowledge and decreased decisional conflict. While widespread implementation trials evaluating utilization outcomes such as admissions and ED re-visits have not yet been published, SDM tools in other settings have been found to reduce utilization while maintaining alignment with patient and surrogate decision-making priorities.^{20,21}

However, even compared to older adults without dementia, guidelines for ED communication and SDM for PLWDs and their care partners are very limited.⁸ Currently, there are no formal tools to support best practices in shared disposition decision making for PLWDs. Future work in this area is needed to support ED health care providers, patients, and their care partners to navigate this complexity.

KEYWORDS

Shared decision-making, dementia, care partners, ED dispositions, communication

AFFILIATIONS

Justine Seidenfeld, MD

ADAPT HSR&D Center of Innovation and Department of Emergency Medicine, Durham VA Health Care System, Durham, NC; Department of Emergency Medicine, Duke University School of Medicine, Durham, NC

Fernanda Bellolio, MD, MS	Department of Emergency Medicine, Department of Medicine (Geriatrics), and Division of Health Care Policy and Research, Mayo Clinic, Rochester, MN
Anita Vashi, MD, MPH, MHs	Center for Innovation to Implementation and Department of Emergency Medicine, Palo Alto VA Medical Center, Palo Alto, CA; Department of Emergency Medicine, Stanford University, Stanford, CA
Courtney Van Houtven, PhD	ADAPT HSR&D Center of Innovation, Durham VA Health Care System, Durham, NC; Department of Population Health Sciences, Duke University School of Medicine, Durham, NC
Susan Hastings, MD, MHs	ADAPT HSR&D Center of Innovation, Durham VA Health Care System, Durham, NC; Department of Medicine (Geriatrics) and Department of Population Health Sciences, Duke University School of Medicine, Durham, NC

CORRESPONDING AUTHOR

Justine Seidenfeld, MD
 ADAPT, Durham VA Health Care System
 411 W Chapel Hill St.
 Durham, NC 27701
justine.seidenfeld@va.gov

CONFLICTS OF INTEREST

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