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Identifying Goals of Care

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Introduction

As a person ages or faces serious illness, decisions about medical care become more challenging. When cure of a disease is not possible, treatments become focused on other goals such as symptom amelioration or extending life. Additionally, both the underlying disease and the treatments may cause suffering to the patient. Finally, as patients age the outcomes of medical interventions are more uncertain due to comorbidities or frailty. Because individuals are more likely to differ in their preferences for or against treatment in these circumstances, decisions are often referred to as "preference sensitive."[1] Preference sensitive decisions vary based on the individual values, goals and circumstances of the patient.

Goals of care is a term commonly used to refer to the entire process of making medical decisions, but it really has several components, including values, goals and treatment preferences (Figure 1). It can involve making decisions for the future, often referred to as advance care planning, or making decisions about medical treatment in the present. Such conversations can occur in the hospital, nursing home and outpatient setting. In this article, we will describe a framework for addressing goals of care, review literature on

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communication about goals and review important outcomes such as medical treatments received and patient or family psychological outcomes.

As patients age, their ability to make their own decisions is more likely to be impaired due to dementia, and delirium is a common cause of diminished capacity during acute illness. Therefore surrogate decision makers, usually close family members, often are involved in the decision making process. Goals of care conversations for older adults may be held with patients, surrogates or both, but can consider the same core components. Surrogates are generally asked to rely on the patient's previously stated preferences, when known. When specific preferences are unknown surrogates are asked to consider how the patients' goals and values should inform treatment decisions, a process called substituted judgment.[2] While surrogate decision making introduces additional ethical and emotional considerations, the approach involves many of the same concepts and skills as goals of care conversations with patients.

Goals of care conversations require physicians to effectively communicate complex information about a medical diagnosis and its prognosis to the patient and family, elicit information about patient preferences, provide support and make shared decisions, and ensure treatments and outcomes are aligned with patient and family preferences. The struggle for clinicians to have goals of care conversations is particularly important for geriatric providers as the need to communicate prognosis and set goals of care to alleviate suffering is both time sensitive and common. These conversations are sometimes conducted by palliative care specialists who are experts in goals of care conversations, but often these conversations are conducted by the patient's primary physician or hospitalists. These communication challenges arise at high rates during end-of-life care when decisions are more preference sensitive. Effective goals of care conversations usually explore values and preferences prior to considering specific treatment interventions.

Terminology

Values

Values are broad concepts that guide our actions, and may include the value of life, family connections, or living according to religious or cultural beliefs and traditions. Balancing quality of life against length of life is a trade-off that must be considered for some highly burdensome treatments. In exploring values, clinicians may ask, "What is most important to you?" or " What gives your life meaning?" For some patients and families, values are closely related to religious or spiritual traditions, and chaplains may be especially valuable in elucidating or clarifying them. The Interprofessional Spiritual Care Educational Curriculum (ISPEC) is a curriculum developed to train non-chaplains how to address spiritual concerns when they arise and to promote collaboration between chaplains and various clinicians, including physicians, to provide comprehensive spiritual care to patients.[3]

Physicians also have deeply held values such as promoting health and reducing suffering.[4] In the vast majority of patient care, patient and physician values are concordant. However, when outcomes are uncertain or the burden of treatment increases, there may be ethical

conflicts between clinician and patient values. Resources such as ethics or palliative care consultation may be valuable and are described below.

Patient-Defined Goals

Studies that ask patients to describe their own goals for medical care have identified categories such as cure, being comfortable or remaining at home.[5] Goals may be broad or specific, but most importantly are defined by the patient or their surrogate. Exploring goals in advance of treatment decisions will help clinicians understand patient motivations for or against particular treatments. Discussions about the patient or surrogates personal goals or the overarching goals of treatment, such as preserving life or focusing on comfort. Examples include being able to recover enough to engage in meaningful conversation, being comfortable, or living to a specific event. Using open ended questions to ask patients about their own goals can help foster communication about specific treatments. Affirming patient goals can be a positive way to connect and build trust. Sometimes patient's stated goals may be impossible or uncertain. Physicians can follow-up with additional probing, by asking about additional hopes. By taking the approach of "hoping for the best but preparing for the worst," clinicians can partner with patients and families while also assisting in making realistic plans for medical treatment.[6]

Treatment preferences

In counselling patients, an important role of the physician is to explore how a particular treatment will help the patient attain their goals and is concordant with their values.[7] Ethical challenges arise when patients select inconsistent plans of treatment. Incoherent plans have the potential to cause patient suffering while not achieving goals.

These include categories of treatment as well as specific decisions about individual interventions A three-part framework is helpful in research and clinical care to describe treatment preferences[8–10] The three general categories are: treatment focused on keeping the patient comfortable, usually by providing pain and symptom management; an intermediate plan of care involving hospitalization, IV medications or monitoring; and full, life sustaining treatments including ventilators, dialysis and major surgery. Research on treatment preferences has found that decision aids and videos may help improve patient understanding of goals of care and may lead to more documented goals of care conversations.[8,9] When properly informed, patients may be more likely to receive comfort focused interventions.[11]

The most specific level of treatment decision making involves a particular intervention such as a surgery or medication. These should generally be considered in light of the broader categories of values, goals and general treatment preferences as well as medical evidence and expert opinion about the value of a particular treatment. In the primary care setting, older adults are at risk for polypharmacy, ordering of duplicative or unnecessary testing, and referrals for potentially unwanted evaluations. The American Geriatrics Society has joined the Choosing Wisely campaign, making a series of recommendations about specific treatments with the goals of reducing burdensome polypharmacy and the ordering of screening tests that are unlikely to benefit older adults.[12]

The Clinical Context

There is ample evidence that culture, race and religion play a role in goals of care and in treatments patients receive (Figure 1). There are some general trends clinicians should be aware of. On average, African American patients and more highly religious patients and families tend to prefer more life sustaining treatments in serious illness.[13,14] However, many patients from these groups do want and receive high quality comfort care as illness progresses.[15,16] Asking questions about the patient's individual priorities and the individual values of the patient is essential.

The goals of care are also dependent upon the clinical situation and prognosis. Knowing the likely outcomes of the patient's condition as well as the range of options is essential to the decision making process. Among geriatric patients, clinical features such as frailty and functional status vary widely from patient to patient. Comorbidities also complicate estimates of prognosis for older adults.[17] These factors may contribute to estimates of patient outcomes being inconsistent across different providers. In some cases, prognostic calculators can help a clinician estimate prognosis in order to guide goals of care discussions.[18,19] Many of these calculators are easily available online.[20] An essential responsibility of the physician is to evaluate these factors prior to conversations with the patient so that the patient can be educated about their condition and realistic goals can be set. Studies have found that patients and caregivers desire different amounts of information, with patients often wanting less information, and caregivers wanting more. Clinicians should be attuned to the patient's desire for information and ability to understand. Teach-back or Ask-Tell-Ask is a useful approach to confirm understanding.[21]

Treatment Plans

After a goals of care conversation, decisions need to be communicated and translated into medical treatments. Appropriately documenting the decisions made as well as the reasons for the decisions can be important to future decision making. The decision may lead to proceeding with a surgery, a hospital admission or other major intervention. Treatment planning also involves deciding ahead of time about emergent interventions such as code status or intubation. Such decisions can be documented by DNR orders in the hospital or Do Not Hospitalize orders in the nursing home setting. An important tool for documenting these types of treatment preferences is the Physicians Orders for Life Sustaining Treatment (POLST) Paradigm and form.[10] POLST has the advantage of transferring across settings such as the nursing home or community. Legally valid POLST forms are available in nearly all US states, although the names of the form and the treatment choices vary. POLST forms include preferences for three categories of medical interventions (comfort focused, intermediate or "selective" treatments, and life sustaining or "full" interventions. Patients also indicate preferences for cardiopulmonary resuscitation. Some states include preferences for antibiotics or artificial nutrition. Unlike advance directives, POLST forms are medical orders that must be signed by a physician (or an NP or PA in some states). There are frameworks that guide the conversations about POLST forms such as Respecting Choices Advanced Steps, in which a trained facilitator guides a patient through a conversation to identify values, goals and treatment preferences.[22]

Outcomes of Goals of Care Conversations

High quality decision making involves considering specific treatment preferences in the context of values, goals and treatment preferences. Defining a “good” outcome requires exploring an individual patient’s perceptions about quality of life because individuals often have different viewpoints on whether death or survival with disability is the better outcome. Therefore an important outcome of this process is that treatments are concordant with patient values and preferences.[5,23,24] Additionally, it is then important that concordance is achieved between preferences the treatments that the patient actually receives.[25]

Clinician Training and Resources

A recent survey of primary care physicians and medical subspecialists who regularly see older adults revealed that sixty-eight percent of physicians report no training related to talking with patients about goals and wishes at the end of life.[26] This was despite nearly universal consensus among survey participants that it is important to have end of life conversations. During medical education, communication training often occurs passively through observation of more senior physicians and trainee trial and error. Since faculty may not be well versed in best communication practices or teaching principles, bedside teaching may be subject to the “hidden curriculum” with the risk of transmitting bad habits. When seeing patients who are under stress from serious illness and face complex value-sensitive decisions that are mired by uncertainty, well-trained faculty physicians can teach communication through role modeling and coaching. There is a high need for communications skills training to ensure that providers are matching treatments to seriously ill patient goals and values.[27]

As goals of care conversations frequently occur during clinical worsening, patients often experience difficult emotions during conversations. Clinicians should expect strong emotions when delivering bad news or talking about goals of care. Patients and families can be supported by actions that convey empathy, including acknowledging patient emotion, allowing some silence when the patient expresses emotion, and statements that suggest partnering and nonabandonment.[28] By conveying empathy, physicians can ensure that conversations remain focused on achievable patient-oriented quality of life goals and values, even when other goals may not be achievable. When the patient raises unachievable goals, physician empathy can be used to provide grief support and resolve conflict.[28,29] There is also evidence that even though spiritual and religious support is important to patients and benefits them, physicians often ignore these issues when patients and families raise them.[30]

Another useful framework, REMAP (Reframe, Expect Emotion, Map the future, Align with patient values, Plan treatment) framework was developed to provide physicians with a step by step process for goals of care conversations when there is a change in condition.[31] This guide can be especially helpful to clinicians who are learning to conduct these conversations but also to experienced clinicians to ensure that all important components of the conversation are addressed. This framework, along with the NURSE mnemonic for responding to emotion, has been used extensively for simulation practice and coaching. The use of simulated patients encourages physicians to reflect on the individual communication

skills important for each step in the process of goals of care conversations. Rapid cycle deliberate practice and debriefing that promotes learner experimentation with new strategies allows learners to compare various strategies.[32,33] Many institutions have incorporated simulation into medical education curricula, and opportunities exist for continuing education for practicing physicians. This teaching format has been demonstrated to increase physician use of high yield skills, including jargon-free discussion of the patient's condition, verbal empathy, and open exploration of concerns.[34]

In older adults, high stakes decision-making about treatment options often requires comparison between a potentially invasive or burdensome intervention (e.g. surgery) with unclear outcomes and an alternative path of supportive care. Decision aids may be valuable in communicating with patients about options. The Best Case/Worst Case (BC/WC) tool provides patients with a side by side comparison of options, with a best case, worst case, and most likely case narrative description of the anticipated course with each option).[35] With a brief two-hour workshop, a group of surgeons was able to implement this tool with reasonable fidelity and with most surgeons reporting use of the tool after six months. Patients report that the graphic aid facilitates deliberation and allows comparison between treatment options, establishing expectations about a range of outcomes.

Early consideration of goals, values, and treatment preferences in the outpatient setting can prevent older adults from undergoing unwanted interventions and help them discuss their priorities with surrogate decision-makers. The Serious Illness Conversation Guide was developed as an aid to discussions in the clinic, typically outside the setting of an acute illness. A training workshop is available to implement this guide, which relies on question prompts that ask patients to reflect on their goals and values. Common electronic medical record systems in the United States have integrated this guide to promote documentation and a particular strength of SICG is consideration of system integration. There are several other published and online resources that address goal development.[7,36] reducing burdensome treatments and tests unlikely to benefit older adults (Choosing Wisely) and supporting spiritual and religious needs of patients and families (Table 1).

Specialty Consultation in Goals of Care

Goals of care has the potential to raise difficult ethical issues and can lead to conflict between families, patients and clinicians, and even among clinicians. Clinicians may experience moral stress, the feeling that they know the right thing to do but are constrained from carrying it out. Discordance among values, goals and treatments can be an important source of moral distress and ethical conflict. In such cases, palliative care consultations and ethics consultations can help to readdress decision making. Additionally, when emotional or religious concerns are prominent, social workers and chaplains can play a role in providing support and navigating the decision making process.

Discussion and Summary

Goals of care conversations are an important but complex skill for clinicians caring for older adults. Although clinicians tend to focus on specific medical interventions, these

conversations are more successful if they begin with gaining a shared understanding of the medical conditions and possible outcomes, followed by discussion of values and goals. Although training in the medical setting is incomplete, there are many published and online resources that can help clinicians gain these valuable skills.

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Clinics Care Points

- Goals of care conversations should address the clinical situation, patient values and patient goals before discussing specific medical treatments
- Clinicians should be prepared to respond to emotion with empathy and to acknowledge and support religious and spiritual needs
- Providing patents and families the opportunity to talk about their concerns will increase satisfaction with the process.
- Ethics and palliative care consultation can help resolve challenges with decision making about goals of care and related treatments.
- Social work and chaplaincy are integral to providing ongoing support to patients.

Key points

- Decision making for older adults is complicated by increased prevalence of serious illness, complexity due to comorbidities, and decisions that are sensitive to the individual preference of patients.
- Goals of care conversations should explore values, goals and treatment preferences.
- Needed clinician training can be attained through structured programs. Many resources are publicly available

Synopsis

Goals of care conversations are an important but complex skill for clinicians caring for older adults. Although clinicians tend to focus on specific medical interventions, these conversations are more successful if they begin with gaining a shared understanding of the medical conditions and possible outcomes, followed by discussion of values and goals. Although training in the medical setting is incomplete, there are many published and online resources that can help clinicians gain these valuable skills.

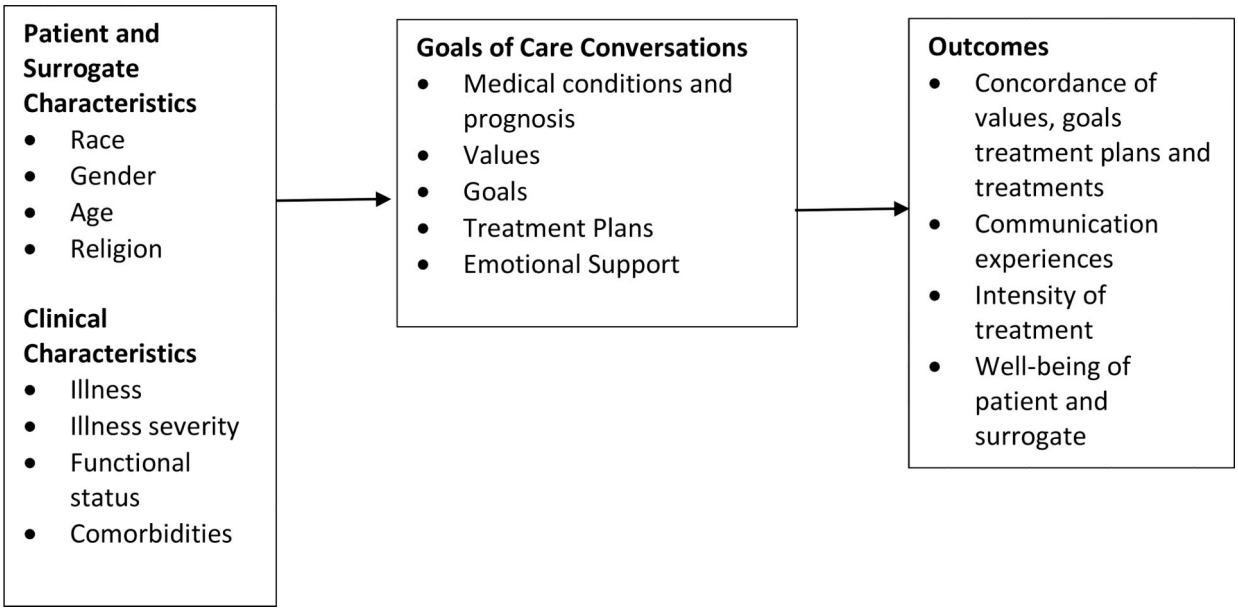

Fig 1.

Model of the patient and surrogate factors, process and outcomes of goals of care conversations.

Table 1.

Published and online resources for clinicians having goals of care conversations with geriatric patients. *Data from Refs* [7, 29, 35]

Name	Access	Description
Respecting Choices	Access to materials is through agreement with Respecting Choices www.respectingchoices.org	Provides training for structured facilitation of advance care planning
Vitaltalk	www.vitaltalk.org	Training for physicians and others leading goals of care conversations
VALUE framework	Publication[29]	Communication strategies to improve decision making
Serious Illness Care	https://www.ariadnelabs.org/areasof-work/serious-illness-care/	A program and guide to improve communication. Includes the serious illness communication guide
Best case/Worst case	Publication[35]	Communication tool for side by side comparison of options, and narrative description of the anticipated course with each option
Patient Priorities Care	Publication[7]	deliberate evaluation of patient values and the development of SMART goals (specific, measurable, actionable, reliable, and time bound) to drive medical decision-making.