CHAPTER 8

Assessment and Care Plans That Support Goals That Matter to the Person

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CHAPTER OBJECTIVES

1. Set the contextual frame for providers to engage in an assessment and care-planning process that elicits and supports goals that matter to the person.
2. Define person-centered care in the context of assessment and care planning for older adults.
3. Describe the process of ascertaining a person's goals in the assessment process and using the goals as a basis for care planning.
4. Identify factors that may affect goal elicitation and use of person-centered goals as the frame for assessment and care planning.

KEY TERMS

Person-centered care

Introduction

Imagine that you are seeing a patient for the first time. She is 84 years old and accompanied by her daughter. The patient has multiple chronic health conditions—some well controlled, such as her high blood pressure and diabetes, and some poorly controlled, such as her chronic obstructive pulmonary disease (COPD). She also has mild cognitive impairment and has come to you with pain in the hip that she lives with on a daily basis. Her previous doctor closed his practice, but the daughter informs you that her mother was considering a hip replacement with that physician.

As a clinician, you review the medical record, vital signs, and the medically oriented problem list collected and synthesized by the nurse. You begin to gather clinical information using open-ended and problem-focused questions such as "What brings you in today?" and "What is troubling you?" Based on the patient's and daughter's initial responses, you begin the standard assessment processes for her overall health, the unstable COPD, and the condition of her hip. You ask her a series of questions that delve deeper and are more disease focused, performing relevant screening exams and tests. Given her mother's mild cognitive impairment, you ask the daughter to confirm and elaborate on what may be happening. As a clinician, you then filter and synthesize all of the responses through medically oriented guidelines and clinical experience into a decision tree as you deliver your professional opinion on care and treatment. You lay out a course of action and interventions and referrals (e.g., pharmaceutical, surgical, rehabilitative).

While this process and outcome are technically appropriate as guideline-informed care, they failed to identify and incorporate the person's goals and values—that is, what she is trying to achieve and avoid. This is the most critical information to ensure that care is concordant with the person's goals. The missing information includes knowing what matters most to this older adult and the reasons underlying her health issues. Goals often expressed by older adults include maintaining independence and function, along with freedom from troubling pain and/or symptoms. Other goals may be longevity, such as being able to be present for a future family event. Clinicians can obtain this information only by asking their patients about their needs, values, and preferences for care in an attempt to understand how they seek to live life every day and what they hope to avoid.

In this case, the older woman wanted to remain at home—that was the single most important thing to her. Her daughter helped her shop, cook, and manage her bills, so living at home had been a good option for her.

Sadly, she was not asked what mattered most to her and was referred to a surgeon to evaluate her hip. She developed delirium in the hospital following the hip replacement and was sent to a nursing home for post-acute rehabilitation. The change of setting caused further deterioration of her cognitive state. She was unable to benefit from rehabilitation and fell in the nursing home, suffering a hip fracture. She never returned to her home, and both her overall health and cognitive state declined rapidly. She died, in constant pain, within a year.

A conscious and deliberate inquiry into "what matters" is at the heart of a **person-centered care** approach to clinical practice, particularly when caring for older adults with complex medical and social needs. This attention to person-centeredness by the clinician can ensure that the interventions included in a jointly created care plan will have a much greater chance of achieving the health outcomes of your patients and their families.

This chapter outlines the contextual frame that allows providers to engage in an assessment and care-planning process that support goals that matter to the person. It also defines person-centered care in the context of assessment and care planning for older adults, and describes the process of ascertaining their goals. Finally, it articulates how this information can be used as the basis for care planning and identify factors that may impact goal elicitation.

Contextual Frame of Older Adults with Complex Health and Social Care Needs

Older adults who seek medical attention generally do so because some component of their everyday functioning has changed for the worse, and they (or family members) do not feel as if they can manage this new daily living challenge on their own. A change can come in the form of various physical symptoms—for example, increased joint pain, decreased vision, difficulty breathing, or confusion—as well as the distal impact of the symptoms, such as an injury from a fall. Increased physical distress over time may signal a more significant health event, such as cardiac arrest or a stroke.

When older adults have a significant medical condition that needs immediate attention, they generally seek help because of the problematic symptoms and functional decline they experience (e.g., "I am having trouble breathing and feel pain in my arm"), not because they are aware of the underlying condition (e.g., "I am experiencing a myocardial infarction"). While the elements of, and solution to, the underlying medical problem are vital, what is generally most important to the older adult in distress is that he or she can return to a state of being where the least amount of medical intervention is needed in daily life.

Older adults may have unreasonable expectations in part because clinicians may not discuss the prognosis (i.e., the likely course of the disease) within the context of overall health, as opposed to just the specific health issue being addressed. Without a clear understanding of prognosis, coupled with treatment options that fit with a person's goals and values, care may unrealistically be seen as fixing the medical problem so the person can get on with the business of living well. Yet when clinicians work with an older adult living with multiple chronic health conditions, the idea of "fixing the health problem" and returning to a pre-illness state is often not the goal.

A survey of frail, older adults at senior centers on what mattered most to them found that their health goals fit into four key domains: (1) independence, which included the ability to live at home and not be a burden on others; (2) improved function, which included being able to do and enjoy specific activities; (3) management of pain and symptoms; and (4) length of life, meaning maximized longevity. In this study, the focus on longevity was the least popular response by far (Fried et al., 2011). These four outcomes are predicated on a clear sense of what the older adult wants as care outcomes and what the idea of "matters most" means in a personal way. However, the goals of care may not be immediately self-evident to the older adult, the family, or the clinician, and hence require dedicated dialogue to elicit and utilize them in a useful manner. For older people with multiple chronic conditions and associated functional limitations, asking about a person's goals in the assessment process has an even deeper meaning and necessity given that treatment protocols across disease states can be often unclear, contradictory, or simply nonexistent.

Historically, adults did not live into old age and experience significant comorbidities coupled with functional impairment. The advent of antibiotics, modern technology, effective public health interventions, and a series of socioeconomic forces have contributed to the U.S. population now having an average life expectancy of 79 years (National Center for Health Statistics, 2017). However, long life does not mean that people live well through the end of their life. As of 2015, *healthy* life expectancy was only 69 years in the United States (World Health Organization, 2016). Why the difference? Because half of all Americans turning 65 today will one day find themselves needing a high level of help with basic daily activities such as walking, eating, getting out of bed in the morning, and bathing (Favreault & Dey, 2015).

At the same time, the number of aging Americans with significant healthcare and daily living needs is projected to grow from 6 million to almost 16 million over the next several decades (Favreault & Dey, 2015). This trend toward greater disability in old age has significant implications for healthcare delivery. Research has shown that the costliest 5% of older Medicare beneficiaries account for nearly 40% of that federal program's annual spending. Older adults with daily living needs coupled with chronic health conditions cost Medicare roughly twice as much as those living with chronic conditions alone (Rodriguez, Munevar, Delaney, Yang, & Tumlinson, 2014).

At a macro level, health systems and federal policy efforts continue to strive for new system transformations to improve care while lowering costs, particularly for those with high healthcare utilization. Taking a bold step, the Centers for Medicare and Medicaid Services (CMS) instituted the "Triple Aim" framework, which calls for better population health, better care for individuals, and lower per capita costs through system improvement. This trend has continued, with CMS announcing its intention to shift from largely fee-for-service payment to value-based purchasing arrangements focused on both costs of care and quality outcomes.

With the advent of value-based payment, how can the healthcare system support older adults with complex health and daily living needs and foster the right kind and amount of care so as to improve cost and quality of care? Increasingly, health systems and leaders are rethinking the care delivery to older adults with these kinds of complex medical, functional, and social care needs, with the aim of better aligning that care delivery with their goals. Connecting the right population with the right set of interventions is critical. The key, however, is meeting the needs of older adults who live with complex care needs where they are and seeing them as whole people, *not just as patients*, through the assessment and care planning process.

What Is Person-Centered Care and How Does It Relate to Assessment and Care Planning?

Healthcare providers and advocacy group of various types have published several definitions of "patient-centered" or "person-centered" care over the last 25 years (Kogan, Wilber, & Mosqueda, 2015). While varying in depth, focus, and utility, a key omission in these definitions is apparent: none has focused on the group of older adults with the most complex and expensive care needs, those also at risk for the greatest harms caused by the care itself (e.g. polypharmacy), and those living with multiple chronic conditions coupled with functional impairment. To meet this challenge, the American Geriatrics Society (AGS) convened a national expert panel in 2015 to clarify the meaning and implementation of person-centered care when serving older adults with multiple chronic conditions and functional limitations. AGS published the following statement:

> Person-centered care means that individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires. (American Geriatrics Society Expert Panel on Person-Centered Care, 2015)

The AGS expert panel also articulated eight essential elements to operationalizing

person-centeredness for an older adult population with complex medical and daily living needs. Two of the essential elements are as follows (American Geriatrics Society Expert Panel on Person-Centered Care, 2015):

- *An individualized, goal-oriented care plan based on the person's preferences.* A thorough medical, functional, and social assessment provides a foundation for the person and family to consider their goals. For some people, the assessment should be conducted in their place of residence.
- *Ongoing review of the person's goals and care plan.* Reassessing the care plan on a regular basis helps to determine the plan's effectiveness, to address the person's evolving health and life goals, and to address changes in the person's medical, functional, psychological, or social status.

The AGS definition seeks to move the locus of control from the clinician and health system to older adults, basing care on their own needs, values, preference, and personal goals. It defines quality and value, not simply through technical measures of care, but through dignity, respect of personal choices, and life goal achievement.

Person-centered care starts with gathering information about the personal needs, values, and preferences of care of older adults with complex medical and daily living needs, with input from family support if desired. This information, in combination with a comprehensive medical and functional assessment, is used to help the older adult person articulate and shape clear, specific, measurable goals that focus on improved or retained functioning rather than a medically defined clinical outcome. All of this information is synthesized into a single plan of care and shared with the appropriate team of providers and community supports. The person's goals in the care plan serve as the guiding vision of success, and the care plan and implementation strategy are updated as the older person's unique circumstances change.

Timing and Nuance of Ascertaining Goals in the Assessment Process

As clinicians provide care and support to an older adult with complex needs, they must demonstrate at least three professional characteristics when ascertaining the older adult's goals during the assessment process: ability to know when and how often to ask about the person's needs, values, and preferences for care; an inquisitive nature balanced with good judgment; and, most importantly, professional courage to ask tough questions that do not have easy medically oriented answers.

Clinicians often wonder when and how often to broach conversations about what matters most to the older adults whom they are treating. While each case may be different, it is prudent to begin any assessment process with questions that elicit the person's needs, values, and preferences for care and daily living. All healing relationships are built on trust, engagement, and patience, and a key to starting this process and moving it in a positive direction is to remember an old social work maxim: "Assessment is intervention." Simply asking a question to another person begins the relationship-forming process and opens up new perspectives of engagement between the older adult, clinician, and support persons involved.

The beginning questions set the tone for the care experience, and inherently shape all future discussions between the provider and the person receiving care. Starting with what matters most to the older adult fosters a relationship of honor and respect so that the individual's clinical, functional, and social assessment information can be placed in context of his or her life and unique personal circumstances.

Drs. Mary Tinetti of Yale University and Caroline Blum of New York University have

spearheaded efforts to elicit persons' values and goals, and then translate them into tailored care and treatment though an initiative known as Patient Priorities Care. Following are some suggested questions that they developed, in collaboration with Aanand Naik and Lillian Dindo of Baylor College of Medicine, and that should be considered as part of the initial and ongoing assessment process (Gerontological Society of America, 2016; Naik, Martin, Moye, & Karel, 2016):

- What brings you the most enjoyment or pleasure in life? (Addresses enjoying life)
- When taking care of yourself, what is most important to you now? (Addresses function)
- Which relationships or connections are most important to you? (Addresses connecting)
- What do you hope your care can do for you? (Addresses managing health)

Two additional key questions are:

- Who else should be part of this conversation with us? If needed, who will help you put in place any care plan that you and I develop together?
- What else should I be asking you?

Using Assessment Information for Care Planning

Once identified, the person's goal becomes the "true north" of their care and ideally is shared with other members of the healthcare team so that they, too, can provide goal-concordant care. The next step is to establish meaningful and measurable health goals. For example, if we were to review what matters to the older woman with hip pain described at the beginning of the chapter, we might consider her risk for delirium and poor outcomes before referring her to the surgeon, given that her number one priority was to remain independent.

Care planning can be driven by the older adult's goals in the context of the clinical and functional profile as opposed to being driving solely by clinical indication and guidelines alone. For example, if an older adult says that she wants the most active life possible and is willing to tolerate pain to achieve that lifestyle, then a clinician can discuss treatment options that minimize the risk of functional decline and support mobility while managing pain. In contrast, if an older adult's goal is to attend a time-bound event such as a family wedding six months from the time of assessment, then the clinician can guide the care plan toward interventions that may delay necessary burdensome treatment and focus on stabilizing the person for travel so as to make attendance at the wedding possible.

While each circumstance is unique, older adults with significant clinical and functional decline rely on personal relationships for support and active help in achieving daily living goals. Their support networks could consist of family, friends, neighbors, members of religious or socially oriented communities, paid personal care providers, and the like. These individuals provide the vast majority of supportive care and are usually key members of the implementation team for the care plan developed by the older adult and clinical providers. Therefore engagement with these personal relationships alongside the older adult can be the difference between success and failure of the care plan.

Additionally, older adults may benefit from receiving a range of community-based supports and services that can help an individual maximize independence, such as Meals on Wheels and chronic disease self-management programs. An assessment process that focuses on the whole person will help uncover needs beyond the medical realm that provide critical support for health and well-being. **FIGURE 8-1** shows potential sources of daily living support for people with substantial daily living needs that can complement clinical services (Gitlin, Szanton, & DuGoff, 2011). Sources of support generally fall into two categories: those bolstering an older person's social environment and those focused on the physical environment. While not an exhaustive list in each category, meaningful access

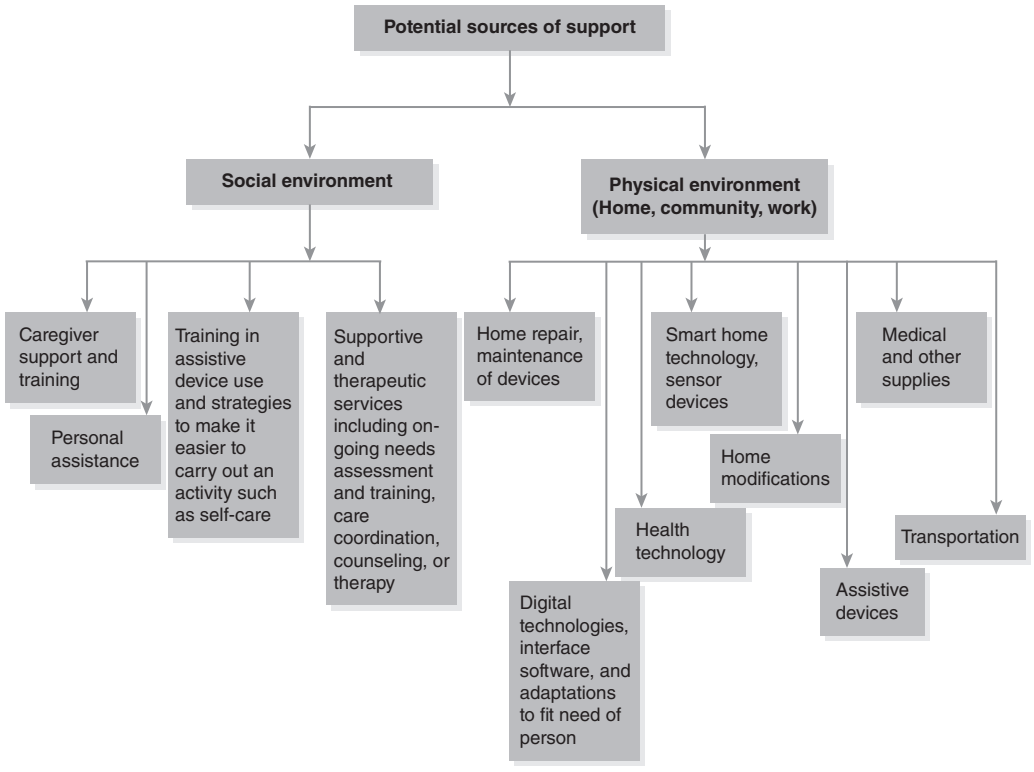

FIGURE 8-1 Potential sources of support for individuals with disability challenges.

to items such as caregiver support and training, home modifications, and transportation can make or break a well-intentioned medically oriented care plan if not considered or effectively addressed in their absence.

Clinicians face a number of critical challenges in implementing assessment and care planning processes to support goals that matter to the older person. First, structural and process issues in the care delivery environment can create tremendous challenges for clinicians who seek to treat their older adult patients in a person-centered manner. The short time frame of appointments, pressures to maintain high volume of visits, and barriers in record keeping that can be shared across care providers—even within electronic health record systems—all create barriers to engaging in a person-centered dialogue. Careful system planning through the application of human-centered design that incorporates the perspectives of older adults and their families can help mitigate structural and process barriers.

Second, there may be clinical barriers or perceived clinical barriers to providing person-centered care. Cognitive decline or behavioral health issues may create challenges related to the person's active participation in elicitation of goals. It may be a cultural preference not to participate in conversations about goals of care. After extending an invitation to discuss these issues, the clinician should respect the person's preferences on this front. When and if the person is unable or unwilling to participate in such dialogue, the clinician can ask the family or paid caregiver for any pertinent information that may help in tailoring care.

Family and other significant others may offer differing views about goals and preferences;

they may contradict the older adult or another member of the family. When conflicts arise that cannot be talked through, a referral to social services or behavioral health might be appropriate. When the conflict revolves around goals of care in advanced illness or at the end of life, a member of the palliative care would also be an effective resource.

Last, and most importantly, clinicians must overcome their own knowledge deficits and bias regarding engagement in person-centered discussions with older adults with complex care needs. The culture of health, and the history of clinical training programs, has focused squarely on clinical assessment and treatment, to the exclusion of the person. Older adults living with chronic health conditions, which by their very nature will not be ameliorated, fundamentally change conversation dynamics and can leave cure-focused clinicians feeling helpless and hopeless. Engaging in a person-centered dialogue is a skill to be actively acquired and practiced. It requires a keen sense of self-awareness of one's own training and biases in relation to multimorbid diagnosis, treatment, and ideas of successful intervention. Personal attributes for clinician leaders that incline them toward person-centered assessment and care planning include patience, good listening and questioning skills, a willingness to tolerate significant ambiguity in the face of unsolved problems, and, above all, humility about both the process and outcomes of care.

Summary

The most important member of the healthcare team is the older adult in partnership with the family and friends who make up the personal support network of the person's own choosing. Taking a person-centered approach to assessment and care planning ensures that the older adult gets goal-concordant care, receives the right interventions at the right time by the right providers, avoids unwanted care, and is supported in terms of his or her overall goals for health.

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