

CHAPTER 1

Through the Older Person's Eyes: What Matters

Terry Fulmer and Bruce Chernof

CHAPTER OBJECTIVES

1. Recognize the history and trajectory of older persons' participation in their own health care.
2. Understand the role of healthcare providers in changing the paradigm to person-directed care.

KEY TERMS

Patient directed
Person centered

Person and family centered
Shared decision making

► Introduction

The greatest success story of the 20th century has been the story of longevity. As illustrated in **FIGURE 1-1**, at the beginning of that century, the human lifespan was approximately 46 years; today, it is nearly 80 years. With added years to life, there has been a paradigm shift away from acute medical management and disease management and toward chronic disease management, with the average person older than the age

of 65 having 3 to 5 chronic conditions and taking 5 to 10 medications. With this complexity in the healthcare regime for older people comes multiple decisions and an important and deeply personal need for older persons to feel that their clinicians are truly in sync with their personal preferences and wishes for care.

The future of health care for older adults—particularly those who have complex chronic needs, functional limitations, or cognitive impairment—will be founded on strong care

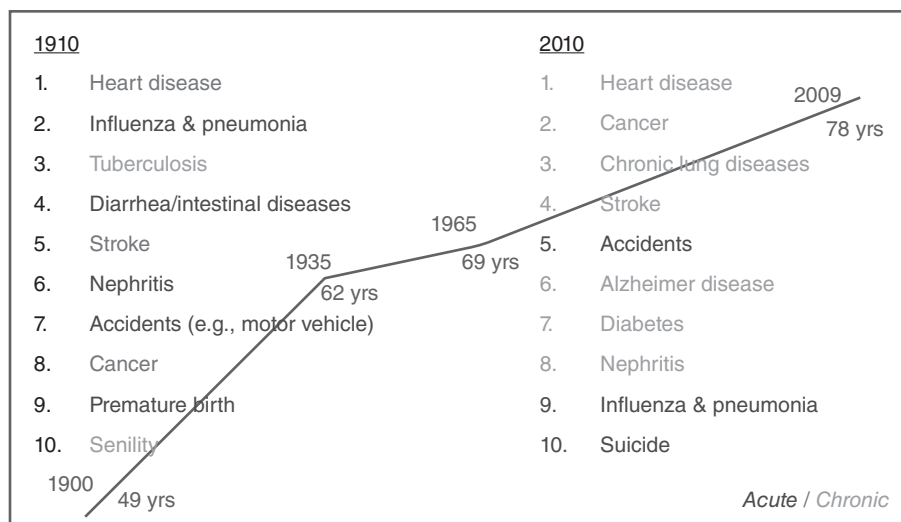


FIGURE 1-1 Life expectancy improvements in the 20th century, Washington.

Adapted from Arias, E., Heron, M., & Xu, J. Q. (2016). *United States life tables, 2012*. National Vital Statistics Reports, 65(8). Hyattsville, MD: National Center for Health Statistics.

planning and coordination that encompass not just medical problems, but an older person's full range of needs. Next generation care planning for older adults will have to balance their personal goals and desires alongside their medical needs. This care planning can be both complicated and nuanced when personal goals and perceptions about best medical care don't entirely align. It is human nature to want autonomy for ourselves and safety for others—sometimes what healthcare providers might recommend as the safest course or the possibility that there might be one more medical intervention that could be attempted—may not be what the older person wants.

The key to care planning in this more complicated and nuanced environment is multifaceted assessment. There are a wide range of general and specific assessment strategies and tools that can help clinicians screen for needs and assess treatments and interventions as well as deeply explore an older adult's personal goals. This multi-faceted approach, using a set of assessment tools tailored to the specific needs of an older adult, provides the foundation by creating the database that underpins **person-centered** care.

The evolution of the person-centered care imperative and the language that describes it really tell the story. In 1973, Woody and Mallison addressed the issue of the problem-oriented system for patient-centered care, drawing on Weed's work in 1969 at Case Western Reserve University. Weed (1969, cited in Woody & Mallison, 1973) was quoted as saying, "the medical record is such a tangle of illogically assembled bits of information that one cannot reliably discern from it how or whether the physician defined and logically pursued each problem." In those early years, as intensive care units were beginning to flourish and technology was developing at an exponential pace, documentation of the person's health, let alone the individual's thoughts or preferences, was extremely limited in the face of this gain in complexity. Rothman's powerful book, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (1991), traces the history of medical decision making from the mid-1960s to today, describing why the doctor-patient relationship has been so dramatically changed by lawyers judges, legislators, and academics. A review of the literature shows



FIGURE 1-2 Evolution of person-centered decision-making in healthcare.

a clear longing by the public and by a vast majority of clinicians to get back to relational care and care planning. Interestingly, the **shared decision-making, patient-directed, patient-centered, person-centered, person-and family-centered**, person-directed narrative has been evolving in a strong and positive way, and this trend continues today (**FIGURE 1-2**). As the baby boomers have come of age—more than 10,000 Americans turn 65 every day—a new type of care, with the person driving that care, is the expectation.

Early on, Charles, Gafni, and Whelan (1997) reminded us that shared decision making in a medical encounter requires at least two people—a patient and a physician. One might argue today that this process now requires the person seeking care and the appropriate clinician—whether that be the social worker, the nurse, the pharmacist, the rabbi, or any other appropriate member of the healthcare team. The notion of patient empowerment and self-efficacy have been another important part of the medical decision-making narrative over many decades (Anderson et al., 1995; Eskildsen et al., 2017; Sak, Rothenfluh, & Schulz, 2017).

► The Importance of Soliciting and Acting on What Matters

In this new era of value- and quality-based payment, what matters to the older person receiving care is now even more important. The tectonic shift that took place in 2001 with the publication of *Crossing the Quality Chasm: A New Health System for the 21st Century* (Berwick, 2002) changed the way healthcare professionals think about the patient voice. Recommendation

4 of that report proposed eight rules for ensuring the patient voice (Berwick, 2002):

1. *Care based on continuous healing relationships.* Patients should receive care whenever they need it and in many forms, not just face-to-face visits. This rule implies that the healthcare system should be responsive at all times (24 hours a day, every day) and that access to care should be provided over the Internet, by telephone, and by other means in addition to face-to-face visits.
2. *Customization based on patient needs and values.* The system of care should be designed to meet the most common types of needs, but have the capability to respond to individual patient choices and preferences.
3. *The patient as the source of control.* Patients should be given the necessary information and the opportunity to exercise the degree of control they choose over healthcare decisions that affect them. The health system should be able to accommodate differences in patient preferences and encourage shared decision making.
4. *Shared knowledge and the free flow of information.* Patients should have unfettered access to their own medical information and to clinical knowledge. Clinicians and patients should communicate effectively and share information.
5. *Evidence-based decision making.* Patients should receive care based on the best available scientific knowledge. Care should not vary illogically from clinician to clinician or from place to place.

6. *Safety as a system property.* Patients should be safe from injury caused by the care system. Reducing risk and ensuring safety require greater attention to systems that help prevent and mitigate errors.
7. *The need for transparency.* The healthcare system should make information available to patients and their families that allows them to make informed decisions when selecting a health plan, hospital, or clinical practice, or when choosing among alternative treatments. This should include information describing the system's performance on safety, evidence-based practice, and patient satisfaction.
8. *Anticipation of needs.* The health system should anticipate patient needs, rather than simply reacting to events.

All clinicians long for faster progress in the march toward this paradigm shift so that we can

better hear the voice of the person in the direction of their care. Indeed, 16 years after the publication of *Crossing the Quality Chasm*, we still struggle to put its recommended concepts into practice. The Institute for Healthcare Improvement has done more than any other organization in the country to keep our feet to the fire on this issue, but much remains to be done to make real changes in the system.

The Lown Institute has helped practitioners in the aging field understand how value, resource utilization, and patient satisfaction are inextricably bound together (Brownlee & Berman, 2016). The monograph by Brownlee and Berman (2016) posits that several barriers to achieving value-based (person-centered) care exist, including a public appetite for the “more is better” concept, our inherent dislike as consumers for understanding healthcare value and costs, a lack of appreciation for the harm that can ensue from overtreatment, and lack of discussion related to price, value, and trade-offs. The following vignette illustrates these points.

CLINICAL VIGNETTE

Mr. T was 98—almost 99—when he died. He was physically small but had a great wide smile, piercing blue eyes, and a shock of white hair. It seemed he spent more time in the hospital than home with his wife owing to his end-stage dilated cardiomyopathy, chronic poorly compensated congestive heart failure, and a host of different arrhythmias. In the same month, Mr. T was admitted to my service three times. During that third admission, I sat down with Mr. T and his wife and said, “I know you understand we can't cure these things, but we can try and manage them so that you can do what is really important to you. Tell me your goals, and let's see if can get there together.”

What became clear immediately was that Mr. T wanted to be home with his wife as much as possible and not in the hospital unless it was really necessary. What also became clear was that his biggest goal was to be alive and as healthy as possible so he could attend his daughter's wedding, which was some six months away. With this brief but clear discussion, we had the outlines of a plan. Every medical decision needed to be made with the plan in mind—that is, would *X* treatment or *Y* medication help Mr. T stay at home and increase his chances of getting to his daughter's wedding?

This “plan” mystified most of the hospital staff at first because Mr. T and his wife guarded it jealously. The couple asked lots of questions when new providers appeared with one more new treatment option that could be tried. They said no even when doctors and nurses stood in front of them, perplexed by their refusal. And most challenging of all, the couple would often say, “We won't say yes or no until you talk to my personal doctor.” Ultimately, though, the plan worked really well. When arrhythmias became more frequent and complex, worsening Mr. T's heart failure, a big family

conference resulted in a change in medications but no pacemaker. The risk of the procedure just wasn't worth it with wedding drawing closer.

Unfortunately, Mr. T spent his 98th birthday in the hospital. When our ward team rounded on him that morning, we asked him what he wanted for his birthday. His reply: "Honestly, just a plate of piping hot spaghetti with lots and lots of red sauce." So, we sent a medical student out to the Italian restaurant around the corner to arrange a birthday lunch. As you might imagine, that plate of spaghetti didn't quite meet the low salt dietary restrictions imposed by the cardiologist.

When the wedding arrived, Mr. T was able to attend and had a marvelous time. The pictures from the day shared by his wife with all the hospital staff were a revelation for everyone. Mr. T died in sleep at home, two days after his daughter's wedding. In retrospect, he had spent less time in the hospital over the past six months compared to similar time periods over the last several years. Also, he felt better than he had in a long time even though his medical problems never went away and were actually getting progressively worse. At the end of his life, Mr. T's care shifted from volume to value, quality of life and quality health were both considered, and ultimately both the providers and the patients were more satisfied.

BEST PRACTICES AND PRACTICE CHALLENGES

This brief synopsis of the genesis and trajectory of patient inclusion is presented here very intentionally in a handbook of geriatric assessment. It highlights the intersection between the goals of the healthcare system (quality of health: to improve health outcomes and prolong life) and the goals of the individual (quality of life: to live with dignity, agency, and a high level of function). In that overlap lies value for healthcare payers, providers, and the older adults who are the recipients of care. Key questions in finding that sweet spot include the following: Are we practicing prudent geriatric assessment? What is the time spent and value of the assessment? To which end, for whom, and with which type of systematic evidence and evidence-based follow-up is the assessment taking place?

Older people have unique needs that are often overlooked. Notably, the traditional public health prevention framework of primary, secondary, and tertiary prevention applies as much to older people as it does to other populations.

Primary prevention focuses on universal opportunities to help people prepare for their needs as they age (such as disease prevention in younger adulthood), as well as the strategies that can help older persons remain successfully in the homes and communities of their choice. These strategies address issues ranging from the physical fabric of the communities in which those individuals live (e.g., are there curb cuts at all crosswalks?), to proactive modifications in the home setting, thinking through transportation options, and explicitly expressing their desires as they age to both family and healthcare providers.

Secondary prevention expressly targets those at risk, providing additional supports and/or services to help mitigate these risks. The traditional acute-care-oriented U.S. healthcare system tends to view secondary prevention as the aggressive treatment of disease (think about a cancer diagnosis or diabetes), with the explicit goal of cure or disease complication mitigation and the prolongation of life. In older adults, however, secondary prevention might include interventions such as a robust falls prevention program for an older person whose vision is limited by diabetic complications or a community engagement strategy to stave off social isolation and depression.

Tertiary prevention in older adults seeks to mitigate the impact of serious chronic, life-impacting conditions and preserve or enhance functional status. Cure is not generally an option in tertiary prevention. Thus, the focus of the healthcare system needs to remain squarely on quality of life and simply the technical quality of health or healthcare delivery.

► Patient-Centered Versus Person-Centered: Sources of Variation Are More Than Just Medical

In the 1980s, frustration with an increasingly fragmented healthcare delivery system caused the Picker Commonwealth Institute (Picker Foundation) to define patient-centered care as healthcare delivery that explicitly incorporates the experience and desires of the patient (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993). The definition of patient-centered care represented an important step forward, ushering in the goal of shared decision making as a critical tenet of the provider–patient relationship. The principles that define effective shared decision making are the backbone the *Crossing the Quality Chasm* report's recommendations outlined earlier.

As population longevity has increased, however, more and more older adults are living with chronic illnesses and functional limitations for many years of their lives and not simply when they are very sick or toward the end of life. They live with these impacts every day, not just when they are formally “patients” lying in a hospital bed waiting for a procedure or sitting in the doctor's office exam room. Research demonstrates that these social determinants of health are important drivers of the variability in medical expenditures (**FIGURE 1-3**).

For older adults, four important sources of variation drive direct healthcare spending: their medical care, health behaviors, social support network, and physical environment (including their home and surrounding community). Patient-centered care largely (but not entirely) focuses on the medical sources of variation and measures quality mostly through the paradigm of “quality of health” measures. As we age, quality of life may be just as important as—and possibly more important than—quality of health alone. Work by Fried and colleagues (2011) has given us a roadmap for helping older persons achieve healthcare decision making that is centered

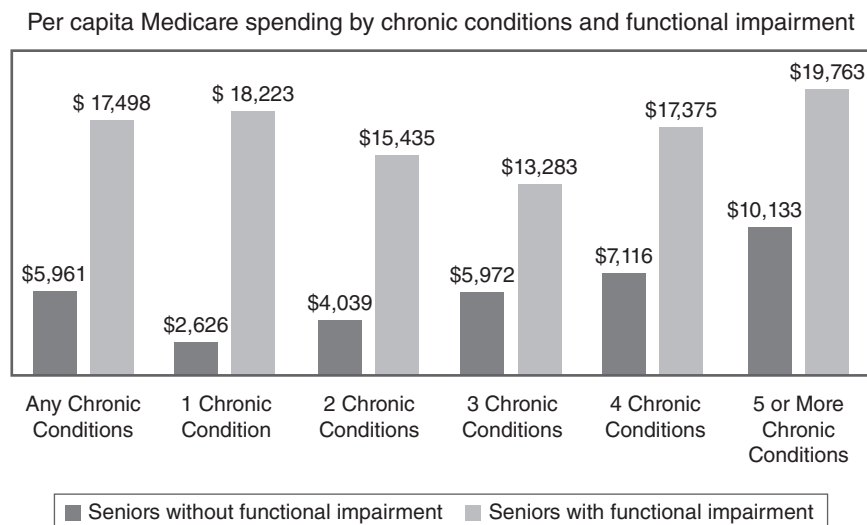


FIGURE 1-3 Per capita Medicare spending by chronic condition and functional impairment.

Rodriguez, S., Munevar, D., Delaney, C., Yang, L., & Tumlinson, A. (2014). *Effective management of high-risk Medicare populations*. Washington, DC: Avalere Health.

on dignity and independence. Addressing the needs of older adults from a whole-person perspective, rather from the narrower perspective of just a patient, is the key to providing better care at lower costs.

To provide a gold standard to guide future program development, the American Geriatrics Society (2016) convened a national expert panel to create a consensus definition for person-centered care:

Person-centered care means that individuals' values and preferences are elicited and, once expressed, guide all aspects of their healthcare, 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.

The principles of sound person-centered care include the following:

- An individualized, goal-oriented care plan based on the person's preferences
- Ongoing review of the person's goals and care plan
- Care supported by an interprofessional team in which the person is an integral team member
- One primary or lead point of contact on the healthcare team
- Active coordination among all healthcare and supportive service providers
- Continual information sharing and integrated communication
- Education and training for providers and, when appropriate, the person and those important to the person
- Performance measurement and quality improvement using feedback from the person and caregivers

Each of these principles requires some form of assessment, whether it be of the elder persons

themselves, their caregivers, their healthcare system, or their homes or the community where they live. The chapters that follow capture the best available evidence and practical tools to help healthcare practitioners and systems leaders implement geriatric assessment that improves both quality of health and life—thereby leading to better care at lower costs. In the future, a new generation of quality measures, such as person-reported outcomes and goal attainment, will help drive the balance between quality of health and quality of life.

► Summary

Geriatric assessment plays a critical role in helping meet the specific needs of older adults, supporting their caregivers, improving the quality of their health care, and increasing the efficiency of the enormous resources we dedicate to healthcare delivery in the United States. The ultimate goal should be to improve the quality of life and health for the older persons themselves. The assessment at every level provides critical insight but not definitive answers. It is important to listen to older persons and honor their desires, and to recognize that their right to agency (choices that they alone control) trumps the healthcare system's overarching expectation of safety and longevity at the expense of all else. Judgment and empathy, rather than just medical expertise, are what healthcare professionals bring to the table in the provider–patient relationship. Geriatric assessment provides an important mapping function to guide shared decision making and inform a plan of care.

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