



## CHAPTER 1

# Connected Care—Closing the Gaps and Filling the Cracks in Health Care

### CHAPTER OBJECTIVES

After completing this chapter readers will be able to:

- Describe the current state of connected and disconnected health care
- Identify forces that drive toward and oppose care connections
- Describe the impact of connected and disconnected health care
- Define connected care principles and activities
- Identify key connected care measures
- Assess the level of connected care actions in the reader's own practice setting

### ► Introduction

This text is about connecting the elements of care in our complex healthcare world to create the best outcomes for our patients and to achieve organizational and professional success for ourselves. While most works on this topic have taken the 25,000-foot view and concentrated on national policy issues and health system issues, or have focused on specialty areas of care coordination and case management, this text comes from, and is aimed at, the front

lines of health care where care is closest to the patient. The goal here is to raise awareness of the serious consequences of fragmented health care and to distill evidence-based best practices in care coordination, care transitions, and collaboration to achieve better outcomes, better patient experience, and lower costs.

The text poses a systemic solution to health-care fragmentation. This solution is called connected care. It incorporates care coordination attitudes and actions into the job of every nurse and every other health professional and embeds

it into the structure and processes of health care and community organizations. Connected care is a comprehensive, systems approach to connecting care activities and achieving better outcomes for patients. It is a philosophy, a set of principles, structures, best practices, strategies, and tools that overcome care fragmentation. The foundation of connected care is patient centeredness. The pillars of connected care are care transitions, care coordination, communication, teamwork, and collaboration.

The connected care approach links disparate elements of care coordination, care transitions, case management, and various collaborative strategies to achieve patient goals and to provide a seamless, safe, and transparent experience for patients. It connects all elements of care through clinician consistency and information sharing at each step in care.

Connected care also includes electronic information exchange, tracking, and information gathering at each step during care. The core daily work of connected care is patient and family caregiver education and completion of all patient-related follow-up tasks so that patients receive the services, medical information, supplies, community resources, and equipment they need.

Also in this chapter, we further analyze the elements of connected care and look at the principles, structures, processes, measures, and tools that you, the reader, can use to create your own culture of connected care. Nurses, with their strong history of championing patient-centered care principles and practices, will be leaders in the implementation of connected care.

## ► Connected Care—And Not: Some Stories

### A Disconnected Care Experience Helps Fuel Medicare Transformation

In March 2016, the *New York Times* ran a profile of Dr. Patrick Conway, then chief medical

officer and deputy administrator for innovation and quality for Centers for Medicare and Medicaid Services (CMS). The article focused on how his experience as a practicing pediatrician has informed his work with CMS. The article describes how Conway's experience is highly relevant to the theme of this text: "His zeal to improve care is rooted in personal experience. He said he was frustrated by the fragmented care that his father received when he was dying of cancer in 2007. He promised his father that he would devote his life to trying to change the healthcare system. His father told him, 'You can't. It's too hard. But you are persistent. If anyone can, it would be you'" (Pear, 2016, p. A9).

Conway went on to lead the Center for Medicare and Medicaid Innovation (CMMI) and was a key force in attempting to remodel the healthcare system during the Obama administration. He was responsible for launching many of the new value-based payment programs that emphasize payment for results and for providing creative care models that have rapidly pushed healthcare organizations toward more integration and collaboration.

### A Health System Executive Experiences "Dis-integrated Care"

Shortly after the article about Conway appeared in the *New York Times*, an executive from a large medical group practice spoke at a regional healthcare conference about his newly minted accountable care organization.

He proudly described the high-level organizational structure, the multiple clinical initiatives, and the technology that the system was using to create a cutting-edge integrated care model.

The focus was on member facilities and physicians, contracts, technology, and metrics. There was little discussion about where the patient, family caregivers, or other healthcare providers fit into this hugely complex system. When asked about patient focus, his reply indicated that the area would need more work.

He went on to say that his experience with his parents was actually motivating him to

develop more patient-centered systems within his organization. He explained that his mother had been treated for congestive heart failure at a highly regarded metropolitan hospital. The hospital was not in his integrated delivery system, but it did have many of the same programs in place. When his mother was discharged from the hospital, she came home with reams of written instructions, newly prescribed oxygen, multiple prescriptions that needed to be filled, and a long list of specialty follow-up appointments to be made. The needed medical equipment hadn't arrived and there didn't seem to be anyone immediately available to help connect the dots for the family. The executive, who had been trained as a health professional, talked about how he and his father felt overwhelmed and despairing. His voice caught as he talked.

This is the stark contrast between the ideal of integrated care and the reality. The executive's speech ended on a positive note. The hospital had actually made a referral to home health care and the agency started care 24 hours later, but the executive and his family had not been fully informed about this process and didn't know who to call in the interim. His parents finally did get some help coordinating care when the home health agency provided nursing case management services and developed a comprehensive care plan with the help of the primary care physician and cardiologist.

The nurse case manager was able to coordinate the fragmented elements of care his parents were receiving for a safer and more satisfying patient experience. What was not accomplished at the system level was accomplished by an individual nurse.

## CASE STUDY

### Cracks and Gaps in a Complex Case

A home healthcare agency received a referral from a local skilled nursing facility (SNF) for a 50-year-old woman who had suffered a series of progressively more serious and debilitating heart attacks that had necessitated multiple hospitalizations, SNF stays, and home healthcare episodes. The referral came via a faxed referral form from the SNF. The referral form was handwritten—both within the lines and sideways on the page. About a third of it was unreadable. There was some information about a wound, but wound care orders were not clearly indicated. The SNF did not call the home care agency to suggest this was a high-risk case that required special attention. When the home care nurse opened the case, she found that this patient could barely get out of her chair and was a serious fall risk. She also had an unhealed pressure ulcer and was incontinent, making wound care very difficult.

The home care agency then struggled to coordinate care for an overwhelmed spouse/caregiver, to manage the patient's deteriorating condition, and to make sense of disjointed orders from multiple physicians. Within a few days, the patient was readmitted to the hospital.

Needless to say, the home healthcare staff speculated, and not in a kind way, about the care that had been provided in the SNF and the lack of communication on discharge. Instead of leaving things there, the agency had a member of the executive team call the SNF administrator to debrief the case and to see if there were ways to avoid similar situations in the future.

A meeting of the home care management team, the home care nurse, and the SNF administrator and clinical team was arranged. The nursing director came prepared with some immediate improvements, including a "heads-up" document that could be sent to home care intake to alert staff to important care considerations.

The SNF team described the care that had been given in the facility and the home health team was better able to understand the course of the patient's stay and some of the factors that had influenced the discharge process. They found that the patient had come home from the hospital

*(continues)*

## CASE STUDY

(continued)

with the pressure ulcer and that the patient's husband had aggressively pushed to have the patient discharged before the facility staff felt she was ready. Ultimately, the SNF and the home healthcare agency forged a better working relationship in the service of patients, but only after being jolted into awareness of their disconnection through a poor patient outcome.

### What Can We Learn from These Stories?

These situations illustrate the reality of disconnection and connection in the daily delivery of health care to patients. The perspective is different in each story (e.g., Dr. Conway, at the national level, the executive at the health system level, and two local healthcare organizations managing a patient transition at the local level). Yet, despite these differing perspectives, the patient and family experience was remarkably similar—that is, fragmented and less than satisfactory. Each of the players in these scenarios had different solutions to the problem.

Dr. Conway helped create new payment models that are still, to some extent, driving the healthcare system toward greater patient focus and integration. The medical practice executive used his own negative experience to allocate care coordination resources and guide his system toward a more connected patient experience. The home healthcare agency and the skilled nursing facility developed a better collaborative working relationship and tools for communication about high-risk patient situations.

### ► The Quality Chasm and Connected Care

Disconnected care and the distress and harm that it causes patients had been a national problem for a long time, but it wasn't until the start of the 21st century that an authoritative national body tackled the problem. The Institute

of Medicine (IOM), in its landmark work, *Crossing the Quality Chasm* (2001), detailed how the American healthcare system had failed to produce quality outcomes and had failed to satisfy patient needs and to manage costs. Much of the document focuses on fragmentation and disconnection in the health system, its negative consequences, and possible remedies.

In the introduction the authors stated: "Indeed, between the health care that we *now have* and the health care that we *could have* lies not just a gap, but a chasm" (IOM, 2001, p. 1). The authors go on to say, "Yet physician groups, hospitals, and other health care organizations operate as silos, often providing care without the benefit of complete information about the patient's condition, medical history, services provided in other settings, or medications prescribed by other clinicians" (p. 4).

The IOM proposed a series of rules and structural changes to bridge the quality chasm. Among many recommendations advanced by the IOM, some are particularly relevant to the connected care approach:

- The patient is the center of control
- Cooperation among clinicians
- Shared knowledge and free flow of information (IOM, p. 8)
- Redesign of care processes based on best practices (IOM, p. 12)

The goal of this text is to help practicing nurses and other clinicians apply these principles and find practical solutions to this problem of healthcare fragmentation and its negative consequences. Nurses, who are perceived as the most trusted health professionals (Gallup.com, 2016),

## ASK YOURSELF

1. How well do you think the American healthcare system connects care elements for patients? Give the system a score from 1–10 (with 1 being the lowest and 10 being the highest score).
2. How well do you think your organization connects care elements for patients to achieve a seamless, coordinated, and transparent patient experience? Give your organization a score from 1–10.
3. Begin to think about areas for improving care connections in your own organization.

are essential to solving this problem. As one patient, interviewed in a study about hospital care coordination, said, “Nurses, it’s up to them to make sure things are going ok” (Beaudin, Lam-mers, & Pedroja, 1999, p. 21).

For the purposes of this text, we relabel fragmentation as “disconnection” and consolidate the wide variety of systems, structures, and best practices that embody the IOM principles into the concept of connected care, which will be the theme throughout the text. We will begin to explore how organizations can create structures and nurses, doctors, family caregivers, and community professionals can develop the mindset and skills necessary to practice the type of communication, collaboration, teamwork, and care coordination that produces true connected care for patients. The chapter includes some exercises and activities to help you, the reader, begin to assess your organization’s level of connected care competence and to identify areas for improvement.

## ► Where Are We Now? The Current Status of Care Connection and Disconnection

### Crossing the Quality Chasm— National Progress

In the years since the IOM Quality Chasm study was published, the healthcare community

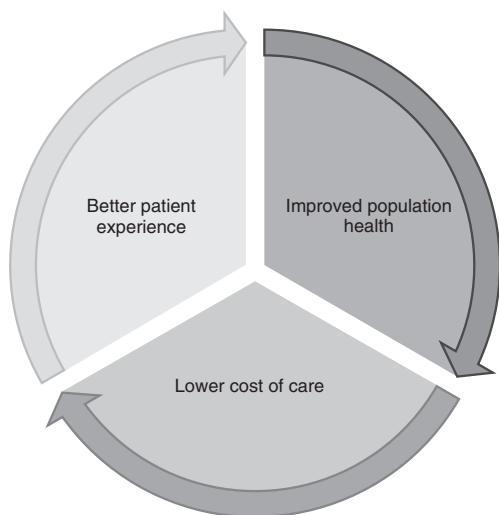
has taken the care fragmentation problem seriously. Solutions have been developed and tested at both the policy and practice levels. Nursing in particular has been at the forefront of creating policies, methods, and tools that better coordinate care for patients. Nurses have also advocated for systemic solutions to disconnection.

The passage of the Affordable Care Act (ACA) tremendously accelerated the drive toward more connected care. As part of its mandate to lower costs and improve health outcomes, the CMS, in 2015, implemented an aggressive timeline for remodeling the health-care system through payment reform. Specifically, CMS instituted a “volume to value” shift in which providers are paid, not for delivering more care, but for achieving better results (CMS, 2015). Connected care principles, practices, and measures are an integral part of this shift.

Value in this new approach to care is embodied in a concept known as “The Triple Aim” (**FIGURE 1-1**). First coined by Dr. Don Berwick, former administrator of CMS, in an article in *Health Affairs* (Berwick, Nolan, & Whittington, 2008), the aim describes three goals for American health care:

- Improve the health of patient populations (groups of patients with like characteristics).
- Improve the patient experience.
- Lower per capita costs.

As volume shifts toward value, payments are being linked to achievement of Triple Aim goals; and new delivery system and payment models are emerging. More recently, the Triple



**FIGURE 1-1** The Triple Aim

Data from Berwick, D., Nolan, T., & Whittington, J. (2008). The triple aim: Care, health, and cost. *Health Affairs*, 27(3), 759–769. doi:10.1377/hlthaff.27.3

Aim concept has been expanded to incorporate the goal of improving the clinician experience. The new construct is called the Quadruple Aim (Bodenheimer & Sinsky, 2014). While the quadruple aim concept has not been universally adopted, it is gaining ground as a core principle of value-based care.

The new payment models are collectively known as value-based payment. Generating and testing these models has been the work of CMMI.

At the time of this writing, with the election of President Donald Trump and the uncertain future of at least parts of the ACA, the future of these integration initiatives is unclear. However, since integration is supported by many insurers and employer groups, the predicted demise of value-based payment and integrated care strategies may be premature.

While value-based payment models may not survive in their current form, the pressures of high costs, patient dissatisfaction, and persistent patient safety problems will almost certainly drive a continued move toward care integration strategies.

The current model of government-sponsored, value-based payment initiatives employs a variety of methods to achieve more connected care for patients:

- Creating care coordination and care transition codes and payments for managing patients with chronic conditions allowing physicians and Advanced Practice Registered Nurses (APRNs) to bill Medicare for care coordination activities (CMS, 2016a)
- Support for new organizational structures, such as patient-centered medical homes (PCMHs) (National Committee on Quality Assurance [NCQA], 2018), which are advanced primary care medical practices that provide extended services and care coordination for patients
- A policy level focus on connected care initiatives through the National Quality Strategy: “Promoting effective communication and coordination of care” is one of the six National Quality Strategy priorities (Agency for Healthcare Research and Quality [AHRQ], 2017)
- Medicare-sponsored, and in some cases, mandated, alternative payment models (APMs) that encourage connected care (joint replacement bundles, chronic care bundling, Medicare shared savings programs) (CMS, 2018a)
- Measures shared across industry segments, such as the Improving Medicare Post-Acute Care Transformation Act (IMPACT Act), which mandates a set of common patient outcome measures across postacute settings including skilled nursing facilities, long-term acute care hospitals, and home health care (CMS, 2014)

CMS is clearly not leaving care coordination to chance. Through its various payment innovation models it is creating some forced connections between previously separated industry segments. Some people would call these collaborations “shotgun marriages” but they are likely to be an enduring element of our newly remodeled healthcare system.



## How Far Have We Come? A Current Snapshot

A September 2016 headline in the online reporting source, Bloomberg News, reads “US Health Care System Ranks as One of the Least Efficient.” The article described the United States as ranking 50th out of 55 nations in healthcare efficiency. In a quote from Paul Ginsburg, professor at the University of Southern California and director of the Center for Health Policy at the Brookings Institution in Washington, DC, the article describes the key reason for this inefficiency: “The U.S. system tends to be more fragmented, less organized and coordinated, and that’s likely to lead to inefficiency” (Du & Lieu, 2016).

Data from a 2011 Commonwealth Fund survey of American views of the healthcare system found that most felt that the healthcare system needed fundamental change. Many cited breakdowns in care coordination, including lost medical tests or lack of information about test results, meager communication between physicians, poor physician continuity, and inadequate patient education (Stremikis, Schoen, & Fryer, 2011).

A 2016 article in *Fierce Healthcare* cited a study by CRICO Strategies that detailed how miscommunication—the most basic form of disconnection—caused 2,000 deaths and \$1.7 billion in malpractice claims in a single year (Budryk, 2016).

The news isn’t all bad, however. In a 2015 report to Congress, the Agency for Healthcare Research and Quality noted that providers had improved discharge processes, providing more patients with discharge instructions. The report also noted that more providers have adopted health information technologies (AHRQ, 2015).

The Chartbook on Care Coordination notes that from 2005 to 2013 the percentage of heart failure patients who received written discharge instructions increased from 57.4% to 94.6%, while hospital readmissions (a key measure of care connection and integration) have declined (AHRQ, 2016a).

At the time of this writing, 17 years after the publication of *Crossing the Quality Chasm*, it is fair to say that we have generated and tested many solutions and made some progress toward reducing care fragmentation. However, our progress has not been nearly fast enough or complete enough. Nurses and other health professionals continue to struggle with highly complex care systems that are seldom fully patient centered and coordinated.

Far too often, these dysfunctional work systems require health professionals to take laborious, and sometimes heroic, action to connect the dots for patients. Stories in both professional journals and the popular press continue to detail the realities of a fragmented healthcare system.

A certified diabetes educator, Stacey DeFillipo, CDE, RD, describes progress toward better coordinated care this way:

Rating our system on coordinating care on a scale of 1-10: five years ago a 2, now a 5. The 5 is an average as some systems are doing well (an 8) and others are still a 2. Care Coordination/Care Management Teams—these are growing by leaps and bounds in health systems and are working well to reduce readmissions. Outpatient care managers working in the primary care practice are responsible to follow up and help patients released from the hospital. They are really helping patients understand their health and health care. (DeFillipo, personal communication, 2017)

## ► Dissecting Fragmentation and Disconnected Care

### The Root Causes of Disconnection

A 2009 article in the *Annals of Family Medicine* describes healthcare fragmentation in eloquent terms: “Underlying the current healthcare

failings is a critical underappreciated problem: fragmentation-focusing and acting on the parts without adequately appreciating their relation to the evolving whole. This unbalance, this brokenness, is at the root of the more obvious health-care crises of unsustainable cost increases, poor quality, and inequality. Fragmentation is at the heart of the ineffectiveness of our increasingly frantic efforts to nurture improvement” (Stange, 2009, p. 100).

Disconnection is now deeply rooted in the current culture of American health care, but this was not always the case. Until the 20th century, the healthcare system was relatively simple and coordinated. Families cared for sick people at home and called in the local family physician when things got more serious or complicated. Sometimes the local public health nurse was also called into service for preventive health teaching, to provide care during public health emergencies such as flu epidemics, or to assist the family doctor in delivering babies at home. Sometimes, the patient might consult a specialist, but typically care was simple, coordinated, and transparent.

In *The Fragmentation of U.S. Healthcare, Causes and Solutions*, Einar Elhauge (2010) states, “Just as too many cooks can spoil the broth, too many decision makers can spoil health care” (p. 1).

In essence, this is what happened to the U.S. healthcare system as specialization, new knowledge, new drugs, diagnostic equipment, information systems, and more healthcare organizations multiplied, and complexity became an essential part of the healthcare fabric.

Absent any coordinating mechanism, these different elements simply became healthcare “silos” (organizations or departments that are isolated from each other and interested only in their own work). Each silo is focused on its own payment model, clinical tasks, and patient population and is disconnected from the rest of the patient’s healthcare delivery system. A good example occurs among elderly patients with chronic illness (Bushardt, Massey, Simpson, Ariail, & Simpson, 2008). In many cases,

patients are seen by multiple physicians, each of whom prescribes drugs for the chronic illness that he or she is treating without regard for, or without even knowing about, what others have prescribed. This lack of coordination often leads to duplicate drug use, higher costs to the insurer and the patient, and a higher incidence of drug-related complications such as falls.

Nurses, like other health professionals, have been caught in their own narrow healthcare silos, focused on performing specialized tasks. Senior managers in healthcare organizations have not always provided the structure, training, or processes that allow front line nurses to practice connected care (Dubree, 2013).

There is a vast amount of literature that analyzes the causes of disconnection in our healthcare system. Most of these factors are well known:

- **Fee-for-service payment structures.** The traditional American healthcare payment system has traditionally rewarded volume of care delivered but has not paid for many care connection activities or for actual health results (Adler & Hoagland, 2012). Many physicians and APRNs in fee-for-service environments limit their care activities to quick, billable visits or procedures.

The time pressures of a busy practice and limited payment for connected care activities create little incentive to make the many phone calls and send the emails and letters needed to create a seamless care experience for patients, who are then left to coordinate things themselves. Indeed, many primary care professionals describe their work as “running on the hamster wheel” (Schumann, 2013).

These fee-for-service structures have been self-perpetuating in part because they have been quite rewarding to certain segments of the healthcare industry such as pharmaceutical companies, medical device manufacturers, and specialty physicians who perform a high volume of expensive invasive procedures.

- **Health professional mindset.** Volume-driven, fee-for-service payments have sometimes



created a mechanical, assembly line view of care. In the fee-for-service environment, the organization designs workflows and processes to maximize the efficiency of the health professionals who practice in it and the payment system that funds it. Many professionals in fee-for-service environments are focused on their own specialized tasks and the one patient in front of them at any given point in time.

Health professionals in these settings often have neither the time nor the energy to think about the next step in care, whether it be with another health professional or the family caregiver. This approach, in which each health professional prescribes different medications, orders different tests, and makes different recommendations without regard to what the rest of the patient's healthcare "team" is doing, leads to confusion, medical errors, and lack of a reasonable and rational care plan for patients.

The result is upset, angry, and overwhelmed patients and family caregivers and health professionals who sometimes are unaware of, or surprised at, patient dissatisfaction as well as wasted healthcare dollars and poor outcomes.

- **Professional "turf wars."** As each profession fights to carve out power and increase status, influence, and reimbursement for its members alone, it inhibits collaboration and can actually alienate other members of the healthcare team. Coordinated care is not possible when health professionals misunderstand or resent each other and choose not to work as a team. For example, a home care agency developed an APRN home visiting program targeted to frail elderly patients who could not get out of the house for medical appointments. While many physicians supported the service, some doctors, although they did not do home visits, refused to refer or collaborate with the APRN for fear of losing revenue and total control of the patient's care. The

recent controversy over expanding the scope of practice for APRNs in the Veterans Health Administration is a good example of this issue (Permut, 2016).

- **Resources dedicated to specialization and not to primary care.** As specialty care has expanded, primary care has declined, leaving many patients without a physician whose primary interest is in treating the whole person (Cassel & Reuben, 2011). Increasingly, specialists and primary care doctors don't communicate with each other, resulting in duplicate medications being prescribed, duplicate tests ordered, and physicians giving conflicting information to patients.

With the rise of the hospitalist specialty, in which physicians with special training in hospital medicine manage all hospitalized patients, many primary care physicians stopped seeing their own patients in the hospital. This system, while providing patients with more expert hospital medical care, has broken the link between the hospital and the next step in care—that is, postacute care or discharge to the patient's home and continuity and follow-up with the patient's primary care doctor.

In recent years, yet another specialty, the "extensivist" (a physician who coordinates care and follows patients from the inpatient to the outpatient setting) has developed to bridge the gap from hospital to outpatient setting (Powers, Milstein, & Jain, 2016). While some see this as a welcome development that fills a needed care gap, others see it as yet another level of complexity in the healthcare system and another chunk of responsibility taken away from the primary care physician.

- **Regulations that drive fragmentation.** The current Medicare and Medicaid payment structures pay for narrowly defined services and do not easily coordinate payments between them. For example, the many parts of Medicare (Parts A, B, C, D)

all pay for different types of services, are highly complex, and are imperfectly coordinated (Elhauge, 2010). Strict rules about professionals operating only within their own discipline and payment system, while protecting patients against fraud and abuse, sometimes limit professional collaboration.

- **Competition and consolidation.** In many healthcare markets, large health systems are rapidly consolidating their reach by expanding and buying up medical practices and ambulatory care facilities to ensure that they gain a larger market share and maintain or increase revenue. Theoretically, getting care from one health system should produce a more seamless, integrated experience.

Sometimes, however, this consolidation is more about market share, physician alliances, contracts between facilities, and health information systems than about a more connected patient care experience. This competition/consolidation drive can leave patients caught in the middle as some of their doctors align with one system and some with another. Systems for communications across and between delivery systems are typically nonexistent, further creating disconnected care for patients. Patients may also choose to escape higher costs, such as health system facility fees, by going outside the boundaries of an integrated delivery system, contributing to a more fragmented care experience.

- **Certain types of health consumerism.** The emerging retail consumer model of health care can be a force that creates more care disconnection. Patients with a desire for convenience and control may opt to receive episodic, point-of-service care in urgent care centers, retail clinics, and via telemedicine. Although in some cases these services are integrated into a primary care or integrated delivery system, they frequently have minimal connection with the patient's primary care physician or primary medical record (Pollack, Gidengil, & Mehrotra, 2010). In

these cases, patients who unwittingly choose a more disconnected form of health care in the name of convenience may end up taking on a heavier burden of care coordination themselves.

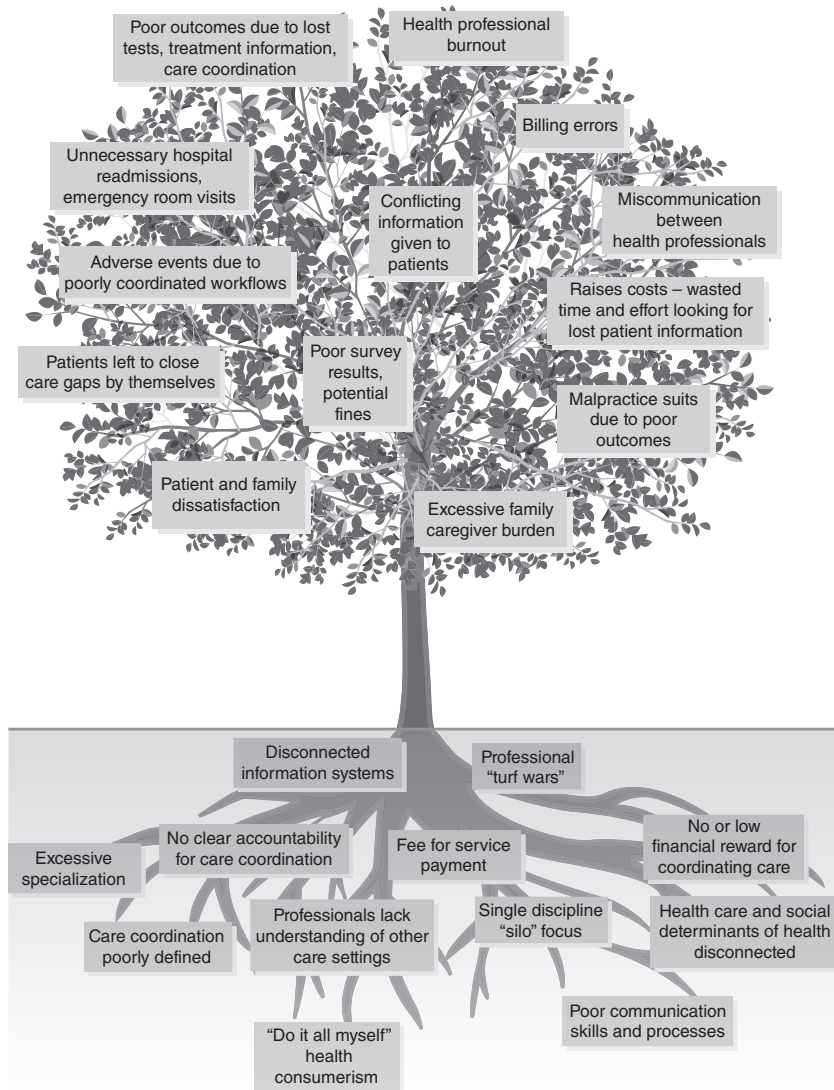
Patients who use multiple pharmacies to fill their prescriptions provide another example of patient-generated disconnected care. Good patient personal health records or health information systems (interoperability) that consolidate information from multiple sources are probably the ultimate solution to this type of disconnection.

- **Health disparities and social determinants of health.** Disconnected care affects patients and families at all socioeconomic levels and across all racial and ethnic groups, but it is clearly worse for those who are handicapped by mental illness, poverty, low health literacy, language barriers, no or poor insurance coverage, and the difficult lifestyle and sense of helplessness that may accompany these problems (Bradley & Taylor, 2016). In a broken and confusing healthcare system, patients and families without the ability to effectively organize and “work the system” may be unable to connect the elements of care themselves. Healthcare organizations and professionals, who insist that their only business is medical care and who do not take any responsibility for finding ways to help patients with issues such as transportation, obtaining prescriptions, or getting food into the house, foster the biggest disconnect of all—treating the illness and not the patient.

**FIGURE 1-2** illustrates the root causes of disconnected care and the symptoms that they produce.

## A Patient-Level View of Disconnected Care

There has been progress toward more connected care through policy and payment changes, and professional care coordination is more widespread



**FIGURE 1-2** The Roots and the Fruits of Disconnected Care

### ASK YOURSELF

- Which symptoms (fruits) of disconnection do you see in your organization?
- Which of the root causes of disconnected care described in this chapter are at work in your organization?

than ever, but the benefits have not always filtered down to the average patient with serious healthcare needs. What looks coordinated and aligned to professionals, who see things through the lens of their own profession or program,

often looks fragmented and confusing to patients. This issue has been well documented in both the professional and popular press, with many stories featuring the negative results of disconnected care experiences (Rabin, 2013).

## CASE STUDY

### Who Connects the Dots for an Elderly Patient with Chronic Illness?

Let's look at the experience of a hypothetical patient with several chronic diseases who moves in and out of the formal healthcare system as her symptoms are controlled or worsen. Mrs. Habib is a 77-year-old woman with four chronic conditions: diabetes, congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), and osteoporosis. She has a primary care physician and sees five other specialists. She takes 15 prescription and nonprescription medications. She has had one emergency room visit, two hospitalizations, and one observation stay in the last six months. She has also had a hip replacement hospitalization and a postop skilled nursing facility stay and two home care episodes of care during this time period. Her family caregivers are her 79-year-old husband, who also has several chronic illnesses, and her 50-year-old daughter, who works full time and has two teenage children.

**TABLE 1-1** illustrates the complexity of the patient's personal healthcare system.

**TABLE 1-1** A Patient's Six-Month Journey Through the Care Continuum

Care Providers and Coordinators	July to December	Patient Information, Medical Records
<b>1. Hospital</b>	<ul style="list-style-type: none"> <li>Two hospital inpatient stays for heart failure, one inpatient stay for hip replacement surgery, two emergency room visits for heart failure, and one observation stay.</li> <li>Emergency room (ER) care coordinator notifies primary care physician (PCP) of visit.</li> <li>Hospital nurse care coordinator coordinates skilled nursing facility (SNF) admission, post hip replacement.</li> <li>For home discharges, care coordinator gives patient instructions and sends referral to home care agency.</li> <li>Hospital arranges postdischarge PCP visit.</li> </ul>	<ul style="list-style-type: none"> <li>Hospital sends electronic referrals to SNF and home care agency.</li> <li>SNF and home care agency access hospital records via hospital electronic medical record (EMR) portal.</li> <li>Hospital notifies PCP of admissions and ER visits by phone call.</li> <li>Hospital sends PCP the discharge summary for one inpatient stay.</li> </ul>

Care Providers and Coordinators	July to December	Patient Information, Medical Records
<b>2. Orthopedic surgeon</b>	<ul style="list-style-type: none"> <li>■ Surgeon sees patient for one preoperative visit.</li> <li>■ Surgeon performs surgery.</li> <li>■ Surgeon sees patient for two postop visits.</li> </ul>	<ul style="list-style-type: none"> <li>■ Orthopedic practice EMR, not connected to hospital EMR, no patient portal.</li> <li>■ Orthopedic office sends a paper report to PCP office.</li> </ul>
<b>3. SNF</b>	<ul style="list-style-type: none"> <li>■ Patient has 15-day inpatient stay following hip replacement.</li> <li>■ SNF physician manages medical care while patient is in the facility.</li> <li>■ Social worker coordinates discharge plan.</li> </ul>	<ul style="list-style-type: none"> <li>■ SNF records on paper.</li> <li>■ Discharge summary faxed to MD office.</li> <li>■ Referral form (W10) faxed to home health agency.</li> </ul>
<b>4. PCP office</b>	<ul style="list-style-type: none"> <li>■ Sees patient monthly.</li> <li>■ Saw patient for one post hospital discharge visit.</li> <li>■ Patient missed one scheduled post hospital visit.</li> <li>■ Had one post SNF follow-up visit.</li> <li>■ One hip replacement preop visit and postop visit for cardiopulmonary symptom exacerbation.</li> </ul>	<ul style="list-style-type: none"> <li>■ PCP EMR is not connected to hospital EMR.</li> <li>■ No patient portal (patient access to EMR).</li> <li>■ PCP office faxes preop info on paper to orthopedic office.</li> <li>■ All instructions and information are given to the patient on paper.</li> </ul>
<b>5. PCP office registered nurse (RN) care coordinator</b>	<ul style="list-style-type: none"> <li>■ RN calls patient regularly to check on symptom control.</li> <li>■ RN calls patient daily after hospital discharge.</li> <li>■ RN stays in contact with SNF during inpatient stay there.</li> <li>■ RN coordinates care with home health agency.</li> </ul>	<ul style="list-style-type: none"> <li>■ RN documents in medical office EMR, but RN notes are not shared with any other providers.</li> </ul>
<b>6. Cardiologist</b>	<ul style="list-style-type: none"> <li>■ Sees patient for three office visits and two hospital visits.</li> </ul>	<ul style="list-style-type: none"> <li>■ Cardiology EMR connected to hospital EMR.</li> <li>■ Cardiologist faxes one paper report to PCP.</li> <li>■ No patient portal into practice EMR.</li> </ul>
<b>7. Pulmonologist</b>	<ul style="list-style-type: none"> <li>■ Sees patient for one office visit and one hospital visit.</li> </ul>	<ul style="list-style-type: none"> <li>■ Pulmonology EMR connected to hospital EMR.</li> <li>■ Patient portal 1 into practice EMR.</li> <li>■ Pulmonologist does not communicate with PCP.</li> </ul>

(continues)

**TABLE 1-1** A Patient's Six-Month Journey Through the Care Continuum*(continued)*

Care Providers and Coordinators	July to December	Patient Information, Medical Records
<b>8. Endocrinologist (+CDE)</b>	<ul style="list-style-type: none"> <li>Sees patient for three office visits.</li> </ul>	<ul style="list-style-type: none"> <li>Endocrinology EMR connected to hospital EMR.</li> <li>Patient portal 2.</li> <li>One note faxed to PCP.</li> </ul>
<b>9. Gynecologist</b>	<ul style="list-style-type: none"> <li>One preventive visit.</li> </ul>	<ul style="list-style-type: none"> <li>Gynecology EMR, uses patient portal 1.</li> <li>No communication with PCP.</li> </ul>
<b>10. Medicare advantage plan high-risk case manager</b>	<ul style="list-style-type: none"> <li>Three phone calls to engage patient, who refuses.</li> </ul>	<ul style="list-style-type: none"> <li>Advantage plan electronic record with claims data.</li> <li>Care coordinator does not have access to MD office or hospital medical records.</li> </ul>
<b>11. State home care support program</b>	<ul style="list-style-type: none"> <li>Coordinates placement of nonmedical personal care assistant and emergency call button.</li> </ul>	<ul style="list-style-type: none"> <li>State agency patient record.</li> <li>Care coordinators cannot access medical records.</li> </ul>
<b>12. Pharmacy 1</b>	<ul style="list-style-type: none"> <li>Fills 12 of 15 medications.</li> </ul>	<ul style="list-style-type: none"> <li>Pharmacy computer system.</li> <li>Portal to insurer.</li> <li>No access to medical records or to other pharmacy records.</li> </ul>
<b>13. Pharmacy 2</b>	<ul style="list-style-type: none"> <li>Fills 3 of 15 medications (prices lower).</li> </ul>	<ul style="list-style-type: none"> <li>Pharmacy computer system.</li> <li>Portal to insurer.</li> <li>No access to medical records or to other pharmacy records.</li> </ul>
<b>14. Laboratory</b>	<ul style="list-style-type: none"> <li>Draws and processes lab tests for all providers.</li> <li>Reports results to providers.</li> </ul>	<ul style="list-style-type: none"> <li>Laboratory computer system.</li> <li>Patient portal 3.</li> <li>Electronic reports sent to specialists, paper reports faxed to PCP.</li> </ul>
<b>15. Home healthcare agency</b>	<ul style="list-style-type: none"> <li>Patient has two 30-day episodes of care with pre-discharge nurse liaison visit.</li> <li>RN case management, physical therapy, home health aide, social work, telemonitoring.</li> </ul>	<ul style="list-style-type: none"> <li>Electronic referral from hospital.</li> <li>Home care EMR.</li> <li>Portal to hospital EMR for inpatient stay.</li> <li>Portal to records of cardiologist.</li> </ul>



Care Providers and Coordinators	July to December	Patient Information, Medical Records
	<ul style="list-style-type: none"> <li>■ Social worker helps with application for state-funded nonmedical home care and stress management for overwhelmed caregivers.</li> </ul>	<ul style="list-style-type: none"> <li>■ Exchange paper reports with state home care support program.</li> <li>■ Fax care plan and supplemental orders to PCP and specialists.</li> <li>■ Give patient and family paper instructions and medication list.</li> </ul>
<b>16. Family caregivers (husband and adult daughter)</b>	<ul style="list-style-type: none"> <li>■ Go to all medical appointments.</li> <li>■ Call clinicians when symptoms get worse.</li> <li>■ Make follow-up appointments. Get patient to lab and medical appointments.</li> <li>■ Ensure all clinicians get medical information from others.</li> <li>■ Stay with patient in hospital. Ensure care coordinator makes a good discharge plan.</li> <li>■ Coordinate scheduling and oversight of PCA with nonmedical agency.</li> <li>■ Calls in prescription refills.</li> <li>■ Barter with state home care program care coordinator for more personal care support services.</li> <li>■ Visit elder law attorney for financial planning.</li> </ul>	<ul style="list-style-type: none"> <li>■ Home medication list.</li> <li>■ Home medical notebook.</li> <li>■ File with instructions from all providers.</li> <li>■ List of providers and phone numbers.</li> <li>■ List of websites and passwords for three patient portals.</li> <li>■ Printouts of information from patient portals.</li> <li>■ Files with administrative paperwork from SNF, home care, state home care support agency, nonmedical care agency.</li> </ul>
<b>17. Nonmedical home care agency</b>	<ul style="list-style-type: none"> <li>■ Do home assessment.</li> <li>■ Schedule and oversee personal care.</li> <li>■ Install and manage emergency alert system.</li> </ul>	<ul style="list-style-type: none"> <li>■ Nonmedical agency patient record.</li> <li>■ No connection with other records.</li> </ul>

**Questions to Answer:**

- There is plenty of care coordination here, but who is accountable for connecting all the dots for the patient?
- Who is talking to whom in this system?
- How many different medical records exist for this patient?
- How do the various medical records tell the patient story – or not?
- What would happen to this patient if there was no family caregiver and no nurse care coordinator in the PCP office?

As the table indicates, keeping track of all these visits, inpatient stays, laboratory tests, medications, and home treatments requires considerable family caregiver time and a high level of organizational skill. The family gets some help from the care coordinator in the primary care physician's office and the home healthcare nurse (when the patient is receiving home care), but in essence the responsibility falls on them. This level of effort puts a considerable burden on another chronically ill older adult (Mr. Habib) and on the couple's adult daughter who is trying to juggle a job, her own family, and her parents' needs.

This is a view seldom seen or appreciated by most of the health professionals involved in Mrs. Habib's care, with the possible exception of the home healthcare case manager (who is actually in the home with the family) and the primary care physician and nurse care coordinator (who see Mrs. Habib regularly over time). Such a broad view of a patient's healthcare services and caregiving support is necessary to real connected care.

**FIGURE 1-3** shows how parts of one patient's healthcare neighborhood connect and disconnect. This diagram details in graphic form organizational connections for Mrs. Habib, whose six-month healthcare journey was detailed in Table 1-1.

## Disconnected Care and Access to Care Management Services

Why, if we have so many care coordination professionals and care management programs, is the experience so disjointed for patients? One reason is that patients have access to care management or care coordination only when they are eligible for those services as part of their insurance coverage or through a facility or program where they receive care.

For example, a patient with a serious chronic illness might get care management services through a nurse care coordinator embedded in a primary care medical practice if that practice is a primary care medical home (i.e., a medical

practice that offers extended services including care coordination). Another way a patient might get care management services is through an insurance program such as a Medicare Advantage plan or a Medicaid high-risk patient care coordination program. These care management services are highly dependent on eligibility.

If the patient changes insurance, or changes primary care physicians, her access to care management may disappear. If you happen to be a patient with chronic illness who is covered by traditional Medicare, unless your primary care physician offers practice level care coordination, you are very likely to be left to your own devices when it comes to care coordination since traditional Medicare has no mechanism to coordinate care for its insured population.

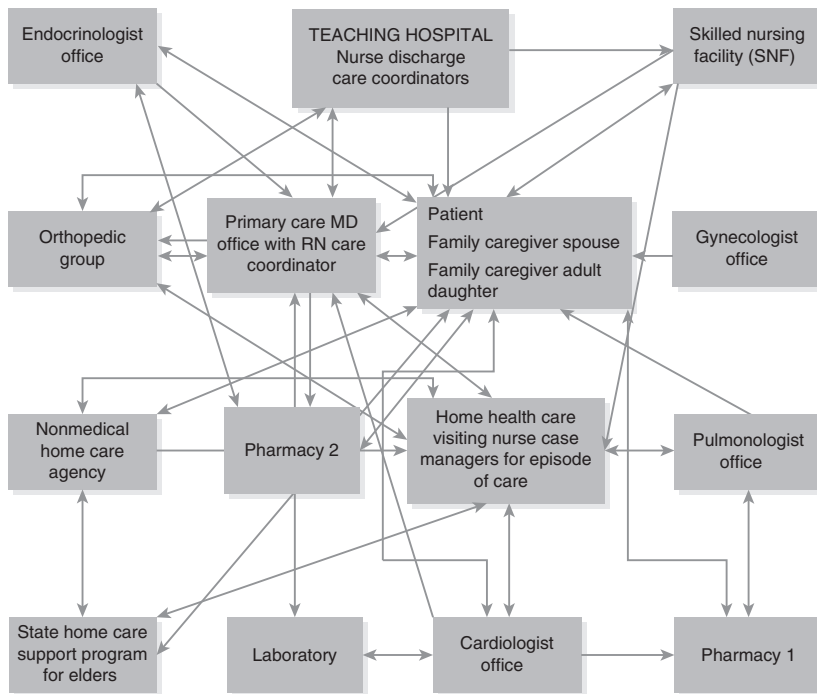
A recent study published in the online *American Journal of Managed Care* described a poll of 1,000 seniors, 85% of whom have one or more chronic conditions. Of those polled, 34% reported that a family member coordinates their care, and 35% said no one does, indicating a serious gap in care coordination for a high need population (Caffrey, 2016).

Even episodic care coordination through discharge planning or episode-specific care coordination (say, ambulatory surgery) has become less available to patients as care has moved out of formal healthcare settings into ambulatory care and lengths of stays in inpatient facilities have become shorter.

In summary, unless a patient or family pays out of pocket for a health advocate or care manager, the patient only gets this assistance when an institution or insurer thinks it is necessary, not when the patient feels confused and overwhelmed by the complexities of his or her healthcare needs.

## Health Professionals' Experiences with Disconnected Care

"Everybody has a story," said an RN, college professor, and mother of a son with a serious chronic illness, when discussing the issues of disconnected care. In researching this book,



**FIGURE 1-3** Mrs. Habib's Health Care Community

I found that most of the patients and health professionals who I interviewed agreed. Few people volunteered stories of satisfying and well-organized care. Most described wide variation in their experience with different parts of the care process. Some could describe at least one excellent experience, say with a nurse navigator in a cancer center, and other examples of horrendous experiences with multiple physicians prescribing conflicting treatments and medications with little to no communication, with the nominal “care connector,” the primary care physician.

While some professionals operate comfortably in task-oriented healthcare silos, many others experience frustration, anger, stress, and ultimately burnout. A recent online survey received (by the author) from the American Nurses Association illustrates this point. The survey, which solicited ideas for continuing education programs, contained multiple stress management–related topics such as “Nurse PTSD,” “Combatting Stress,”

and “Effective Strategies for Nurses to Achieve Work Life Balance” (ANA, 2016). In the original IOM Quality Chasm Report, the authors note, “Poor designs set the workforce up to fail, no matter how hard they try” (p. 4).

## Healthcare Organizations and Disconnected Care

Healthcare organizations are both victims and agents of disconnected care. Caught in a tornado of change as the healthcare system shifts from a volume to a value model, healthcare executives often describe their position as having one foot on the dock (fee-for-service payment) and one foot in the canoe (value-based payment).

The political turmoil of the 2016 presidential election has created possibly more forces for disconnection as the system resets itself for a new reality. Added to these major forces is the

continuing drive by both federal and state agencies to cut costs and reduce fraud. While on one hand, the CMMI pushes for creative ideas, collaboration, and the development and testing of new models of care, the other divisions of CMS create new regulations that demand more resources, more bureaucratic structures, and in many cases more rigidity.

As government payers, employers, and insurers struggle to control healthcare costs, payment rates are dropping, margins are shrinking, and business as usual has become more difficult. At an organizational level, the symptoms of disconnection are common but not always recognized. Complaints about “miscommunication”—patients getting conflicting instructions, dollars being wasted on missed appointments, patients not understanding when to report changing symptoms, having wrong phone numbers, lacking patient follow-up, and patients receiving medical bills with errors—are examples of disconnection in daily clinical life. Most organizations see these as “just the way things are,” not as symptoms of a deeper and more serious problem. Without a connected care measurement system, symptoms of disconnected care only come to light during complaint reviews, quality audits, state surveys, case conferences, and formal and informal conversations among staff and managers.

Many organizations, overwhelmed by conflicting demands and regulatory changes, take their eye off the ball of connected care while they hunker down and try to survive the change tornado. Others continue to move forward with collaboration and coordination efforts, and despite

a less than ideal climate, generate solutions and innovations.

## Fragmentation and Connection: The Push and the Pull

Our American healthcare system and our healthcare organizations are a volatile mix of fragmented and connected care delivery structures, payment models, and activities. Some of these forces push toward connection, while others pull toward fragmentation. There is progress on many fronts, but the forces of fragmentation are very much alive and well.

One helpful tool in visualizing these dynamic forces is force field analysis (**FIGURE 1-4**). This tool, developed by organizational psychologist Kurt Lewin (1951), visualizes dynamic forces that drive toward, and oppose, change. Organizations and teams use it to achieve change management goals by identifying negative forces that must be overcome or positive forces that must be strengthened for change to occur. The force field model is useful in visualizing the forces that impact connected care in your professional world.

### ACTIVITY

1. Think about the bigger healthcare system in your own community and your own state.
2. Create your own force field analysis using the diagram as a guide.

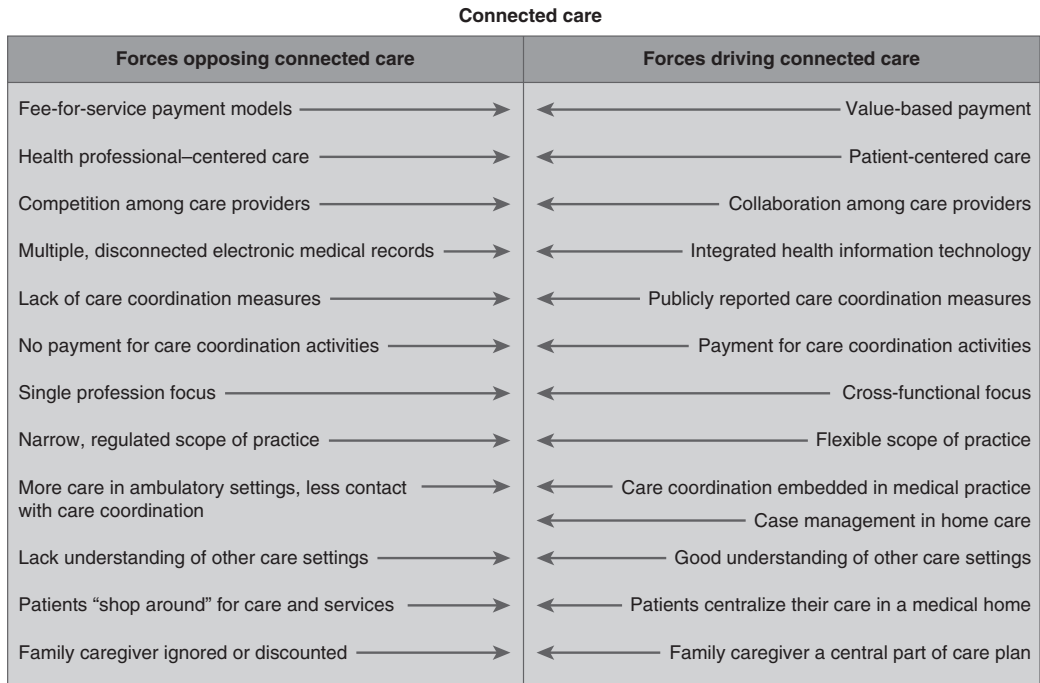
### ASK YOURSELF

1. How many disconnected care stories do you hear at work? Is this a widespread problem?
2. How well is your organization weathering the forces of change and providing new ways to offer connected care to patients?

## ► Measuring Connected Care

### Care Coordination: A Key Element of Connected Care Measurement

Care coordination has become a generic term for the various care connection activities developed



**FIGURE 1-4** Force Field Analysis Graphic

to solve healthcare fragmentation and a key focus for measurement. Care coordination, however, is a difficult concept to pin down. A 2007 analysis of healthcare quality improvement strategies (McDonald et al., 2007) identified over 40 definitions of care coordination. Two of the most commonly used definitions come from the National Quality Forum (NQF) and the AHRQ:

- The NQF describes care coordination as “a function that helps ensure that the patient’s needs and preferences for health services and information sharing across people, functions, and sites are met over time” (NQF, 2006, p. 1).
- The AHRQ definition of care coordination is “the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services” (McDonald et al., 2007, p. 1).

The authors of the AHRQ (2014) Care Coordination Atlas, a work designed to describe and summarize useful care coordination measures, describe the rapid evolution of the field of care coordination over the three-year period from the first edition (AHRQ, 2010) to the 2014 version. While the field has moved forward in the years between the two editions, the authors indicate that continued ambiguity in care coordination definitions and lack of consensus around a single conceptual model still persists (AHRQ, 2014). Fuzzy definitions have not, however, been a barrier to the development of multiple care coordination strategies, roles, software, products, and services. Almost daily, healthcare news journals, commercially sponsored white papers, free webinars, blogs, and product announcements flood professional email inboxes, claiming to have found the ultimate solution to the problem of disconnected care (**FIGURE 1-5**).



**FIGURE 1-5** Word Cloud of Care Coordination Terms and Programs

## ► What Would It Look Like if We Did It Right?

### Connected Care Measures

Formal measurement efforts have focused on two elements of connected care: care coordination and care transitions. In recent years, the development of care coordination measures has been the focus of intense effort by policy makers, academicians, and care coordination specialty groups. As these measures have migrated into accreditation, public reporting, and value-based payment models, they have also become of vital interest to administrators and clinicians.

The NQF (2006) has developed a list of endorsed care coordination measures including:

- Hospital readmission rates
- Percentage of patients who received a transition record at the time of discharge
- Number of unintentional medication discrepancies per patient (NQF, 2014)
- Patient age experience of care coordination using the Consumer Assessment of Health Care Providers and Systems (CAHPS) survey (CMS, 2016b)

Nursing, because of its widespread involvement in care coordination, and especially in specialty care coordination roles, has also developed

measurement models that build on those of NQF, ARHQ, and other theorists (American Nurses Association [ANA], 2013).

Care coordination measures are used in a variety of important ways:

- **Public reporting**—Medicare reports many care coordination measures (such as hospital readmission rates) on its website (Medicare, 2018). This public reporting system provides patients, families, and professionals with comparative data about healthcare organization performance. Examples are the Medicare Hospital Compare and Medicare Home Care Compare websites (Medicare, 2018). Both feature readmission rates and patient satisfaction data comparing organizations against state and national benchmarks.
- **Value-based payment**—CMS has included care coordination measures in the standards for new, alternative payment models such as accountable care organizations (i.e., groups of providers that work and are paid together to provide care for a group of patients) (CMS, 2018b) and bundled payment (i.e., payment for all elements of care provided for a single diagnosis or surgery) programs. These measures include hospital readmission rates, health information systems standards, and CAHPS



measures. In these settings, measures are used to determine payments.

- **Cross sector measurement mandated by legislation**—The IMPACT Act of 2014 (CMS, 2014), which creates a unified measurement system across postacute settings, includes several care coordination measures such as 30-day readmission rates, postdischarge medication reconciliation, and transfer of health information and care preferences when an individual transitions to a different setting. Some of these measures are currently mandated, while others are still in development.

## What Does It Take to Perform Well on These Measures?

The NQF (2010) has identified five domains for care coordination measurement and created a list of associated care coordination best practices for achieving higher scores on key measures. These domains and associated best practices provide a roadmap for organizations that plan to improve their level of connected care:

- Healthcare home—a single location where the patient receives primary care and where his or her primary medical record is kept
- A proactive plan of care and follow-up
- Communication among providers and across settings
- Information systems that link and share vital patient information
- Care transitions (Modified from NQF, 2010, pp. 7–38)

Using the NQF best practices that are part of these domains, healthcare organizations can create a self-assessment of their own connected care effectiveness.

## Organizational Connected Care Measures

For most organizations, connected care measures will be part of their accreditation requirements, and if they are Medicare participants,

part of their publicly reported measures. Organizations may develop their own operational goals for connected care. Following is an example of home health agency connected care measures and goals:

- **Outcome measure.** A home healthcare agency has a 30-day readmission rate of 16%. The agency goal is to improve its score to the level of the state benchmark, 15%.
- **Patient experience measure.** The same home healthcare agency scores 82% on the Home Health Consumer Assessment of Healthcare Providers and Systems (HCAHPS) national survey question: “How well did the team communicate with patients?” The agency goal is to achieve or surpass the state benchmark score (85%).
- **Internal process measure.** The agency has found that patients are being readmitted because of poor instructions given at the end of the home care episode of care. The agency’s goal is to reduce by 50% readmissions due to poor instructions. The agency will measure performance by calling patients two days after discharge, checking their understanding of discharge instructions using a standardized form and asking patients to rate the quality of the discharge instructions that they received.
- **Nursing consistency measure.** The agency has a standard of having no more than three nurses visit a patient during an episode of care. The electronic medical record is used to generate monthly reports that flag patients with too many nurses on the case.

### ASK YOURSELF

- What are the official care coordination quality measures for your industry segment?
- How well is your organization performing on care coordination measures?
- What are your organization’s target improvement goals for these measures?

## ► Beyond Care Coordination: Connected Care

While care coordination can be extraordinarily helpful to patients, it is often narrowly focused on strategies employed by health professionals within the structure of the healthcare system. It is often layered on top of a fragmented, disconnected system, as opposed to being embedded into the work of all professionals.

Few healthcare organizations extend their care coordination activities outside the boundaries of their own walls into the real patient world of care coordination activities that exist in families, friendship networks, community groups, faith communities, mobile applications, and social media.

Because it is unlikely that our healthcare culture or payment system will fully transform itself to an integrated model providing coordinated services to all patients anytime soon, a more comprehensive approach that can be adopted by healthcare organizations, large and small, would be very helpful in improving the care experience for patients. Connected care is such an approach.

### Why Connected Care Is Vital

Numerous studies have documented the negative impact of care fragmentation. One study, which reviewed over 500,000 healthcare claims from commercially insured patients, found that more fragmented care demonstrated less use of clinical best practices, cost more, and generated more avoidable hospital admissions (Frandsen & Joynt, 2015).

Patient harm, including disability and death, for patients who have been the victims of high-risk fragmented care is well documented as are the malpractice risks associated with disconnected care (Budryk, 2016). For organizations, disconnected care can generate citations or sanctions on state surveys, producing

thousands of dollars in fines, a public relations nightmare, and expensive corrective action. Even with so much evidence about the negative impact of fragmented care, executives and clinicians, consumed by a tidal wave of regulatory changes, market demands, and competing internal priorities, do not always focus on connected care approaches.

These constant distractions leave little time or energy to think about connecting with other providers or to consider the next steps in care in a way that creates a safe and seamless experience for patients. Yet, despite these obstacles, there are excellent reasons to make connected care an organizational strategic goal and to embed it into the daily fabric of clinical work:

- It is a key national health priority and a key part of the National Quality Strategy (AHRQ, 2015).
- It can lower costs and help organizations succeed with new payment models.
- It reduces patient harm by eliminating miscommunication, medical errors, and fragmented follow-up.
- It can improve patient satisfaction by creating a seamless experience.
- It may lower survey, accreditation, and malpractice risk for healthcare organizations.
- It is a key factor in reducing health professional dissatisfaction and burnout that results from the inability to provide good quality care in a fractured and dysfunctional healthcare system.

The impact of connected care—or its opposite, disconnected care—influences every aspect of a healthcare organization's performance. Many people characterize organizations that practice effective connected care as “having their act together” or “running a tight ship.” Having this type of reputation can have a positive impact on organizational growth. The potential positive impacts of connected care on achieving Quadruple Aim goals and on employee satisfaction justify the level of effort and allocation of resources necessary to create a culture of connected care.

## Crossing Your Own Quality Chasm: Organizational Connected Care Solutions

We described connected care as a systems approach to creating a safe and seamless patient experience. Connected care requires a health-care culture change in which healthcare organization operations and individual health professional behaviors are aligned around creating a seamless care experience for patients. In this way it is somewhat like the patient safety culture movement, which seeks to embed patient safety attitudes and actions into every aspect of a healthcare organization's operations (Oh, 2012). Culture change starts with a set of guiding principles.

### Connected Care Principles

- It's all about them (patients and caregivers), not just about us (health professionals).
- We're all in this together.
- We share relevant information to meet patient needs.
- We do the right things right.

(Modified from IOM, 2001)

**It's all about them, not just about us.** Connected care is about collaboration with the patient, not just adherence by the patient. In the connected care model, professionals filter all their actions through a patient lens.

Professionals co-create care plans with patients and work to incorporate patient goals. In the best case scenario, patients and professionals are mutually respectful of each other's expertise and effort, and work together as a team to achieve patient goals. Using the skills of active listening and motivational interviewing, professionals help patients articulate what is important to them and then take action to help them achieve their needs and wants. Professionals constantly ask themselves how their actions impact the patient experience and they ask patients for their perceptions and opinions in a very

straightforward way: "How do you think we are doing on planning your discharge?"

This principle also applies to helping patients deal with what they don't know; namely, the pitfalls they might encounter at the next step in care and how to cope with them. For example, a nurse care coordinator, helping a patient prepare for discharge after a skilled nursing facility stay, would ask how the patient will get food, what types of transportation she has access to, and how much real help she will have when she gets home.

The family caregiver or other care partner is the second patient in connected care. He or she is often the patient's most ardent advocate and frequently carries the heaviest burden in the care coordination effort. Professionals must do detective work to find out who is in the patient's formal and informal care support system and then develop mechanisms for communicating with these vital helpers. Because this work is patient directed, patients may sometimes choose not to participate in connected care. After using reasonable means to create a collaborative partnership, health professionals must respect this choice.

**We're all in this together.** Connected care is all about collaboration and teamwork, not just between people in the same organization or profession and those who have the right degrees or certifications.

Nurses talking only to nurses and doctors talking only to doctors doesn't always produce coordinated results. The first step is to look outside your narrow professional silo and see the relevant parts of the patient web of care. To collaborate effectively, professionals must put aside status concerns, professional turf issues, jargon, and insider information. Collaboration of this type starts with dialogue about what each profession can do for the patient and by creating a common language for discussing patient care.

**We share relevant information to meet patient needs.** Connected care at risky handoff points, such as transitions between care settings, starts

with thinking about the patient's next stop along the continuum of care, what the people in that care setting need to know, and what they can do to help. All too often, professionals assume that the information they find most convenient to give is the information that the next step in care needs. This is often not true. If agencies and organizations communicate about what they need to properly care for the patient and then the referring agency provides that information, care transitions will be smoother and more seamless for patients.

A good way to do this is to have periodic conversations about “what do you need from us?” with referral sources or collaborating agencies. A good example is the use of a standard referral form for communicating patient information and orders for home health care. When a skilled nursing facility, a medical office, or a hospital refers a patient to home care, the care coordinator or physician office typically uses a standard referral form to convey patient information and initial orders for care. If the form is faxed, the agency typically needs a phone call or an email “heads up” to ensure that the faxed form is not lost.

The form should provide patient demographics, key diagnoses, medications, brief information about patient treatment and condition, a list of services requested, and specific medical orders for wound care, home treatment, monitoring, or other services. Without these elements, the referral is incomplete and the home care agency must track down the referring clinician to clarify pieces of information.

**We do the right things right.** Organizations that value connected care devote attention and resources to creating patient-centered, lean and effective work processes that reduce handoffs, eliminate unnecessary complexity, and ensure teamwork between professionals and across departments. Using data from patient satisfaction surveys, outcome measures, chart reviews, readmissions debriefings, patient conversations, and workflow observations, the part of the

healthcare organization responsible for quality identifies key work processes that impact care connections and may need improvement. Typically these are:

- Admission processes
- Referring the patient to outside care organizations
- Appointment and phone call processes
- Internal care transitions
- Coordinating the work of multiple health professionals and support staff
- Communicating and managing orders with primary care and other physicians
- Discharge processes

Using process improvement teams, tools, and techniques, the organization reduces waste, streamlines process steps, improves communication, meets patient requirements, reduces labor and staff frustration, and reduces the number of things that “fall through the cracks.”

## ► Key Elements of Connected Care

Connected care consists of a foundation (patient centeredness) plus the five pillars mentioned earlier (care transitions, care coordination, communication, teamwork, and collaboration). There are also some additional elements that integrate and unify the patient experience (**FIGURE 1-6**). Let's examine each of these key elements in more depth:

1. **The organization is aligned around connected care principles and practices.** Ideally, connected care should be a key organizational goal. It should be supported by senior management through inclusion in the organizational strategic plan, regular management attention, resource allocations, giving time for connected care activities, and having measures that track achievement of connected care goals.



**FIGURE 1-6** Connected Care Key Elements

2. **Organizational structures support connected care.**

Some organizations are actually built to provide connected care for patients and families:

- **Patient-centered medical homes** are one such structure. A PCMH is defined by the National Committee on Quality Assurance (NCQA) as “a model of care that emphasizes care coordination and communication to transform primary care into what patients want it to be” (NCQA, 2018).
- **Medical neighborhoods** are groups of primary care providers and specialists who see the same patients and have collaborative

care arrangements (Greenberg et al., 2014; Patient Centered Primary Care Collaborative, 2017).

- **Accountable care organizations** are groups of providers who band together to provide care to a population of patients, usually with a value-based payment model that pays for results and not for more services (CMS, 2018b).

In traditional healthcare organizations, structures can be altered to provide more connected care to patients. For example, a home health agency combined its nursing and therapy scheduling teams so that

patient visits would not overlap and would be better coordinated and more predictable for patients and families.

3. **The organization applies evidence-based best practices to care transitions processes.** This means using the tools and techniques from proven models such as the Care Transitions Model™ (Coleman & Min, 2006) and the Naylor Transitional Care Model (Naylor et al., 2004). These models include processes for ensuring transition accountability, educating patients about self-care, sharing patient information with other organizations and professionals in the continuum of care, ensuring that all pending patient care tasks are complete, and ensuring that the handoff to the next step in care is complete before ending services.

4. **The organization employs professionals who have specialized skills in care coordination/case management.** The most common roles are care coordinators, who manage patient discharges and care transitions to the next step in the continuum; case managers, who implement complex patient care plans over extended periods of time; and liaison nurses, who come into the hospital from postacute settings (SNFs and home health care) to facilitate patient transitions to the next step in care (Evans, 2015).

These professionals act as role models, consultants, and resources for other health professionals, who are not specialists but who incorporate care connection strategies into their daily work.

5. **Connected care skills are used by every clinician and every employee.** To create a true connected care culture, every employee must be accountable for monitoring and connecting the elements of care for patients and families. “That’s not my job” is emphatically

not the kind of statement that should ever be heard in a connected care organization. Each employee must be accountable for “closing the loop” to ensure that care tasks are completed in a way that meets patient needs. A good example is calling a patient back with lab results or ensuring that a medication refill is promptly called to the pharmacy.

6. **The organization employs interdisciplinary teamwork strategies such as the AHRQ Team STEPPS® program (AHRQ, 2016b) to build effective healthcare teams.** The organization also uses internal team collaboration strategies such as single professional interdisciplinary conferencing and complex case conferences for clinical teams.

7. **The organization collaborates with other healthcare organizations.** The healthcare organization develops working relationships with other related organizations in its healthcare community. One common method for doing this is participation in hospital readmission collaborative groups (i.e., meetings between hospitals and postacute facilities to analyze complex cases and improve care transition processes to reduce readmissions) (Bradley et al., 2013). Other cross-functional groups may have different goals such as the development of patient education materials.

In highly integrated delivery systems, group “huddles” or team meetings that include partners from each part of the care continuum from hospital to SNF, medical practice, and home care, are held to discuss care strategies for high-risk patients. No matter what the stated purpose of the group, relationships develop between health professionals who



attend. These relationships can later be helpful when one organization needs the help of another to connect elements of care for a patient.

While none of these efforts approaches fully aligned connected care, it does illustrate how a community of willing health and community service providers can work together through formal and informal efforts to connect the elements of care for high-risk patients. This is the raw stuff of connected care.

8. **Electronic systems are used to share information and to track patients across the care continuum.** Information systems are as connected as possible. While few settings in the United States have fully interoperable information systems, there are ways to connect some electronic elements of the patient's story. Most organizations have the ability to use secure email to communicate with other health professionals in other settings. Many hospitals provide electronic referral portals where postacute providers can access patient information from the hospital record. Some integrated delivery systems use shared electronic databases or electronic patient tracking systems (that show which facility or provider is currently caring for the

patient) with their preferred provider partners. Many hospitals, physicians, and outpatient facilities provide patient portals (i.e., password-protected websites that allow patients to see a portion of their own medical records) into their electronic medical record, so that patients can access their own medical information and share it with all members of their health team, if they choose.

Integrating these strategies into a coherent whole is the key challenge in implementing a true connected care culture. This text explores each of these elements in greater detail.

## Collaboration in a Real Healthcare Community

Without a broader view of the various providers of health care and supportive services in a community, it is difficult to provide connected care for patients. In a healthcare community without strong integrated delivery systems, connections between organizations must be intentional and both informal (through personal relationships) and formal (through structured networking groups or improvement collaborative meetings). **FIGURE 1-7** and the following case study paint a picture of the various resources that interact with or are available to patients in a real healthcare community.

## CASE STUDY

### Connected Care Activities in a Real Healthcare Community

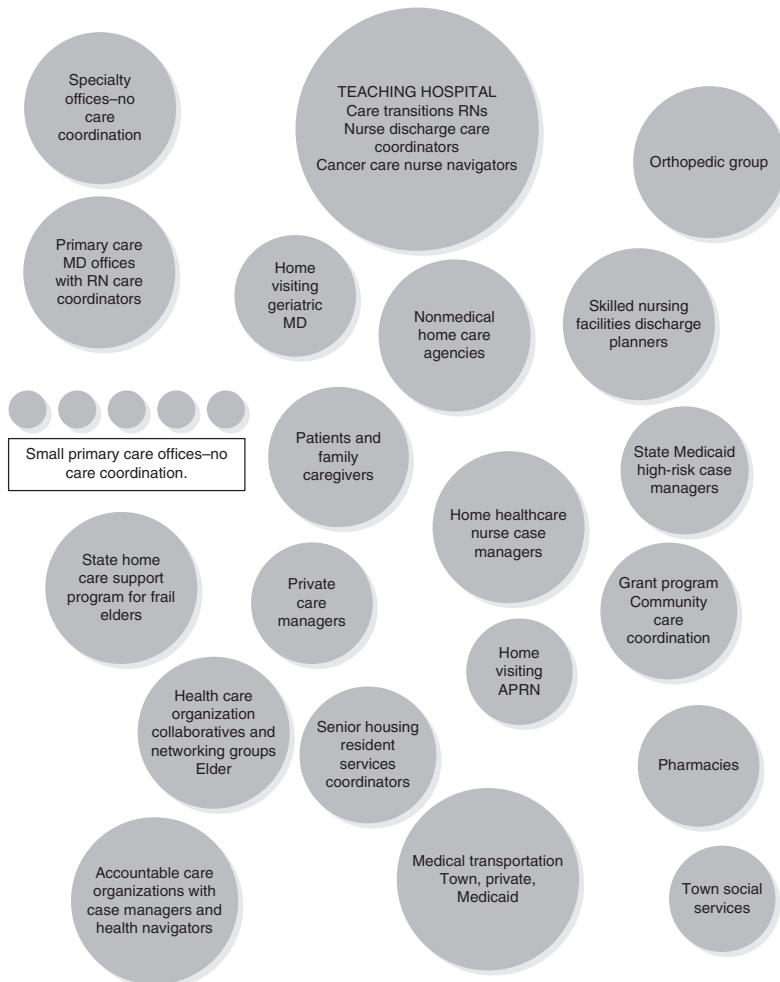
The following list provides examples of collaboration that occurs in the community depicted in Figure 1-7:

- The large teaching hospital in the community uses an electronic medical record that allows skilled nursing facilities and home care agencies to receive referrals electronically and to read selected parts of the patient hospital record.
- Patients who choose to use the hospital electronic medical record patient portal can see portions of their own medical record and retrieve medical test results online.

## CASE STUDY

(continued)

- The hospital sponsors a monthly collaborative meeting of hospital case managers and staff from skilled nursing facilities and home care agencies where participants work together to reduce readmissions by sharing case study information, learn about hospital care coordination initiatives, and develop relationships that often lead to better collaboration on patient cases in the field.
- There are numerous healthcare and eldercare networking groups in the community, in which participants educate each other about their particular specialized care service and educate the public about how to better use the healthcare system.
- Several accountable care organizations (ACOs) in the community use a single online system that tracks patients through the care continuum and allows ACO providers to report back to and collaborate with the ACO care managers.



**FIGURE 1-7** One Health Care Community

- A statewide grant program funded a local skilled nursing facility to provide care coordination to patients who have complex serious illnesses and no access to care coordination. Through outreach to providers, the care coordinator has been able to connect the elements of care for many patients without other resources.

## Who Provides Connected Care?

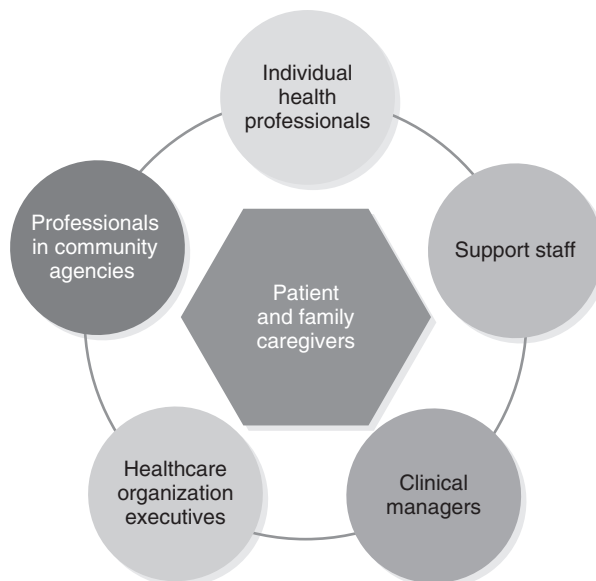
Connected care requires the active engagement and collaboration of healthcare and human services professionals and from every level of the healthcare organization from executive to front line staff. It also requires teamwork with health and human services professionals in community agencies. **FIGURE 1-8** illustrates the circle of support required to provide effective connected care to patients and their family caregivers. These roles range from that of a senior executive, who must align his organization around connected care goals, to the resident services coordinator in elderly housing who must find support for a high-risk patient who is discharged home without adequate support.

## ► Nursing and Connected Care

### How Nurses Impact Connected Care

Nursing, as the largest healthcare profession (Bureau of Labor Statistics, 2015) with a presence in every segment of the healthcare industry, is essential to achieving connected care. Nurses are typically present at every step of the patient journey. Patients often see nurses as logical care connectors. Nurses foster connected care in four fundamental ways:

- Providing connected care for patients as part of front line nursing practice
- Practicing in specialized care coordination, care transitions, and case management roles
- Achieving system change for better care connections through management, executive, and policy roles



**FIGURE 1-8** Working Together for Connected Care

- Acting as informal connected care advisors for personal networks of family, friends, neighbors, and professional colleagues

The American Nurses Association Congress on Nursing Practice and Economics (2012) describes the essential role of the registered nurse in the daily practice of care coordination, which is one core element of connected care:

Patient-centered care coordination is a core professional standard and competency for all registered nursing practice. Based on a partnership guided by the healthcare consumer's and family's needs and preferences, the registered nurse is integral to patient care quality, satisfaction, and the effective and efficient use of health care resources. Registered nurses are qualified and educated for the role of care coordination, especially with high risk and vulnerable populations. (p. 1)

Nurses in their historic role as the “glue” in the healthcare system often instinctively weave connected care principles into their daily routine. Getting food for the waiting patient and family, making a phone call to find a helpful benefit program, tracking down missing lab tests, ensuring that the patient has a follow-up medical appointment after a hospital stay, or assembling the right information for patient self-care are all normal and natural activities that help connect the dots for patients, but aren't typically labeled as formal care coordination or care transitions.

## Some Nursing Connected Care Activities

Parish nursing is a good example of community-based connected care. Parish nurses are members of a faith community who help members of their congregation with wellness activities and health-related problems. The American Nurses Association recognizes parish nursing as a type of specialty practice and describes it this way: “Today

the parish nurse plays many roles: integrator of faith and health, health educator and counselor, referral advisor, health advocate, support-group developer, and volunteer coordinator. Besides congregations, settings for parish nurses include long-term care, hospice, day care, soup kitchens, schools, seminaries, and other faith-based community settings” (Patterson, 2010).

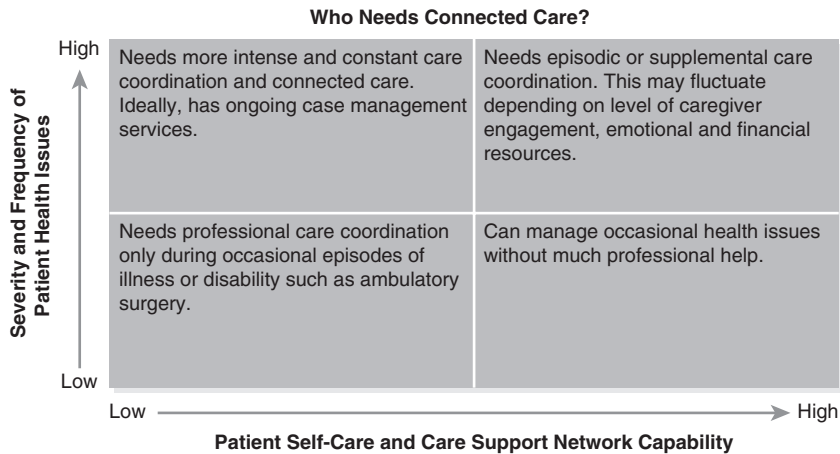
Nurses make up the largest proportion of professionals with job titles such as care coordinator and case manager. Indeed, nurses have made a concerted effort to define these roles as nursing-specific competencies.

Most nurses, even if they are not in a formal care coordination role, act as informal advisors for family and friends who have no access to care coordination services. This informal role often involves providing basic information about how the health system works, who to call for what, advising about which health facilities and doctors have the best reputation, and providing “insider” information about how to manage healthcare and insurance company bureaucracy. Consider the informal requests for care coordination help that one nurse (the author) managed in the last several months:

- A former neighbor, whose husband has fast progressing dementia, emailed for help finding a hospital bed for her husband who was no longer mobile.
- A friend who was facing a colon resection for diverticulitis called for help to find a network surgeon covered by her state exchange insurance plan.
- A friend called to ask whether he and his father, who lived in a nursing home, had the right to refuse a referral to hospice care which was being aggressively recommended, by the facility medical director.

### ASK YOURSELF

What nursing activities do you do on a daily basis as part of your regular nursing practice or in your private life to help connect pieces of care for your patients, family, and friends?



**FIGURE 1-9** Who Needs Connected Care?

These types of nursing connected care activities, while not formal or official, help people without other resources connect the dots for themselves.

## Who Needs Connected Care?

Not everyone who uses the healthcare system needs help with connected care (**FIGURE 1-9**). Many people now manage their own care using notebooks, calendars, mobile devices, on-line medical records, patient portals, tracking apps, retail health clinics, telemedicine, and on-line medical information.

Many patients fall into a middle range where they need connected care after surgery or during treatment for a serious illness such as chemotherapy for cancer treatment. Once the intense phase of the illness is over, these patients can go back to coordinating their own care. For frail, elderly patients with multiple serious chronic illnesses, and especially those with weaker caregiver support and/or socioeconomic barriers to health, more continuous connected care is essential to better outcomes, especially in reducing medication errors and hospital readmissions.

It is important to note that the target population for connected care is both the patient and his or her network of family caregivers

and informal support helpers who surround the patient throughout the care journey. Supporting the caregiver so he or she can continue helping coordinate patient care is an essential, and often missed, element of successful connected care.

## Visualizing Connected Care in Daily Work

To create a connected care culture, clinicians must be able to visualize how connected care looks in clinical practice and internalize this vision into their own practice. Let's look at a few examples:

**One or more health professionals, usually in a primary care setting, works with the patient to create a care plan that incorporates patient goals, self-care and care coordination ability, social determinants of health, and level of caregiving support.** Many times this is far from reality on the front lines of health care. Most care plans are developed by a single professional, looking at the patient through the lens of his or her role (e.g., “nursing care plan,” “social work care plan”). Methods of charting can help to better integrate information from all disciplines and alleviate this problem. Incorporating patient goals into care planning is a relatively new idea for most professionals and requires

some training in techniques such as active listening and motivational interviewing.

**The patient-driven care plan is used by all professionals who care for patients as the core of their own specialized care plans.** This means that each specialty or inpatient professional would be obligated to communicate with the patient, family, or primary care physician about how his or her specialized care plan might impact the core, patient goal-directed care plan.

**Everyone involved in the patient's care coordinates with the patient's primary care medical practice.** In most settings, this means ensuring that the patient has a primary care physician and communicating with that physician about the patient's status. A phone call to notify the physician that the patient has gone into the hospital is an example.

Home care, hospitals, and skilled nursing facilities often adopt a standard that their staff must help the patient make an appointment with his or her primary care physician within seven days of discharge. This appointment is vital, because it allows the primary care clinician to modify the care plan based on a recent inpatient stay and it provides an opportunity to reconcile medications that the patient was previously taking with those that were prescribed at discharge.

**Every health professional, not just care coordination specialists, take accountability for connecting the elements of care for patients and ensuring that no information or activities "fall through the cracks."** This is the sometimes tedious job of the care coordination element of connected care—ensuring that test results come back and that they are reviewed, that a course of action is developed and that the patient is informed, verifying correct family and doctor phone numbers, asking about how the patient will get medical supplies at home, and so forth.

Medication reconciliation (reconciling differences between medications prescribed in different settings or by different doctors to achieve one, current, and accurate medication list) is another vital (maybe the most vital) activity in this area. It also involves assessing and probing for potential gaps and cracks in care before a care

transition. For example, a patient may insist that he is fully able to prepare his own medications at home, but when asked to demonstrate how he sets up his weekly pill box is unable to sort the medications correctly.

**The organization has structures and processes to deal with high-risk handoff points such as transitions of care to and from outpatient settings.** Care transitions are the highest risk parts of the care continuum, where the most errors and patient harm typically occur. The organization should recognize these high-risk handoff points and have structures in place to manage them.

For example, SNFs and home care agencies should have procedures for ensuring that when a patient is sent to the emergency room or is admitted to the hospital there is a process for communicating the medication list and other relevant patient information. Intake and admission is another high-risk point. One way to handle this is to have a clinical liaison from the receiving facility or agency visit the patient in the inpatient facility to assess care needs and to educate the patient and family about the next step in care.

**Information about the patient (the patient story) flows smoothly from one part of the care continuum to the next and ultimately back to the patient at home.** While this problem is often framed as a problem of health information systems interoperability, it is much more about the end goal of communication than the means of achieving it. This means that each health professional informs the next step in the care continuum about what he or she needs to know about the patient to provide effective care.

It also involves "telling the patient story" so that the patient becomes a real person with real problems and not just a collection of physical findings, diagnoses, and lab tests to those who read the medical record. It would also mean that each time the patient leaves the health setting and goes home to self-manage, he or she gets the education, information, and resources to care for himself or herself correctly and to know when to call for further help.



**All employees who care for or provide service to the patient coordinate their activities and work as a team.** Nothing makes patients and families more upset and confused than having different staff members and health professionals providing disjointed services and getting a different set of explanations and instructions from each member of the care team. For example, in an outpatient surgery center, all members of the clerical, medical, and nursing staff should be clear on the preoperative, surgical, recovery room, and discharge steps in care.

Each person in the process chain should prepare the patient for the next step: “First I will do some preliminary testing, then you will see the doctor and then you will sit with the booking secretary. It should take about an hour in total.”

**All members of the care team should provide consistent and reliable information and should respond effectively to patient questions.**

All team members should be using the same language and giving instructions that mesh. Written instructions should be clear and unambiguous. Ideally, there should be a set of frequently asked questions available. A good way to test for this problem of disjointed instructions or coordination is to ask a friend or family member to review the steps in your process and read your patient instructions. Care disconnects will become immediately visible to someone who is not part of the process.

**The patient’s family caregivers and other key helpers are treated as important members of the team.** As in the case study of Mrs. Habib’s medical care system and journey through the care continuum, family caregivers and other patient helpers are key members of the care team and they usually carry the heaviest care coordination burden for very ill patients. The healthcare organization must identify who these care support

Check off all the elements of connected care that you recognize in your organization.

1. ☐ Your organization creates a patient-driven care plan that incorporates an assessment of patient’s self-care ability and patient goals and includes strategies to address these abilities and goals.
2. ☐ The patient-driven care plan is used by all professionals who care for the patient as the core of their own specialized care plans.
3. ☐ Key professionals involved in the patient’s care, or discharge, keep the patient’s primary care provider(s) informed and ensure follow-up with primary care clinicians.
4. ☐ Information about the patient (the patient story) flows smoothly from one part of the care continuum to the next and ultimately back to the patient and caregivers at home.
5. ☐ Every health professional, not just care coordination specialists, take accountability for ensuring that there is consistent follow-up of patient care tasks and handoffs. Patients get test results, medical equipment, appointments, insurance information, and referrals that they need in a timely and coordinated way.
6. ☐ All members of the care team give patients consistent information and they respond effectively to patient questions.
7. ☐ All employees who care for or provide service to the patient coordinate their activities and work as a team.
8. ☐ The organization has structures and processes to deal with high-risk handoff points such as transitions of care to and from inpatient settings.
9. ☐ The patient’s family caregivers and other key helpers are treated as important members of the team.
10. ☐ The patient’s entire “web of care” including community organizations and formal and informal caregivers is included in your organization’s connected care communication.

**FIGURE 1-10** Connected Care Clinical Self-Assessment

people are, what their roles are, how much they are available to help, and what information and resources they need to support the patient. For example, in large families, each adult child may have a specific role to play in his or her parent's care. When the patient gives permission, the family caregiver should be an integral part of any patient decision making and patient education activities. In some cases, the family caregiver may be so stressed and overwhelmed that he or she must actually be treated as "the second patient."

**The patient's entire "web of care," including support people in community organizations, are included in the patient chain of communication.** Health professionals all too often focus only on the patient and not on other care helpers who may be helping the patient with self-management support. This is especially vital for patients who have little or no family caregiving support. For example, a frail elderly person who has no family and lives in subsidized housing may have no support other than the building resident services coordinator, who is seldom, if ever, in the chain of healthcare communication. One way to uncover this information is to ask questions like "Who, besides your family, might help you when you go home?" If there are other people involved, the health professional could ask the patient for permission to include these helpers in care planning. Other resources for patient support that are often overlooked are neighbors and private paid helpers such as companions, homemakers, and personal care assistants.

### ASK YOURSELF

Based on the assessment results, what goals could you set for improving connected care in your organization, department, and personal practice?

## ► Chapter Summary

Health care in the United States has suffered from care fragmentation and disconnection due to a fee-for-service payment system, excessive

specialization, health professional "silo" mindset, health professional "turf wars," and regulations that promote fragmentation and some aspects of consumer health choices. This fragmentation has produced adverse events for patients including patient injuries, deaths, readmissions, and excessive, wasteful healthcare expenditures. Connected care is an approach to reducing fragmentation and disconnection that incorporates care coordination techniques, but also embeds connected care activities into the work of every health professional. Nurses because of their broad, patient-centered view and their presence in every part of the healthcare system are uniquely positioned to practice connected care.

The healthcare industry has made a concerted effort, which has been accelerated by the Affordable Care Act, to create more connected care, to improve payments for care coordination, to better measure care connection activities, and to educate health professionals in connected care techniques. While some of these efforts have proved effective, the United States still ranks poorly on health outcome measures and efficiency. More work remains to be done. Health professionals must apply a set of connected care principles and practices to their daily work life to better connect the dots for patients and to achieve better health outcomes, lower costs, and improved patient satisfaction.

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