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Coordination at the Point of Need

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5.1 INTRODUCTION

Globally, for individuals with chronic or prolonged conditions such as cancer, care is complicated, fragmented, and poorly coordinated [1]. It is not unusual for individuals with cancer to experience transitions from home to physician office, clinic, outpatient service, emergency department, inpatient hospital, and community-based settings attended by different practitioners and numerous specialists at each. The challenges faced by individuals and their family members are many. For instance, specialty oncology care—involving surgery, chemotherapy, radiotherapy, and other treatment modalities—occurs in cancer centers which may be geographically distant from patients' homes. Oncology specialists involved in an individual's care may not be in close communication with a patients' primary care provider. For others, particularly older adults, care may occur in the absence of family or community support. Cancer care problems are compounded when care is provided in fragmented and disconnected systems and providers do not have adequate access to information about the care received by patients in other settings. The burden then falls on the patient to try and coordinate across the many members of their care "team."

Many individuals with cancer also have multiple comorbidities that further complicates the delivery of coordinated and effective care. Health-related activity

over the life span is both dynamic and diverse. Over time, individuals experience some times when health care services are needed and at other times there is little interaction with the health care system. Accordingly, persons with cancer are likely to benefit from care coordination interventions. However, recent national reports criticize the current state of cancer care for inadequate coordination of care transitions, for not being patient-centered, and for not basing care decisions on the latest scientific evidence [2]. Moreover, no large-scale studies have focused on outcomes of care coordination interventions in oncology patient populations. Such studies are needed at all stages of the cancer care continuum—from prevention and screening to diagnosis and treatment through survivorship and end of life—to understand the ways in which care coordination might uniquely benefit patients with cancer. The challenge of care coordination is depicted in Fig. 5.1.

Recent national reports criticize care for not being person-centered, not making care decisions on the latest scientific evidence, and not adequately coordinating transitions [2–4]. As further evidence of the changing perspective on care coordination is the move by the Centers for Medicare & Medicaid Services (CMS) to implement a new payment and care delivery model for cancer called the Oncology Care Model [5]. The new program aims to improve quality of care and population health while lowering costs. To this end, CMS will fund physician-led oncology practices to implement innovative approaches to delivering chemotherapy, where reimbursement is based on the quality of the outcomes achieved, rather than on the volume of services provided [6]. The three key areas of focus are (1) linking payment to quality, (2) improving and innovating in care delivery, and (3) sharing information broadly to support and improve decision making. Application of health information technology (HIT) is an explicit requirement of participation in the program, and there will be many opportunities for technology to support quality improvement in this model [7]. For example, participating providers must employ an electronic health record (EHR) that fulfills federal criteria for demonstration of meaningful use, provide 24/7 patient access to clinicians who have real-time access to relevant medical records, and implement a data-driven continuous improvement process [7].

The Oncology Care Model has met with some criticism for its continued reliance on a payment model that, while reformed, is still viewed by some as essentially fee-for-service [8]. In 2014, the American Society of Clinical Oncology proposed more extensive payment reforms to
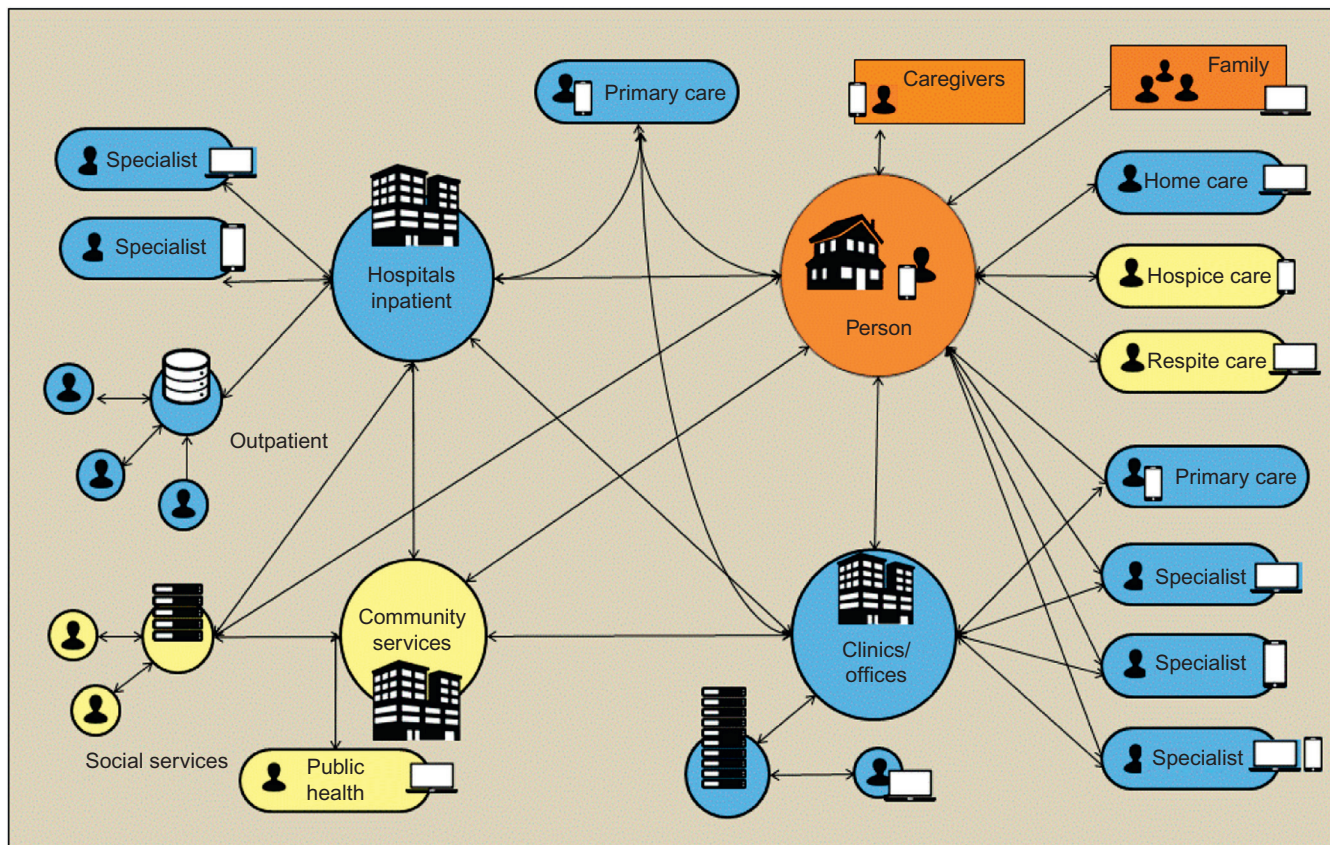

FIGURE 5.1   The challenge of care coordination.

support patient-centered oncology care [9]. These recommendations included a major shift away from fee-for-service payment models (ie, billing for office visits and chemotherapy administration), and instead toward payment models that would support telephone or e-mail visits, care planning, and care coordination [9].

Despite criticisms, the Oncology Care Model marks the beginning of important changes in the delivery of oncology care. The US Department of Health and Human Services has declared its intention for 85% of fee-for-service payments to be linked with quality by 2016 [10]. Care coordination plays a central role in these efforts including, potentially, new forms of payment for care coordination for individuals with chronic diseases [10]. Cancer will be the first chronic disease specifically targeted for these payment model reform efforts. Therefore, the Oncology Care Model serves as an important first step in demonstrating whether these innovative approaches to care coordination and novel applications of HIT can improve quality and reduce costs.

These national efforts highlight that the coordination of care must extend beyond traditional points of care which refer to the time and place where health care services are delivered, typically in hospital and ambulatory settings. Central to the major premise of this chapter, coordination must also occur at the "point of need," or all the times and places when health-related conversations occur and health choices and decisions are made among individuals, their family and caregivers, clinicians and health care teams, and community resource providers. One example of a point of need is when individuals experience nausea related to chemotherapy at home and seek resources or advice on how to manage their symptoms. Another example is the transition from active treatment to survivorship when the oncology team communicates and plans with the individual, family, and primary care provider about monitoring and following up needs.

5.2 FRAMEWORKS FOR CARE COORDINATION

5.2.1 Definitions of Care Coordination

No consensus definition exists for the term care coordination, which has evolved to refer to many interrelated concepts including care management, case management, disease management, and shared care. In a recent systematic review more than 40 different definitions were identified for the term, which the authors synthesized as follows:

> 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. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care [3].

Among patients with chronic conditions, including cancer, effective care coordination is increasingly viewed as a promising approach to achieving the triple aim outcomes of improved patient experiences of care (including quality and satisfaction); improved population health; and reduced per capita cost of care [11,12]. Indeed, a recent Institute of Medicine (IOM) report suggests that care coordination could result in $240 billion in annual health care savings [13]. Mechanisms through which care coordination is believed to lead to triple aim outcomes include improved treatment adherence; increased provider use of evidence-based guidelines; improved communication within and across care teams; improved care transitions with reduced fragmentation of care; improved symptom monitoring; and improved access to needed services [14]. Importantly, effective care coordination interventions are expected to reduce potentially preventable health service use including costly emergency department visits and inpatient readmissions. Successful care coordination models have demonstrated reduced hospital admissions and expenditures across a variety of chronic conditions [15–23].

5.2.2 Elements of Care Coordination

Care coordination activities involve assessment, planning, implementation, and evaluation and are typically supported by evidence-based guidelines and protocols [24]. The activities are organized by the care coordinator with the participation of other care team members, including the patient, caregiver/family members, and health care providers. The care coordination process promotes the active engagement of the patient (and caregiver) in his/her health care through self-management and ongoing encouragement, direction, and reinforcement.

Comprehensive assessment is required to understand the health care needs, goals of care, and resources available to patients with complex chronic conditions such as cancer. Usually this assessment occurs face-to-face, often over several meetings, and data are collected across multiple domains (eg, physical, social, psychological, cognitive, lifestyle, cultural, developmental, spiritual, demographic, financial, environmental, functional, social support, resources, and health service use). Assessment data are collected systematically, often using standardized instruments, and are used to understand patients' identified values and preferences for care. Assessment results include documentation of the patients' perspectives on

the most difficult aspects of managing their illness, their fears, their baseline knowledge of their conditions, and their goals for care. This information informs the development of care plans that include goals shared by the patient and care coordinator [24].

Care Planning includes collaborative activities toward developing a plan of care with participation of the patient, family, and health care team. Patients participate in this process by setting their goals for care and assisting the team to personalize and prioritize care plan recommendations. Through the care planning process, a comprehensive, evidence-based plan of care is developed to address all of the patient's health-related needs in the context of the patient's values, requirements, and preferences.

Implementation activities include identifying barriers to the achievement of the agreed upon action plan, with the patient and care team engaging in problem solving to reduce such barriers. In this phase, the care coordinator may be involved in teaching about disease processes, medications, and evidence-based self-management strategies; health coaching to reinforce positive steps taken by the patient; and making referrals to appropriate health and community services and supports. Above all, implementation activities involve coordination of health and community services, including efforts to synchronize communication between all of those who provide care for the patient—including specialist physicians; hospital and emergency staff; rehabilitation therapists; mental health professionals; home care providers; social workers; and community-based agencies (eg, exercise programs, faith-based organizations, and other support groups). This coordination is especially important during transitions between hospitals and other sites of follow-up care.

Evaluation involves proactive monitoring, with documenting patient progress toward care goals, performing a reassessment at each contact (especially following emergency department visits or hospital admissions), and revising the goals and/or plan of care accordingly.

Several frameworks have emerged for understanding care coordination as the organization of care, complementary to the delivery of care, and for highlighting the importance of informatics. In the following section, we introduce three complementary frameworks: chronic care model (CCM), integrated patient care (IPC) framework, and community-wide care coordination (CWCC). The CCM provides a theory of how chronic care operates, the attendant elements of high-quality care, and suggests best practices in the realms of the model. The IPC framework focuses on measurement of the elements of integration which is prerequisite to evaluating interventions. And, CWCC expands the scope of coordination to encompass points of need in relevant communities.

5.2.3 Chronic Care Model

One of the foundational frameworks underlying care coordination is the CCM that explicates the relationships among structures, participants, services, interactions, that lead to high-quality health care and health outcomes [25]. A related review of randomized clinical trials (RCTs) and observational studies, successful interventions, and chronic care programs yielded identification of common elements of high-quality chronic illness care to provide effective and appropriate care of chronically ill patients, as well as strategies for the individuals and families to cope with illness and its therapies [26]. The identified elements fall into the following categories: (1) use of plans and protocols; (2) reorganization of the practice to meet needs of patients; (3) attention to information and behavior change needs; (4) ready access to clinical expertise; and (5) supportive information systems. This model has been widely applied to inform comprehensive consideration of infrastructure and intervention aspects of approaches to chronic disease management.

Recent work applying the model to care coordination focuses on the goal of smooth handling of referrals and transitions (http://www.improvingchroniccare.org/index.php?p=Change_Package&s=354). This led to an updated model adding two elements: (6) building relationships and agreements among providers (including community agencies) with shared expectations for communication and care; and (7) developing connectivity via electronic or other information pathways that encourage timely and effective information flow between providers and community agencies. The elements are listed in Table 5.1 in a side-by-side comparison with the two frameworks described below. The table compares how each of the frameworks describe components related to concepts of person, plan, technology, within team, across team, and time.

5.2.4 Integrated Patient Care

In the IPC framework, Singer et al. propose that integration or coordination as a process is distinct from the object of integration, which may be organizational structure, activities, or alternatively, patient care [27]. This distinction suggests that an integrated delivery structure is not equivalent to IPC as they are two different targets. For example, accomplishing the structural components of a patient-centered medical home such as availability of a patient portal for requesting appointments and offering visit summaries is not necessarily evidence of accomplishing the outcome of patient-centered coordinated care. The authors also operationalize a definition of IPC as "coordinated across professionals, facilities, and support systems; continuous over time and between visits; tailored to the patients' needs and preferences;

TABLE 5.1 Comparison of Care Coordination Frameworks

Category	Elements of high-quality chronic care related to chronic care model (CCM)	Domains of integrated patient care (IPC)	Domains of community-wide care coordination (CWCC)
1. Person	*Patient self-management and behavioral change support*: Systematic attention to the information and behavioral change needs of patients	*Patient centered*: Care team members design care to meet patients' (also family members and other informal caregivers') needs and preferences; processes enhance patients' engagement in self-management	*Person-centered coordination:* Empowers individuals to exercise autonomy, collaborate in decision making, and optimize coordination. Supports development and delivery of coordination activities that respond to individuals' values, needs, and preferences. Individuals are patients at some points, but not at all points
2. Plan	*Explicit plans and protocols*: Use of a protocol or plan that provides an explicit statement of what needs to be done for patients, at what intervals, and by whom. Use of evidence-based guidelines	*Shared responsibility*: Both the patient and his or her family and care team members are responsible for the provision of care, maintenance of good health, and management of financial resources	*Shared care planning*: An inclusive process of comprehensive assessment, goal-setting and planning, implementation, and evaluation of an individuals' course of health over the life span. The resulting documentation, an evolving shared care plan, may have greater detail on shorter time periods when intensive focus is necessary
3. Technology	*Supportive information systems for population health and panel management*: Information about patients, their care, and their outcomes, tracking for population health, and panel management *Developing connectivity via electronic or other information pathways* that encourage timely and effective information flow between providers and community agencies		*Health information technology enablement*: Helps individuals to fulfill CWCC activities with the information and tools to achieve health outcomes. Helps teams to support individuals' health goals, efficiently manage groups they serve, and contribute to population health goals. Enables coordination at points of need
			Point of need for coordination
4. Within team	*Clinical expertise*: Ready access to necessary expertise *Practice redesign*: Reorganization of the practice to meet the needs of patients who require more time, a broad array of resources, and closer follow-up. This includes the organization of the practice team and the allocation of tasks among them, the management of patient contact (appointments, follow-up), and the use of a variety of health care professionals	*Coordinated within care team*: The individual providers (which may include physicians, nurses, other clinicians, support staff, and administrative personnel who routinely work together to provide medical care for a specified group of patients, "care team") deliver consistent and informed patient care and administrative services for individual patients, regardless of the care team member providing them	*Within teams*: There are three types of teams: family teams, health care teams, and community teams. Within the team, there are certain roles and responsibilities, specific activities that regularly occur, particular information that is helpful, and unique workflows to address
5. Across team	*Building relationships and agreements* among providers and community agencies with shared expectations for communication and care	*Coordinated across care teams*: All care teams that interact with patients, including specialists, hospital personnel, and pharmacies and deliver consistent and informed patient care and administrative services, regardless of the care team providing them Coordinated between care teams and community resources: Care teams consider and coordinate support for patients by other teams offered in the community (eg, Meals on Wheels)	*Across teams*: The person, family teams, health care teams, and community teams interact with each other. Teams may also have intense interaction as is the case when multiple providers are simultaneously delivering health care services. Communication must occur between those health care teams, individuals, and family teams to coordinate appointments, reconcile medications, and assure that treatments are not in conflict

(Continued)

TABLE 5.1   Comparison of Care Coordination Frameworks *Continued*

Category	Elements of high-quality chronic care related to chronic care model (CCM)	Domains of integrated patient care (IPC)	Domains of community-wide care coordination (CWCC)
6. Time		*Continuous familiarity with patient across time*: Clinical care team members are familiar with the patient's past medical condition and treatments; administrative care team members are familiar with patient's payment history and needs *Continuous proactive and responsive action between visits*: Care team members reach out and respond to patients between visits; patients can access care and information 24/7	*Over time*: Conventionally, care coordination occurs in the context of one health care service such as a hospitalization with 30 days of follow-up after discharge. In contrast, the CWCC perspective on time is over the continuum of care, and the life span of a person. Different teams are active at different times, and the level of participation also varies

and based on shared responsibility between patient and caregivers for optimizing health." This operationalization highlights the patient-centeredness of the IPC framework and supports measure development for the components of coordination.

5.2.5 Community-Wide Care Coordination

A conceptual framework for person-centered, CWCC builds on the previous two models and emphasizes the dynamic relationships and workflows between and among players and defines a new concept of "point of need" for coordination [28]. A point of need is any time and place when health-related conversations occur and health choices and decisions are made among individuals, their family and caregiver teams, clinicians and health care teams, and community resource teams. While members of teams may not identify themselves as such, we describe them as teams because they are known to each other and their activities supporting health of an individual are codependent.

The person with whom health is being coordinated is the person or individual. Family teams include patients and those close to them such as family members, friends, and other informal caregivers who are involved in their health. Health care teams are made up of clinical, ancillary, or administrative personnel and may be discipline- or setting-specific. There are also community teams that offer resources such as preventive health screenings, health outreach, and education; instrumental support services such as meals, transportation, and respite care; or social support via online patient communities and in-person groups.

The person, family teams, health care teams, and community teams interact with each other. They may have minimal interaction as is the case when a referral is made, with one team handing off a request for a service to another. For example, an individual might receive a flyer from a community organization advertising free blood pressure screenings at a health fair. This community team member might suggest the individual follow up with a primary care provider. An example of a more involved case is a care coordinator on a health care team who refers individuals to a transportation service to help them attend their appointments. The individual and family team might coordinate multiple trips over a period of time, involving ongoing coordination with that community service.

The shared care planning process includes individuals, family teams, health care teams, and community teams as appropriate. In alignment with person-centeredness, the inclusion of participants in the process should be driven by the individual. Thus, care is coordinated dynamically across teams and over time, but the person is always engaged.

The point of need for care coordination, that is, when health-related conversations occur and health choices and decisions are made, can occur for an individual, within teams, across teams, and change over time.

To illustrate the relevance of this framework to individuals, lung cancer survivor Janet Freeman-Daily offers a personal account of the story of her care coordination over 4 years of lung cancer treatment in Box 5.1 (used with permission).

Below is an illustration of the CWCC framework and its dynamic nature applied to the cancer continuum (Fig. 5.2). The top frame shows that the person is the center and involved in every phase of the continuum and care coordination. The second frame shows the teams that might be involved during the prevention and screening phase of the continuum of an individual's health. The three types of teams are represented by circles: family teams are gray circles, health care teams are dark gray, and community teams are light gray. The intersections between teams (where circles overlap) are points of need where a component of care coordination is required, for example, data collection, planning, decision making,

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BOX 5.1

JANET FREEMAN-DAILY'S CARE COORDINATION STORY

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Being in treatment for advanced lung cancer over the past 4 years, I've experienced many issues with care coordination.

Person-Centered Coordination: I like to share decision making with my health care team. When I was nearing the end of my postdiagnosis hospital stay, I was surprised to hear "you're being discharged in an hour"—no one had asked what questions I had about my follow-up care, or even whether I had a ride home. I was given a piece of paper with contact information for only *one* of the four specialists on my new health care team, and told I had prescriptions waiting at a pharmacy. I wasn't sure how to go about gathering the rest of the information I needed. This system was evidently efficient for the hospital, but not for me, the patient.

Shared Care Planning: Even when a facility has exceptionally good teamwork, patients can still be uncertain how to proceed when an issue arises. For instance, when I develop severe shortness of breath after a chemo session, should I contact my oncologist or my pulmonologist? When I developed intense chest pain upon swallowing during concurrent chemo and radiation, who do I contact for pain medicine: the radiation oncology nurse, or the oncology nurse?

Across Health Care Teams Coordination: When I travel away from my home care team for a second opinion or a clinical trial, the only way to transfer my data between facilities is via fax or hand carry because EHR systems cannot yet share data. I keep a stack of radiology image CDs along with pathology, radiology, and other vital reports in a three-foot-deep file drawer at home because facilities often cannot fill records requests on short notice. When I was discharged after a 10-day hospital stay, I was told a contractor would contact me to train me and provide supplies for daily peripherally inserted central catheter (PICC) line care and maintenance. No one asked me about the distance to the contractor from my home—after a couple of weeks, I accidentally discovered I could have my weekly PICC line flush at a clinic four miles away instead of driving 20 miles to the contractor's site.

Across Health Care Team and Family Team Coordination: The patient as well as family members and other caregivers may share responsibility for the patient's well-being. Having multiple caregivers involved increases the risk of miscommunications and inaccurate data. During my hospitalization after my cancer diagnosis, several family members visited me in the hospital. No one (including me) was present for every update from the health care team. This led to miscommunication and different interpretations of my status. For example, my sister (who had talked to the surgeon alone while I was in recovery) left the hospital convinced I was dying. However, I as the patient (who talked to the oncologist while I was alone) heard I might be curable. The opportunity for miscommunication is compounded for patients whose condition requires the coordination of data collection and medication among multiple caregivers. No effective tools exist to coordinate data, communication, and status updates between the health care team and caregivers/family members who tend the patient at different times of day.

Across Time Coordination: When I developed a pulmonary embolism on a clinical trial, the trial facility had no record of another blood clot I'd had over 2 years earlier at my home facility (good thing my chemobrain remembered). EHR systems evolve over time too, creating additional issues—a software upgrade scrambled my insurance data in the billing system, and suddenly I was billed thousands of dollars for my periodic scans and clinic appointment that my insurance had covered for years. Chronically ill patients spend more time unraveling insurance snafus than healthy patients, just when they need fewer things to worry about. My care facilities provide an online patient portal, but appointment scheduling and e-mail messages sent via the EHR system seem to vanish in the ether. Fortunately, most of my providers respond to e-mails and voicemails promptly. However, most of my health care data is not accessible via the online portal, and I am only able to correct errors in the records if I stumble upon a person with the correct authority, time, and savvy.

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information sharing, tracking and monitoring, communication, or logistics. Some individuals have family members or friends who are involved in their health but others do not. We do assume that a family team is available for everyone. The person, family team if there is one, and primary health care team may be involved. If the individual receives a result that suggests referral to

specialists for diagnosis and treatment, a patient navigator program (one type of community team) might assist with that transition.

The third frame shows the diagnosis and treatment phase. The roles of teams, who they interact with, and the intensity of effort (depicted by the size of the circle), differs over time. In this phase, many additional health
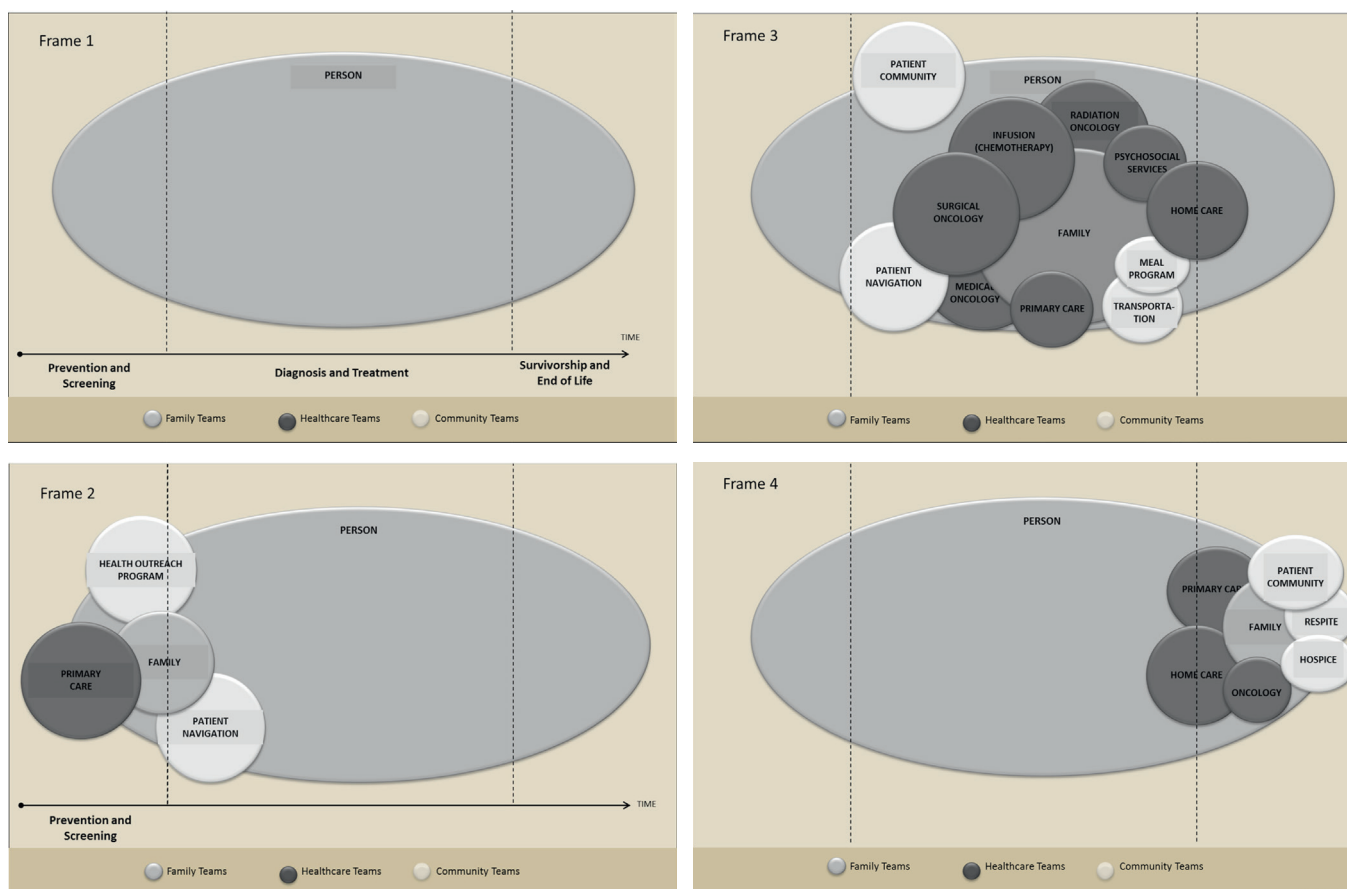
FIGURE 5.2   Community-wide care coordination over the cancer care continuum.

care teams representing specialists are involved and likely have a greater role in coordinating with the person and their family team. For many individuals who receive a diagnosis, one of the first things they do is look for patient groups (a community team) who can provide information and support.

In the fourth frame, treatment is ending, and the individual enters a survivorship phase in which they try to regain health and are vigilant regarding potential reoccurrence. A primary health care team likely becomes more involved again, but specialty health care teams may interact periodically for check-ups. The continuum is not simply linear: an individual may experience alternating periods of survivorship and diagnosis/treatment and continue prevention/screening activities throughout. Over the continuum, there are different combinations of participants and teams, changing points of need, as well as varying requirements.

All three frameworks address the concepts of person, plan, and the coordination within and among teams. CCM and CWCC explicitly address the need for HIT to support care coordination while IPC and CWCC expound on the importance of time and longitudinal coordination. Finally, CWCC highlights the central role

of teams including the person/family team and the community team. CWCC also defines the point of need as well as the dynamic nature of the relationships among the teams over the life span. The life span perspective, in contrast to time between visits with providers, is particularly important for cancer survivorship.

5.3 HIT FUNCTIONS FOR CARE COORDINATION

While EHRs are necessary they may not be sufficient to enable a learning health care system for cancer envisioned by the IOM, which recommends infrastructure and "real-time analysis of data from cancer patients in a variety of care settings" [29]. Several authors have described HIT functions necessary for both general care coordination and cancer care coordination. The compilation below, organized by the coordination concepts from Table 5.1, illustrates the breadth and depth of requirements. Requirements described in this section are followed by examples of projects and studies that have implemented some of these functions in the next section.

5.3.1 Person-Centered Coordination

Patient- or person-centered care coordination is responsive to the needs, values, and preferences of the individual. Individual access to comprehensive and actionable health data for the individual and their family and caregivers is a first step in achieving person-centeredness. A comprehensive data set is important to allow individuals to fully participate in their care. This includes the information in the EHR, clinician notes, care plans, tests, and results [30]. To make this information actionable, educational materials and decision tools should also be offered that are relevant to the individual's health status at opportune moments [31]. Both of these requirements suggest that infrastructure must be in place to understand when and where those opportune moments occur such that those tools can be targeted appropriately. In addition, information about the individual's situation and preferences, such as self-management capability and family or caregiver resources; observations of daily living and patient-reported health status such as side effects, and experiences; and preferred contact, should be in the EHR so that the care team can be responsive to the individual [32,33]. A longitudinal patient health record (PHR) owned by the individual and populated by interoperable monitoring devices and EHRs is one possibility for enabling infrastructure.

5.3.2 Shared Care Planning

Shared care planning is a process that involves collaboration among patients, family and caregivers, health care teams, and others to develop a shared understanding of both the goals and interventions that make up the trajectory of care. During planning, tools for assessing risk are helpful in identifying those patients who may require more intensive coordination. These tools may be in the form of scoring algorithms applied to clinical indicators in the EHR or data collected from interviews or other patient-generated data. Availability of relevant literature and evidence-based guidelines for treatment planning and ongoing tracking of care plan items are equally important [31]. The documentation of the outcomes of this planning process, referred to as a shared care plan, should be accessible to all relevant parties, editable, and revised as care progresses. The shared care plan may also become the basis for a transition of care summary that serves to communicate fundamental information to the family and other health care and community teams.

The Office of the National Coordinator for Health Information Technology sponsored the Standards and Interoperability Transitions of Care Initiative to define an interoperable longitudinal care plan to improve coordination across transitions of care involving acute and long-term providers, home health agencies, rehabilitation, and social and other support services [34]. The components of this care plan are detailed health concerns; patient and clinical goals; interventions and instructions; and health status evaluation populated with computable, standardized data. One study suggests that a transition of care summary should also include rationale and communication elements such as: name and contact information for all clinicians and who to contact with questions; advance directives; medications and reason for medication; management of high-risk medications; patient's ability to comprehend, remember, and capacity to consent to treatment; any impairments; patient likes and dislikes, problems, goals and expectations, and self-management plan; and patient instructions [35]. One exemplar of a longitudinal care plan specific to oncology is the survivorship care plan. The survivorship care plan offers a summary of the patient's treatment course, recommendations for follow-up care of symptoms and problems, ongoing cancer surveillance, and health promotion that may be helpful both to the patient and to future health care teams [36]. Both the process and documentation of shared care planning could be collected, analyzed, communicated, and updated through HIT.

5.3.3 Within and Across Health Care Teams

The primary HIT system used by health care teams is the EHR. For coordination with the health care team, a robust EHR should support not only the aggregation of data, but also the analytical and workflow needs that are critical to effective care coordination. A recent review of HIT functions and chronic care management process and clinical outcomes found several positive relationships: data in or connected to an EHR, reports of guideline adherence and unfinished care plan elements, and specialized chronic care order entry systems with disease-specific checks and order templates, referrals to a specialist or nurse care manager, and team member role-specific orders [37]. Other key functions for health care teams include: electronic access to guidelines/decision support; structured problem; allergies; medication lists; tracking of tasks against care plan; trends over time about complications and deterioration; roles and contacts of health care team members; and comprehensive care plan for all conditions [32]. The coordination across health care teams that may practice in different specialties, locations, or organizations requires additional capabilities for sharing of records/health information exchange, follow-up on referrals and reporting back of findings or patient disposition, and cross-organizational tracking of care plan activities [31,32].

5.3.4 Across Multiple Teams

Collaboration between health care teams and person/family teams share requirements with those described in patient-centeredness and shared care planning as those are domains in which much of the activity is collaborative. There are other requirements specific to the collaborations between these teams for which the full loop of communication and follow through are critical [29,31,32]. This loop begins with easy scheduling of appointments perhaps through a portal or PHR that streamlines the process for health care sites and improves accessibility for patients. Electronic downloadable visit summaries and patient education materials allow the person/family team to recall what occurred at the visit and the intended plan of care, and to follow up on their responsibilities. The loop continues with tracking of orders for labs and radiology not only to confirm fulfillment but also to assure that results, interpretation, and additional instructions have been provided to both the health care team and patient. Secure messaging and up-to-date contact information for the health care and person/family teams must be available to facilitate these communications.

Medication reconciliation is another function that relies on active engagement of person/family and health care teams in order to prevent adverse drug events and to achieve clinical goals. Reconciliation requires performing a comprehensive inventory of all prescribed and over-the-counter medications including name, dosage, frequency, and route; identifying the medications the person is actively taking and not taking; and identifying the source of medication orders/prescriptions. With this information, teams can prevent adverse drug interactions, make timely therapeutic changes as appropriate, and develop tactics to enhance adherence. The data for medication reconciliation may be sourced from EHRs and/or pharmacy management systems and patient self-report, and are needed at initial reconciliation and on an ongoing basis as changes are made. Medication reconciliation requires one type of patient-generated data related to medication adherence, but there are numerous others. Data such as physical activity and food consumption may serve primarily self-management purposes. Other data such as signs and symptoms may benefit from clinical input to self-management and be relevant to timely care coordination intervention or patient reported outcomes. Strategies for identifying, reviewing, and responding to patient-generated data are also needed.

Little attention has been paid to the elicitation of HIT functions or enabling technical infrastructure needed for care coordination within person/family teams and community teams, or across multiple, diverse teams whether family, community, or health care. In addition, coordination over the life span has received almost no attention.

5.4 CURRENT EFFORTS IN INFORMATICS AND COORDINATION AT THE POINT OF NEED

There have been a number of studies of HIT and care coordination in chronic disease management that demonstrate potential for improving outcomes including early intervention based on remote reporting of signs and symptoms via a handheld device [38], communication with care coordinators via videophones and messaging [39], and patient reporting by telephone [23]. There are still serious implementation challenges, however [40], and persistent health disparities when using HIT for care coordination [41]. Most coordination interventions still use low-level interactive technologies, such as telephone and fax, and so far no interventions have tackled the challenges of coordinating care across multiple teams, multiple settings, and over time [35]. Projects that have addressed the challenges of coordinating care in oncology are fewer, and have focused primarily on health care teams or their limited interaction with patients. These are described below.

5.4.1 Within and Across Health Care Teams

Health care teams enjoy the most comprehensive features for care coordination, particularly with robust EHRs. Galligioni et al. developed an electronic oncological patient record and highlighted the ability of "total" management of patients with cancer. Their data also revealed that providers felt it was "additional work" and had a "negative impact on doctor–patient relationships" [42]. While the authors reported their system was developed applying a user-centered design approach, the user-centered focus was on providers and did not include patients. Although EHRs and the variety of functions they may include (eg, decision support tools, electronic ordering of chemotherapy) offer many solutions to address the complex needs of cancer patients, significant barriers remain in their widespread acceptance and use [43].

An additional challenge of HIT-enabled care coordination is significant overlap of activities that may seem distinct; for example, and perhaps most noticeably, communication, workflow, and symptom management. Communication tasks could include items such as appointment reminders and patient-provider e-mail/messaging but it also may include notification about symptom management concerns of patient-reported symptoms via electronic questionnaire. Further, this notification on symptom management concerns could trigger further communication and workflow needs.

5.4.2 Within Person and Family Teams

There are several social networks that support care coordination among family teams. These online communities primarily focus on coordination of instrumental support for activities of daily living. Social networks that allow for both within family team and community team collaboration can have a significant impact on health care throughout the cancer continuum [44]. While very promising in the opportunity to provide connections and support, concerns remain about inaccurate information, lack of professional oversight, and overall misuse [44].

One example, while not exclusive to oncology populations, is CaringBridge. CaringBridge, founded in 1997, serves approximately 500,000 people a day. Anderson et al. evaluated connection and social support among CaringBridge users during a health care event and identified four key benefits: "providing information, receiving encouragement from messages, convenience, and psychological support" [45].

Lotsa Helping Hands is another patient support social network founded in 2005. While there is no published literature identified evaluating care coordination activities using this site among an oncology population, the need for community involvement and support is clearly described by Mangurian who wrote of her personal experience navigating system complexities as a parent of a pediatric oncology patient [8]. Among those with cancer, few studies evaluate the engagement of family members and caregivers of patients' use of technology to support communication and workflow [46,47].

5.4.3 Across Person and Health Care Teams

Cancer care across the continuum often involves complex treatment choices and decisions. Technology-enabled decisional support and aids, including prevention efforts in cancer care via educational modules and guided web-based interventions, may offer great promise in supporting patients, family members, and caregivers. However, within the limited research that has been conducted, almost all literature is focused on the development and testing of tools and interventions, with little known about how to overcome significant implementation barriers [48–51].

While much of the literature on care coordination among health care teams focuses on workflow support and communication, symptom management is almost inextricably linked to communication, as most of the reported outcomes examine patient-provider communication. Examples include appointment reminders, including text messaging [52–54], provider order entry [55], electronic messaging [56], and unique studies examining the communication between providers and insurance companies [57] and patients' reviews of provider documentation of medical appointments [58,59].

Research examining technology-assisted, self-report assessments for symptom management, quality of life concerns, self-care support for improved patient-provider communication, and patient distress in oncology have been widely published; although, many of these studies have evaluated the acceptability and/or use of technology, not specific health outcomes [60–63]. In a review of the use and possibilities of electronic patient-reported outcome systems (ePROs) in oncology clinical practice, Bennett et al. identify areas across the cancer continuum that "support multiple clinical activities, including assessment of symptoms and toxicities related to chemotherapy and radiation, postoperative surveillance, and symptom management during palliative care and hospice" [64].

In 2009, Abernethy et al. published results from a longitudinal pilot study of 66 metastatic breast cancer patients using eTablets over a 6-month period [60]. Patients completed electronic surveys on symptoms and quality of life. They examined the feasibility and acceptability of the "Patient Care Monitor" (PCM) and found that most patients found it easy to use, read, and navigate, with 74% indicating the PCM would help them remember symptoms to report to their clinician. Bausch reported that patients with cancer were able to use a web interface during chemotherapy to report treatment toxicity symptoms during an 8-week period [65]. In later studies, Bausch examined the feasibility of advanced cancer patients reporting toxicity symptoms and found that while satisfaction with the symptom reporting was 91%, only 51% of patients felt communication with their care team was improved [61,62]. Relatedly, Bausch evaluated the nurses' use of the symptom reporting data and identified that "only one of the seven nurses discussed reports with patients frequently, with insufficient time being the most common barrier to discussions" [62]. Finally, Snyder et al. evaluated the use, usefulness, and acceptability of PatientViewpoint among prostate and breast cancer patients and their providers [66]. PatientViewpoint is a web-based tool that allows providers to assign symptom questionnaires/surveys to patients, which upon completion may be linked to their EHRs. Similar to other studies, results show that most patients (92%) found the system easy to use, and 70% of patients found the system "useful" and helped them to remember symptoms to discuss with their provider. Additionally, only 49% of patients reported that it helped improve communication with their provider and surprisingly, only 39% identified improved quality of care [66]. Among providers, 79% reported using the symptom data and among a median score of three patient-identified concerns only one was reviewed during the patient's appointment [66].

Additionally, some literature reports on the use, feasibility, and validity of specific technology-enabled instruments and surveys [67,68]. Fann et al. evaluated the feasibility and the construct validity of the Patient Health Questionnaire-9 (PHQ-9) depression screening among a diverse group of cancer patients using a web-based touchscreen survey format [67]. Feasibility was measured with completion of the survey (96%) and the time (mean) it took to complete the survey (2 minutes). Taenzer evaluated an electronically administered quality of life survey (European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30) versus the same paper-based survey among lung cancer patients [68]. Outcome measures included patient satisfaction, patient and provider discussion of concerns identified by the survey, and provider documentation. While patients in both groups reported high satisfaction, patients completing the electronic EORTC QLQ-C30 identified more quality of life concerns, with more concerns discussed during the patient's appointment.

More recently, intervention studies have examined the effectiveness of technology-enabled symptom reporting and symptom management on patient-reported outcomes. Kroenke et al. conducted an RCT over a 12-month period, comparing the effectiveness of telecare management on pain and depression, along with automated home-based symptom monitoring by interactive voice recording or Internet, in patients with cancer among 16 community-based oncology practices, both urban and rural [69]. A nurse and physicians specialist team led the telecare management. Overall, the authors found greater improved pain and depression outcomes among those receiving the intervention [69].

Additionally, Berry et al. conducted a multisite RCT of 660 patients with various cancer diagnoses and stages [70]. They evaluated the effect of the Electronic Self-Report Assessment-Cancer (ESRA-C) on patient-provider discussions of patient-reported symptoms and quality of life issues. Patients completed assessments on touchscreen notebook computers and provider teams received a graphical summary report prior to the patient appointment. Berry and colleagues found increased discussion of patient symptoms in the intervention group. In a related RCT of 752 cancer patients recruited from two comprehensive cancer centers, traditional symptom and quality of life assessment combined screening with "targeted education, communication coaching and the opportunity to track/graph symptoms and quality of life over time" [71]. Berry et al. conclude that education, support, and coaching when added to symptom and quality of life screening reduces distress, particularly among those older than 50 years.

To address the symptom management concerns of oncology patients, studies are beginning to evaluate technology-enabled symptom management tools and online interventions [7]. Grimmett et al. have begun an exploratory RCT of 125 posttreatment cancer survivors to address fatigue using online self-management intervention compared with paper leaflets [7].

5.4.4 Across Multiple Teams

Online social support (virtual support groups, discussion groups, etc.) facilitates care across person/family teams and community teams when the support is provided from those outside the family team. In a recent review by Bouma et al., Internet-based support programs were evaluated and summarized into three categories: "social support groups, online therapy groups for psychosocial/physical symptoms, and online systems integrating information, support, and coaching services" [72]. They reported improved effects on both quality of life and social support in each category [72]. The Young Adult Program at the Dana-Farber Cancer Institute in Boston, Massachusetts created an institution-specific website to "meet the supportive and emotional needs of young adults (18–39 years old)" [73]. The website includes social networking and has demonstrated increased connectedness among those who participate [73]. Caregivers may also benefit from online support communities, although research is more limited [74,75]. While the majority of the online social support literature is focused on diagnosis and active treatment, interventions across the cancer continuum show promise, including screening [5,76].

One area where considerable work has been done is patient navigation, which represents an area that engages the person and multiple teams. In cancer care, patient navigation has long been used to facilitate patient access to timely and appropriate care [77]. Rooted in a community-centered approach to care coordination, the original goal of patient navigation was to reduce disparities in cancer outcomes by targeting efforts in the prevention and screening phases of the cancer continuum [77]. Since its inception, patient navigation has been shown to improve follow-up time between abnormal screening and diagnosis in a variety of other settings and populations, including in cervical, colorectal, and prostate cancers [77]. The concept of patient navigation has expanded to encompass many navigator roles and interventions across the cancer care continuum from prevention through survivorship and end-of-life care [77]. A 2011 review of patient navigation studies noted the increasing heterogeneity of patient navigator backgrounds. While navigators are still most commonly trained lay people from the target community, nurses, or private independent practitioners (http://www.medsavvyhealthadvocates.com), navigation programs have now been implemented with case managers, social workers, tumor registrars, and even peer cancer

patients serving in these roles [78]. The majority of studies on the efficacy of patient navigation have examined cancer screening rates as outcomes. Nine out of ten efficacy studies published between 2007 and 2010 found statistically significant effects of patient navigation interventions on screening rates or improved stage at diagnosis. For example, one patient navigation intervention achieved a 55% mammography rescreening rate compared to 1.5% in a control group, and another achieved a 27% colorectal cancer screening rate compared to 12% in the control group [78].

Patient navigation interventions have not been as consistently successful in other phases of the cancer continuum. A 2011 systematic review found that only two of seven identified studies on the efficacy of patient navigation interventions for patients in active treatment demonstrated significant differences in outcomes between groups receiving patient navigation and controls [79]. Individuals who received patient navigation during treatment for head and neck cancers reported improved satisfaction with care and emotional quality of life, and also had significantly fewer hospitalizations compared with those who did not receive patient navigation [79]. Among patients undergoing radiation therapy for cancer, those with patient navigators experienced significantly fewer treatment interruptions compared to those without navigators (3 fewer interrupted days, on average) [79]. In more recent work, patient navigation interventions in the active treatment phase have been reported to help patients address financial and communication barriers as well as transportation difficulties [80], and to increase the proportion of patients receiving recommended adjuvant therapy for breast cancer [81].

Differences in outcomes might, in part, be explained by differences in the groups targeted for patient navigation, and by the person in the role of navigator. For example, many studies of patient navigation in the active treatment phase of care use clinical navigators, such as nurses or case managers. Using clinical navigators who are part of the system of care may not be as effective as using lay navigators who are part of the patients' community. The use of community-based navigators has been a critical element of many successful patient navigation programs, and may help promote trust between patients and care providers in some communities [82]. In addition, patient navigation interventions may be most appropriate when targeted at groups who are likely to have problems accessing needed care or understanding treatment options [83]. One study, for example, found that having a clinical navigator reduced time between diagnosis and oncologist consultation significantly for elderly patients, but made no difference for younger patients [84]. Similarly, many successful navigator interventions have been implemented in communities with

historically low rates of participation in recommended screening and follow-up care, whether due to access, transportation, or other cultural barriers to receiving care [85,86]. Perhaps not surprisingly, then, studies of patient navigation interventions in groups that are not targeted based on their need for assistance overcoming barriers have not demonstrated the same substantial benefits [87]. A meta-analysis of patient navigation studies conducted between 2007 and 2011 determined that patient navigation did have a moderate effect in reducing treatment delays. However, these effects were not seen immediately, but only after the first 90 days of care [79,88]. In addition, the greatest benefit was seen in centers that had the most substantial delays in follow-up care preimplementation [89].

While the best approaches to implementing patient navigation programs and the most appropriate measures of their success are still under discussion, their potential to benefit care coordination and clinical outcomes is now widely accepted. Since 2011 the American College of Surgeons Commission on Cancer has required a patient navigation process for the accreditation of cancer programs [90]. As these programs develop, the potential of patient navigation to improve a variety of outcomes across the cancer continuum will become more clear.

Looking at HIT, there are many ways in which it could enhance and improve patient navigation programs. Evaluation of navigators' activities reveals that patient navigators generally spend a great deal of time gathering or documenting information in patients' electronic medical records, and work with a variety of individuals to plan care, including the patient, family and caregivers, community support services, and clinical providers [91]. HIT tailored to the needs of patient navigation programs would not only support navigators in performing their job duties, but also allow for large-scale data collection and analysis of the outcomes of such programs. Several such programs exist, such as OncoNav [92], NurseNav [93], and Cordata Oncology [94]. Most software offers some level of integration with commonly used EHR systems and, perhaps because of this integration, is designed primarily for clinical nurse navigators. However, some programs offer communication with patients and other care team members through web-based portals. Others offer "community navigation" features that can assist in implementing patient navigation programs and tracking community-wide outcomes across a system of care [93]. While few technology solutions have been developed specifically for community-based lay navigation programs, the Harold P. Freeman Patient Navigation Institute offers online training for lay navigators as well as mobile learning apps [95].

Outside of patient navigation there are only a few studies of care coordination across teams, particular those that engage family and community teams with

health care teams. One such study, an RCT, used technology supported communication "to assess the effects of an online symptom reporting system on caregiver preparedness, physical burden and negative mood" [96]. Metastatic or advanced breast, lung, and prostate cancer patients and their caregivers were recruited from five US cancer centers to participate in the Comprehensive Health Enhancement Support System (CHESS), an online symptom reporting and education tool. Both groups had access to the tool with one group having the additional Clinician Report (CR), which offers an alert function to clinicians about certain electronic patient-reported outcomes. Patients and caregivers in the CHESS+ CR group reported "less negative mood," which the authors conclude may suggest that they "experience less emotional distress due to the CR's timely communication of caregiving needs in symptom management to clinicians" [96]. This area is addressed more substantively in Chapter 10, "Advanced Cancer: Palliative, End of Life, and Bereavement Care."

Another study in progress involves an RCT of a Personal Health Network (PHN) which aims to demonstrate and evaluate a comprehensive platform for coordinating care during chemotherapy [97]. The PHN is a social networking platform delivered through either a tablet application or website to patients undergoing chemotherapy, their family members, nurse care coordinators, extended health care team, and community resources. The PHN includes the following functions:

- Health care, family, and community team members invited into an individual's PHN.
- Patient self-report assessment instruments and outcomes reported online. This and other instruments used at visits and in-between visits to monitor symptoms.
- Nurse care coordinator performed evidence-based protocols appropriate to the needs, symptoms, and requests of the patient.
- A shared care plan published to all members of the PHN.
- Care plan activities scheduled, assigned to members of the PHN, and tracked.
- Nurse care coordinator monitored care plan, with communication to physicians and other care team members as needed.
- Patient education materials, instructions, and plans delivered to individual and family team through the PHN library, with notification by voice/text message that resources are available.
- Communication among individual, health care, family, and community teams using voice/text messaging, audio/video calls within PHN, and reminders are pushed to participants.

Fig. 5.3 shows screenshots of the tablet application.

5.4.5 Shared Care Plans

A critical component of a care coordination program is a collaborative, accessible, and well-monitored shared care plan. Shared care plans have evolved as an approach to promote coordinated care for individuals with chronic diseases who have multiple providers involved in their care. Ideally, shared care plans should facilitate communication between health care and patient teams, across health care teams, and across time. Since the shared care plan is, as its name implies, meant to be used by multiple groups, its purpose is not only to provide traditional, clinical care planning, but also to promote self-management and patient engagement.

Despite its potential, shared care planning has not been extensively implemented or studied. A 2007 Cochrane review of shared care interventions found limited evidence that such interventions improved outcomes other than medication management [98]. Reviewers noted that relatively weak study designs and scant descriptions of the "usual care" received by control groups limited the ability to detect potentially important benefits of the interventions [98]. Major limitations of the reviewed studies included a lack of patient involvement (ie, care was shared between health care teams but not between health care and patient teams), and underuse of potentially helpful HIT support [98]. The Institute for Healthcare Improvement and Agency for Healthcare Quality and Research both provide links to shared care plans on their websites (http://www.ihi.org/resources/Pages/Tools/MySharedCarePlan.aspx, http://www.orau.gov/ahrq/sms_tool_06.asp?p=sms_home). In both instances, the care plans are patient-led. Although intended for use by all health care team members, these shared care plans are currently not integrated as part of the medical record, placing the responsibility for initiating and coordinating these documents on the patient. Research that tests the effectiveness of web-based shared care plans that have some level of interoperability with commonly used EHRs will provide important insight into the feasibility of using shared care plans to enhance care coordination for individuals with chronic diseases.

In cancer care, the survivorship care plan, a form of shared care plan, has been recommended as a specific approach to shared care planning to help improve the transition from active treatment back to long-term surveillance and survivorship care [99]. Survivorship care plans are addressed in greater detail by Beckjord et al. in Chapter 9 "Survivorship." However, there is still no consensus on the best way to implement these care plans. As with shared care plans in other chronic disease settings, HIT is both a current barrier and a potential future solution for effective implementation of cancer survivorship care plans. With a multitude of EHRs currently on the market, finding a survivorship care planning template

FIGURE 5.3   Personal Health Network for chemotherapy care coordination. (A) Members of the individual's Personal Health Network, (B) task view of shared care plan, (C) nurse care coordination symptom management protocol, (D) patient self-report instrument, and (E) self-management library.

FIGURE 5.3　Continued

that not only works for the oncology practice, but also allows for patient interaction and communication with other specialists and primary care providers who may use different EHR systems is a major challenge with no immediate solution [100]. However, promising pilot studies demonstrate that cancer survivorship care plans can be successfully implemented, at least in settings where providers and patients all have access to the same EHR system [101]. Integrating the survivorship care plan into an oncology practice's EHR allows for some information to be automatically populated, rather than manually documented by the oncologist, saving valuable time. Patients in the pilot studies generally felt the care plans were useful and easy to access. However, missing information about care that was received from providers outside the system was problematic [101]. Substantial resources are needed to implement survivorship care plans. Future research is critical, not only to demonstrate whether or not the benefits of survivorship care planning justify the use of these resources, but also to evaluate approaches that make their implementation more feasible [102].

5.5 OPPORTUNITIES FOR ONCOLOGY INFORMATICS AT THE POINT OF NEED

There are numerous opportunities to contribute to the improvement of oncology care coordination through HIT. First, there is a need for a comprehensive elicitation of HIT requirements for care coordination. There is a large gap in the understanding of the requirements for within person/family teams beyond instrumental support for activities of daily living. While most of the work has focused on the health care team and the EHR, we must move beyond the health care team and consider the requirements across multiple teams including the interactions among health care, family, and community teams as they interact around coordination of care for individuals. In considering these teams as a complete community around the individual, the multiple points of need become apparent as does the criticality of systems for organizing the varied and complex workflows across them all. This comprehensive view of care coordination would set the foundation for shared accountability in which patients are empowered and central to decision making throughout their life span.

HIT for integrated care coordination across a community is emerging, however, there are few comprehensive platforms that can support care coordination across the diversity of participants. An informal search led by one of the authors aimed at identifying and assessing commercial platforms involved companies known to the authors, an extensive web search, phone interviews, and system demonstrations (Kim, Lindeman, unpublished). Among the 25 systems reviewed, none provided adequate capabilities such as those described in this

chapter. Most were able to address health care team coordination with limited functions for patients such as a portal for results delivery and appointment scheduling requests. All were lacking functions for deeper person-centered engagement and coordination across multiple teams, which limits the potential to accomplish shared decision making and accountability. The findings from this informal assessment of commercial platforms is not surprising given the preponderance of published literature that addresses only the early stages of design and feasibility.

Perhaps a function of the nascency of the field, there is little evidence of efficacy of HIT-enabled care coordination. However, the field would be enhanced if studies paid attention to effectiveness of implementation even when conducting early stage investigations. Without effective implementation of a technology-enabled care coordination program, the potential efficacy of the intervention may never be realized. This would suggest the greater use of user-centered design of both HIT and the intervention itself including all potential participants, and the measurement of implementation and care coordination variables.

HIT is a critical enabler of emerging care models such as the Oncology Care Model and the Learning Healthcare System for Cancer that depend upon effective care coordination to improve health care, cost, quality, and ultimately population health. There is great opportunity for informatics to collaborate with clinicians, patients, and all individuals who participate in the complex and complicated processes of coordination to design, implement, and evaluate HIT solutions to address the challenges we face in aiming for those outcomes.

LIST OF ACRONYMS AND ABBREVIATIONS

CCM Chronic care model
CHESS Comprehensive Health Enhancement Support System
CMS Centers for Medicare and Medicaid Services
CR Clinician Report
CWCC Community-wide care coordination
EHR Electronic health record
EORTC European Organization for Research and Treatment of Cancer
ePRO Electronic patient-reported outcome system
ESRA-C Electronic Self-Report Assessment-Cancer
HIT Health information technology
IOM Institute of Medicine
IPC Integrated patient care
PCM Patient Care Monitor
PHN Personal Health Network
PHQ-9 Patient Health Questionnaire-9
PHR Patient health record
PICC Peripherally inserted central catheter
QLQ-C30 Quality of Life Questionnaire-Core 30
RCT Randomized clinical trial

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