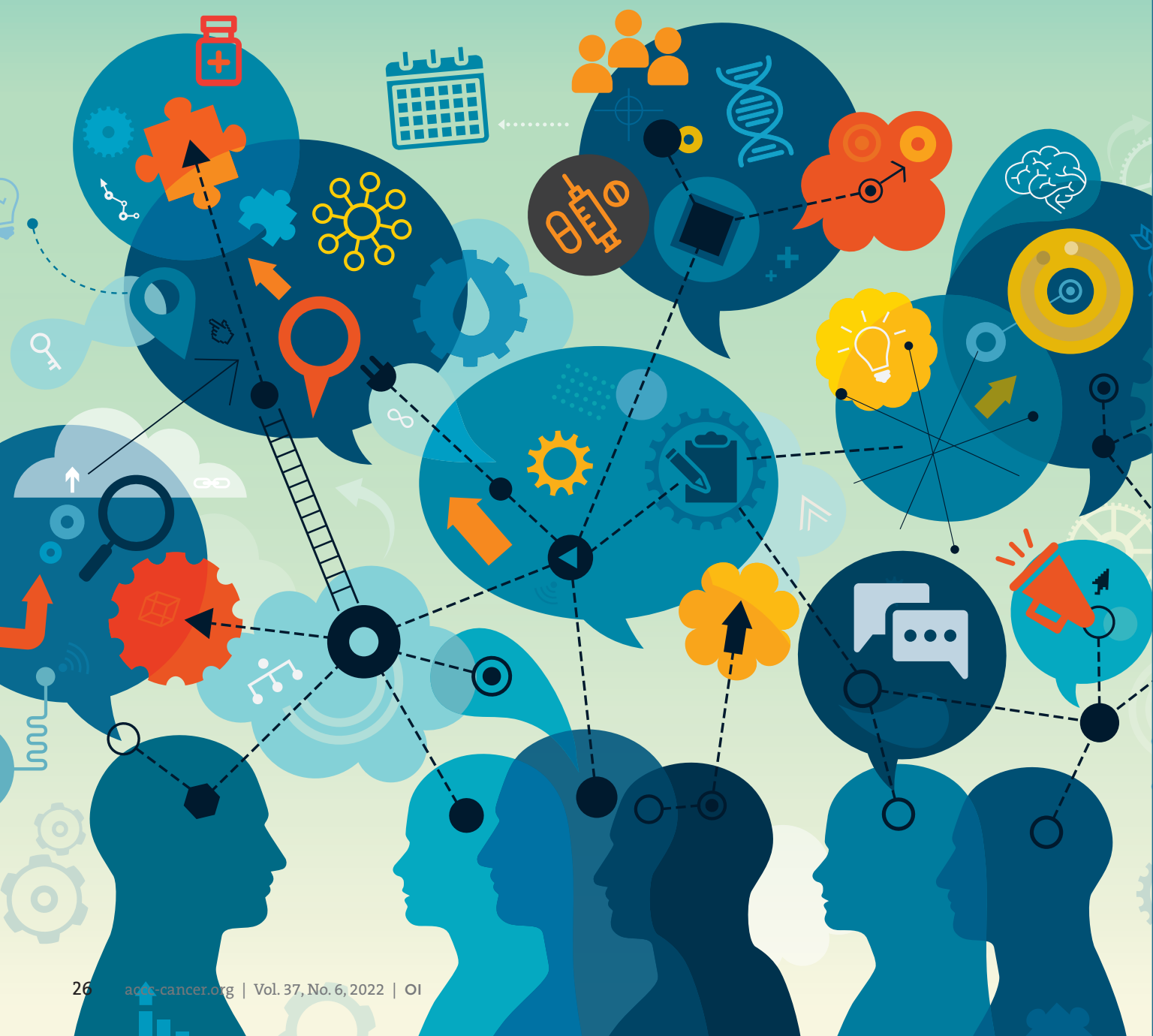


Improving Cancer Care Teamwork:

Five Patient-Centered Strategies to Strengthen Care Coordination



This article outlines five common challenges experienced by patients with cancer and their caregivers and provides potential solutions for overcoming these obstacles. Authors share discussion topics and tools that providers can use in patient discussions to empower patients and caregivers to participate in shared decision-making and care management.

To ensure that patients receive safe, quality, and equitable cancer care, provider efforts must be coordinated efficaciously.¹ Care coordination entails deliberate, organized care activities between multiple parties to facilitate the appropriate delivery of healthcare services.² When cancer care is coordinated effectively, meta-analytic evidence suggests that care efforts lead to improved outcomes (e.g., patient experience and quality end-of-life care).³ Conversely, poorly coordinated cancer care results in a host of negative outcomes, including adverse drug interactions, unnecessary tests and procedures, disparate information, and higher healthcare costs.¹ Further, inadequate coordination can result in miscommunication, conflicting advice, delays in care, and conflicting or incompatible treatments.⁴ These issues can ultimately cause substantial psychological distress in patients.⁵ Put simply, subpar care coordination results in suboptimal processes and outcomes.⁶

Unfortunately, subpar care coordination is not uncommon due to the vast network of providers involved in cancer care, with care coordination challenges observed at both the health system and clinician level.⁷ Treating cancer requires nursing, medical, and allied professionals—from diverse care settings—to work together over extended periods of time due to the multitude of tests and treatment modalities (surgery, adjuvant chemotherapy,

and radiotherapy) available.⁸ In fact, providers are dynamically affiliated with multiple hospitals, networks, and insurance plans but are not necessarily affiliated with each other.⁹ Some studies estimate that approximately 10 different provider types with different backgrounds and training are involved in cancer care,^{10,11} and others posit that as many as 28 providers work interdependently to provide quality cancer care to a single patient.^{12,13}

Arguably even more critical is that patient records and data are not integrated between multiple clinic locations and across health information technology systems.⁹ Given the diverse nature and involvement of providers, medical institutions, and healthcare plans, an optimal care coordination model remains elusive, resulting in extensive, heterogeneous care coordination models.^{14,15} This problem will likely be further compounded given that care coordination becomes more difficult for patients with comorbidities, and there is an expected increase in an aging population with comorbidities.^{16,17}

Due to the heterogeneity of models and the difficulties in coordinating care, patients with cancer are often tasked with coordinating their own care.¹⁸ Because patients and caregivers typically do not have any formal training, they may struggle with navigating the complex landscape of cancer care delivery.

With this foundation in mind, this article offers providers prescriptive guidance that can be discussed with patients and caregivers who are faced with the daunting task of coordinating and managing their own care. Specifically, we outline five challenges that patients with cancer and their caregivers often experience and provide potential solutions for overcoming these obstacles. It is hoped that understanding these challenges and being equipped with strategies to overcome barriers will result in patients and caregivers who are knowledgeable, engaged, prepared, and assertive regarding their own cancer care.

Challenge: For patients with cancer, managing their own care can be complex.

Solution: Patients with cancer should organize and maintain a log of important information, dates, and follow-up plans.

Medical appointments inherently involve abundant information; patients arrive with various concerns, and providers deliver considerable details and instructions. Although patients with cancer experience multiple concerns, many remain unspoken or unrecognized, resulting in reduced patient satisfaction and poorer outcomes.^{19,20} Additionally, providers often have extensive follow-up plans to guide patients through their care, but patients may inadequately execute these follow-up plans. Lack of adequate communication between specialists and primary care providers surrounding follow-up plans has been identified by oncology physicians as the major reason why patients with cancer experience delays and “fall through the cracks” in terms of treatment.¹³ Poor compliance to prescribed care plans or even unaddressed concerns and unasked questions may be attributable to patients’ lack of comprehension around complex medical information; however, these behaviors may also be attributable to failures in prospective memory (i.e., intentions to act in the future).²¹

A seemingly obvious but underutilized strategy to adequately answer questions, address concerns, and record pertinent care information is for patients with cancer and their caregivers to keep a log of questions, record the answers to their questions, and take notes during patient and provider discussions.²⁰ A potential question for patients to ask, especially when multiple providers are actively involved in their care delivery, is, “Can you please make sure my primary care physician receives this information, or is there a way that I can get this information to them?” Maintaining and using an organized log of questions and answers has been demonstrated to increase patient-centered care by ensuring that patients’ primary concerns are addressed.²² Moreover, the literature shows that incorporating plans into a patient-held record improves understanding by patients and families.²³

One example of a tool that can be used by patients to keep track of their own care and follow-up plan is the personal health record. Updated by patients and/or caregivers, these records can help them keep track of appointments, diagnoses, medications, and similar information pertinent to their care history and trajectory. Personal health records can be paper- or electronic-based and may have varying levels of integration with hospital-maintained electronic health records. For a review of personal health record system architectures, see Roehrs et al.²⁴ These tools are noted to be particularly important for improving care during emergency situations and transitions in care when transferring to new providers and/or in multidisciplinary care team situations.²⁵

Given the complexity of cancer care and multitude of providers involved, it stands to reason that these benefits could be particularly notable for patients with cancer. Although the benefits of personal health records have been thoroughly modeled²⁶ and their utility supported by government agencies like the Office of

the National Coordinator for Health Information Technology,²⁷ many barriers hinder widespread adoption (e.g., technological issues related to interoperability of systems, patient factors affecting use^{28,29}). Several studies cite provider- or organization-initiated education and emphasize the increasing usage of personal health records.^{25,29,30} Personal health records that are available for use will vary over time and across providers, but providers should educate patients with cancer about personal health records and, where possible, educate patients and caregivers on specific systems that may be available. Patients or caregivers should bring a copy of their personal health record to all appointments irrespective of clinical specialty. For providers, confirming the accuracy of these records and assisting patients in revision of their personal health record when necessary is critical.

Challenge: Often, patients with cancer do not feel heard.

Solution: Open communication between patients and providers should be encouraged and cultivated.

In addition to health record organization, patients and clinicians need to make a collaborative relationship with effective communication a high priority and a core value in cancer care delivery.^{20,31} In a seminal review, Ong et al. identified three basic functions for communication in cancer settings: 1) exchanging information, 2) fostering treatment decisions, and 3) facilitating interpersonal processes to create a positive relationship between the patient and provider.³² Despite the functionality and importance of communication, earlier work indicates that the physician-patient relationship is one of the most common difficulties in medicine.³³ Although challenging, patients and clinicians need to speak capably and comfortably about various facets of clinical care.³⁴ A 2020 National Cancer Survey by the American Society of Clinical Oncology revealed a lack of these types of conversations; for example, only 26 percent of patients discuss end-of-life care with their provider(s).³⁵

A significant amount of research demonstrates that the quality of medical practice and treatment outcomes depend on positive interactions between providers and patients.^{22,36,37} Simply put, open and effective communication is essential. Poor communication can lead to high unnecessary cost burden, with one study suggesting that communication inefficiencies cost U.S. hospitals \$12 billion annually.³⁸ Poor communication has also been related to refusal, noncompliance, and abandonment of treatment,³⁹⁻⁴¹ as well as late relapse in cancer when it leads to treatment non-compliance.⁴² Additionally, poor communication has a negative influence on symptom management, treatment decisions, and patients’ experiences and quality of life.⁴³ In contrast, effective communication can lead to many benefits, including increased treatment adherence and compliance, adjustment of expectations, self-regulation, and coping,⁴⁴ which can result in increased return-to-work rates and improved function.³⁷ Effective patient-provider communication is especially important in the treatment of chronic diseases, such as cancer, which necessitates regular encounters with medical professionals and complex healthcare decisions.⁴⁵

Prior to an appointment, providers, patients, and caregivers can elevate their encounters by arriving with a mindset of understanding, respect, and empathy.⁴⁶ Though all parties contribute to an encounter, patients with cancer can leverage specific tools and actions to facilitate better communication with providers. During the appointment, patients should start by setting concrete boundaries and expectations early in their appointment.⁴⁷ Being clear about expectations allows the provider to know what the patient hopes to accomplish during the current interaction, and it also fosters strategies for improving future encounters. Additionally, one systematic review suggests that patients should seek confirmation that they have the correct understanding from their providers and encourage their providers to repeat their exact words.⁴⁸ In addition to setting expectations, patients can leverage specific phrases that are useful for uncovering information and expanding communication. For instance, Barrier et al.⁴⁹ recommends employing the phrase “what else?” to aid in acquiring deeper information and building positive relationships. Beyond the actual encounter, patients can engage in reflection. Specifically, patients should reflect on what aspects went well and what aspects went poorly⁴⁷ and share this information with providers at their next appointment.

Challenge: Patients with cancer do not always see themselves as integral to their health.

Solution: Patients with cancer should assert themselves in their care and care decisions.

Even though healthcare professionals certainly play a role in promoting patient involvement in clinical care and there are numerous research efforts aimed to target improvement in this area (e.g., Bergeson et al.²³), it is imperative that patients advocate for themselves and seek to participate in the decision-making process alongside their providers. Bergeson et al. posited that as care becomes more complex, patient involvement becomes increasingly paramount, given the potential consequences.²³ Patient disengagement may lead to preventable illness, suboptimal outcomes, and wasted resources.⁵⁰ Researchers have shown that individuals who play an active role in their care achieve better outcomes. In fact, Griffiths et al. demonstrated that greater patient involvement during consultation leads to greater satisfaction and, perhaps more important, better health.⁵¹ The benefits of patient involvement can be linked to Bandura’s social cognitive theory of behavior.⁵² Essentially, by getting involved in their own care, patients may grow increasingly confident in their abilities to manage their care (self-efficacy), which may result in greater likelihood that their goals will be achieved (outcome expectancy).⁵¹

One way for patients to be more engaged and involved in their care is to be more assertive. Research has long demonstrated that assertiveness may change provider behavior.⁵³ Andersen et al. found that patients who were more assertive actually received more interventions, compared to their less assertive counterparts.⁵⁴ Some explain the relationship between assertiveness and care with Street et al.’s ecological theory of patient-centered commu-

Goal setting and action plans are integral elements within self-management programs that enable patients to effectively steer their care and cope with their illnesses.⁶⁵

nication, which states that multiple levels should be considered (e.g., mutual interactions between clinicians and patients, social context, and clinical context).⁵⁵ When the interaction between patients and clinicians is such that patients exhibit assertive behaviors and clinicians counteract with facilitative behaviors, that interaction fosters ongoing participation and engagement from patients.⁵⁶ Patients can demonstrate assertiveness by making requests, asking questions, and expressing opinions.⁵⁷ As with everything, balance is important; providers should discuss the benefits and potential side effects of all evaluations and interventions with their patients to avoid unnecessary and/or harmful care activities.

Challenge: Maintaining motivation is often difficult for patients with cancer.

Solution: Patients with cancer should establish an actionable plan to remain in control.

Cancer is not simply a physiological disease; it has psychological ramifications as well.⁵⁸ Studies have repeatedly demonstrated a link between cancer and depression.⁵⁹ In fact, depression and anxiety are more common in patients with cancer, as opposed to the general population,⁶⁰ and as many as 70 percent of patients being treated with chemotherapy report experiencing depression.⁶¹ As a result of these psychological effects, it can be challenging for individuals with cancer to maintain their motivation. In some populations, a lack of motivation is associated with development of cancer information overload.^{62,63} As the name suggests, cancer information overload is a negative disposition that occurs when patients become inundated with information pertaining to their diagnosis and care plan.⁶² Consequently, patients who lack motivation and experience this type of overload may have difficulty processing information, which may ultimately detract from knowledge. Such confusion and gaps in knowledge lead to poor retention, recall, and adherence to recommendations.^{63,64}

Goal setting is one mechanism patients can use to facilitate motivation, self-management (i.e., the patient’s ability to organize, plan, and support their own care), and behavior change.²³ Goal setting serves to motivate and provides a foundation for patients to care for themselves and remain in control of their health. Goal setting and action plans are integral elements within self-management programs that enable patients to effectively steer their care and cope with their illnesses.⁶⁵

...having having another person at an appointment can reduce the burden on the patient because the family member can function as a scribe or record keeper to update documents like a personal health record, while the patient focuses on their interactions with the provider.

Gardner et al. use the SMART approach to assist patients with goal setting.⁶⁶ This framework includes five components that individuals should adhere to while creating objectives: specific, measurable, achievable, realistic, and time bound (SMART). Being specific requires participants to provide details in terms of exactly how, when, where, and what they are going to do. For instance, if a patient's goal is to achieve medication compliance, they could specify what medication(s) they need to take, when they will take it, where they will take it, and how they will take it. The measurable aspect is indicative of how the participant will be able to track their goal progress and completion. Continuing with the medication example, a patient could use a tracking tool to log their progress. The achievability element involves considering the participant's abilities and resources to determine whether the individual can realistically achieve the specified goal. To determine whether the medication goal is achievable, one should evaluate the patient's ease of access to the medication, associated memory aids to remind the patient to take the medication, and the patient's cognitive ability to understand the context of the medication's use (where and how to take it). The realistic piece of this framework is heavily influenced by the previous element—an individual's ability to complete a goal depends upon their abilities, resources, and potential challenges. To ensure that the medication compliance goal is realistic, one would assess the patient's relevant abilities, resources, and anticipated obstacles to compliance. The final aspect of the SMART approach is time bound, and this has to do with the time frame that is being associated with the goal. This will largely depend on the goal that is being set. For instance, the period in which the patient is seeking to comply with the medication regimen can range from the short to long term, depending on the time frame they need to take the given medication.

Challenge: Support is key for patients with cancer to maintain active involvement in their care.

Solution: Patients with cancer should seek support in peer groups, among their family, and through community resources.

Cancer is an all-encompassing illness, making it difficult to deal with it alone. Some outlets that are available to patients, where

they can seek support, include patient support groups, family members, and educational programs to aid in managing one's self-care. Coping with and managing a chronic illness like cancer is cognitively and emotionally taxing, necessitating support.⁶⁷ According to Jerant et al., patients identify low family support and lack of awareness of support resources, such as self-management programs, as some of the most frequently noted barriers to active self-care.⁶⁸ Patients who have a strong family support system seem to cope with their conditions better than those who do not.⁶⁸ Thus, speaking with a clinician or researching online for self-management support services and programs is beneficial. Patients who are involved in these types of programs speak very highly of the information and emotional support these services provide.⁶⁸ Patients with familial and caregiver support also report greater satisfaction with their care coordination.⁶⁹ A good first step to get better support for a patient with cancer is for them to request the contact information of social workers and/or patient advocates at their cancer program or practice.


There are many additional avenues of support for patients with cancer. One option is support groups, which can lighten the emotional load that family members might not understand by providing experiential insights. Several studies have found evidence touting the benefits of patient-to-patient mentorship.^{70,71} In fact, such mentorship demonstrates improvement in well-being, self-efficacy, behavior change, and health outcomes.⁷² Importantly, support groups can be face-to-face or virtual, with those who are supported by social media experiencing many of the same beneficial outcomes.⁷³ Another option for support is designating a family member to help patients navigate their care. Because family members have intimate knowledge of the patient, family members may be able to ease communication between patients and their providers.⁷⁴ If patients have expressed difficulty communicating with their providers, family members can act as interpreters, especially when patients cannot effectively communicate their needs or communicate at all.⁷⁴ Even for patients who can communicate, having another person at an appointment can reduce the burden on the patient because the family member can function as a scribe or record keeper to update documents like a personal health record, while the patient focuses on their interactions with the provider. Clinicians are uniquely qualified to provide support as well because patients do not always know the correct questions to ask.⁷⁴

Finally, the internet has a wealth of useful self-management educational programs.⁷⁵ As with any information provided online, patients should consider the credibility of the sources and check with their provider to ensure their validity and applicability. One integrative review found that such self-management programs are helpful for individuals with cancer.⁷⁶ Another systematic review found that clinicians see self-management programs as desirable.⁷⁷ These programs empower patients and their families to accomplish their own goals.⁷⁸ One theory is that these programs increase patients' self-efficacy by increasing their engagement.⁵¹ Specifically, self-management education can provide patients with the necessary tools to recognize issues with their treatments or the disease itself and take initiative to pre-emptively solve problems.⁷⁵

(Continued on page 32)

Concluding Thoughts

Quality cancer care necessitates that a network of providers all seamlessly coordinate their efforts. However, due to a multitude of issues (e.g., confusion in roles and responsibilities, barriers to multidisciplinary team meetings, and poor communication during care transitions),¹³ effective care coordination is often not achieved and the “gold standard” of care coordination remains largely unanswered. Consequently, the responsibility of care coordination can sometimes fall upon patients and caregivers. Even though this responsibility should not be solely placed on patients and their caregivers, the current state of cancer care remains in crisis.⁷⁹ Until substantial change is made, patients and caregivers need tools and resources—like the five solutions presented in this article—to effectively coordinate their care. Figure 1, page 31, is a replicable tool for providers to share these strategies with their patients.

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