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Emerging Challenges in Advanced Cancer Care: Opportunities for Enhancing Patient-Centered Communication

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Introduction

As diagnostic and treatment options for cancer continue to evolve, cancer care has witnessed exciting progress. In particular, precision oncology, which uses biomarkers to identify targeted treatments for cancers, has improved outcomes in some cancers such as breast cancer, colorectal cancer, lung cancer, and acute myelogenous leukemia [1]. However, even as prognoses for some cancers and some populations have improved, cancer continues to pose enormous and life-limiting challenges to many patients. The sad reality is that many diagnosed with cancer today will face an advanced and recurrent or metastatic disease. An estimated 606,520 people diagnosed with cancer will die from the condition in 2020 [2]. While the 5-year survival rate for all cancers is estimated to be around 67%, the 5-year survival rates are much lower for cancers of the pancreas (9%), liver (18%), lung (19%), and esophagus (20%) [2]. People with advanced cancer have varied unique needs, from managing treatment-related side effects to psychological symptoms, strained social relationships, and financial burden. High-quality communication in and outside of the clinical care context is needed to identify and address the needs and priorities of patients and their loved ones. Research into how to foster patient-centered communication is of critical importance to improve cancer care and the quality of life of all those with advanced cancer.

Many of the myriad communication challenges in advanced cancer have been documented in the literature; for some, promising opportunities exist to improve and enhance patient-centered communication. To begin with, as illustrated by the term, “financial toxicities” of cancer, cancer-related costs are a major barrier to quality of life and psychosocial well-being, with negative impacts exacerbated for patients who have battled cancer for a long period of time. Patients’ concerns over limited insurance coverage or surviving relatives’ financial strains, as well as the lack or opaqueness of financial information, require patient-centered financial literacy interventions and improved cost communication. Another set of challenge in advanced cancer care stem from shifts in technologies and communication platforms. Increasing reliance on technology in oncology—such as the use of online health portals, telemedicine, mHealth/Apps for symptom monitoring and reporting, and Internet for

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health information—has added demand on patients to access and use technology while also offering new opportunities for patient-centered communication.

Coinciding with technologic evolution, social media has become ubiquitous. Patients and caregivers routinely access cancer-related information on social media, yet such information is often of mixed quality and accuracy. As the health information landscape is increasingly challenged by the spread of misinformation (e.g., falsehoods, myths, and unproven “miracle cures”), greater demand on digital and health literacy is placed on patients and caregivers [3–5]. This trend necessitates improved patient-centered communication to empower patients to access online cancer information and mitigate the impact of misinformation.

Moreover, patients facing advanced cancer often require significant caretaking from family members and other loved ones serving as informal caregivers [6]. Caregivers’ well-being, information needs, and communication preferences are other emerging areas in advanced cancer care. Innovative interventions are poised to improve and integrate communication across patients, caregivers, and the healthcare team and to offer support for informal cancer caregivers.

Finally, while frontline therapeutics have introduced new treatments options, these new modalities may not be available or accessible to many patients. Consequently, communication challenges can ensue when some patients, upon learning about the promises of precision medicine, have unrealistic optimism or face increased confusion and uncertainty regarding their prognosis and care plans [7]. These challenges have inspired research to improve prognostic and goals of care communication as well as ways to ascertain patient values and preferences.

In addition to the key areas outlined above, a major “elephant in the room” since early 2020 is the additional challenges to care brought on by the COVID-19 pandemic. COVID-19 has upended every aspect of life, including enormous impacts on health and quality of life for those with advanced cancer. For example, concerns over virus exposure are preventing hospital visits, social isolation limits meaningful social connections, and the threat of dying without seeing loved ones has made a difficult prospect even worse. Unique health communication opportunities to support cancer patients through this crisis are beginning to be explored and implemented.

In summary, care for patients with advanced cancer is facing new and unique challenges today, bringing on new opportunities to enhance patient-centered communication. This chapter reviews critical components of each of the above-referenced issues. In each section, an overview of issues pertaining to communication will be discussed, followed by a sample of recent interventions as exemplars of opportunities to inform and improve patient-centered cancer care.

Financial Burden in Advance Cancer: Promoting Cost Conversations

People with advanced cancer often undergo intensive and costly treatments which generally undermine their financial security. Those who are underinsured, low-income, or racial and ethnic minorities are especially vulnerable to financial burden as a result of a cancer diagnosis [8]. About a third of people with advanced cancer report financial distress to be even more severe than physical or emotional distress [9]. The experience of financial burden and distress among people with advanced cancer remains under-addressed [10], despite evidence of impact on stress, quality of life, treatment decision-making, and care utilization [9, 11]. Furthermore, a longitudinal study found that patients experiencing financial hardship had, counterintuitively, over three times higher likelihood of receiving intensive and costly care [12] which can induce additional stress and suffering.

Cost conversations between patients and healthcare professionals are one critical communication opportunity to alleviate stress and help patients with advanced cancer make treatment decisions that are aligned with their goals and values. To date, patients' preferences for cost conversations far outstrip their actual occurrence. Though most cancer patients report wanting to discuss costs with their doctors and most oncologists recognize the importance of out-of-pocket costs, cost conversations remain rare [13]. For providers' part, most oncologists (84%) report considering out-of-pocket costs in treatment recommendations, yet fewer than half (43%) actually discuss costs with their patients [14]. A major barrier to cost discussion is the overall lack of transparent, accurate, accessible information about cancer costs [15, 16]. Ninety percent of surveyed physicians reported that education, web-based resources, or expert guidelines on cost-effectiveness of therapies would be useful [17]. Even with knowledge barriers addressed, providers and patients alike may feel uncomfortable about discussing treatment costs [18, 19]. Some patients worry that discussing financial challenges may cause them to receive suboptimal care [19]. Further, in general, patients lacking financial security are less likely to feel heard and understood by their healthcare providers, suggesting open, patient-centered communication about costs of care may be a key aspect of quality care in this population [20].

Key characteristics of effective cost discussion and how to implement them are beginning to be studied. Resources to support cost communication are especially salient in advanced cancer care, when trade-offs between length and quality of life tend to have significant cost ramifications and patients' preferences, values, and concerns are particularly important to ascertain [21]. In response to pressure for increased transparency in care costs (e.g., out-of-pocket costs to treatment), some health plans have developed price estimator tools for their members [22], and there is some effort to embed similar tools in the electronic health record (EHR) for physician use (https://www.cms.gov/newsroom/fact-sheets/medicare-advantage-and-part-d-drug-pricing-final-rule-cms-4180-f). The effects of these tools on cost conversations need to be measured so they can be adapted and integrated into care to support effective patient-centered cost conversations and care.

Future research efforts to support cost communication in advanced cancer may include educational tools for patients and providers, team-based care models that support patients in navigating health insurance, as well as patient-centered communication when cost conversations occur. Some newly developed tools and interventions are notable in their inclusion of cost communication: for example, one tool for people with diabetes provided a tailored list of local and national resources related to diabetes management and other social services; it was shown to significantly increase the frequency of cost conversations [23]. A primary care setting's provider training on cost communication strategies also increased the frequency of such conversations [24]. An app designed for cancer patients to support initiation of cost conversations tailored to their individual information needs and demographics has demonstrated promise in improving patients' self-efficacy and supporting cost conversations [25]. Increasing the frequency of cost conversations is an important first step. Future development and evaluation of such tools to include assessment of quality and efficacy of cost communication can help address a critical aspect of advanced cancer patients' well-being.

Information Technology in Cancer Care: Realizing Its Potential and Addressing Its Pitfalls

Rapid expansion of web-based electronic health (eHealth) and mobile health (mHealth) tools is both promising and concerning. Increased access to the internet can empower patients and caregivers to access health information and actively participate in their care. Telemedicine and patient portals can facilitate communication with healthcare providers between visits and support connections between care teams, enhancing continuity of care for advanced cancer patients [26–30]. However, there are concerns that technologies are not effectively integrated into clinical care. For example, technology may hinder effective patient-provider communication by limiting nonverbal signals such as eye contact, physical proximity, touch, or introducing frustrating delays or lags due to connectivity problems [28, 31].

Scholars have cautioned that technology ought to supplement, but not replace, in-person communication in cancer and that technology-mediated communication may not be appropriate for all patients [28, 32]. Indeed, realizing the benefit of eHealth tools requires access and technology literacy that some lack. Evidence suggests that disparities persist in the use of internet for health-related reasons. Older adults, racial/ethnic minorities, and those with lower incomes and education levels are all less likely to use technology for health-related reasons [33–35]. Individuals from these groups are also more likely to receive advanced cancer diagnoses. Potentially adding to disparities in technology use, providers may hesitate to offer eHealth-based services to patients they believe are too old or too ill to participate [36]. Narrowing these disparities requires patient-centered communication to support patients' meaningful and sustained use of potentially valuable technologies.

Palliative care is one promising context where technology (e.g., telehealth) can support advanced cancer care. The American Society of Clinical Oncology (ASCO) guidelines recommend that palliative care be delivered alongside oncology care for all advanced cancer patients [37]. Technology can help patients and caregivers connect and interact with providers, particularly when patients have limited mobility, or live in regions where access to palliative care remains low [38]. In recent systematic and scoping reviews [31] assessing the impact of video-based palliative care interactions, video consultations were found to approximate face-to-face interactions better than phones or emails. Video facilitates nonverbal communication and offers providers insight into patients' home lives, helping them respond with empathy and build rapport with patients [28, 38]. Moreover, in one qualitative study of home-based palliative care, patients described feelings of trust, closeness, and relief associated with telehealth consultations [39]. Other studies found video-based palliative care consultations to decrease anxiety for rural cancer patients [40] and to reduce hospital admissions and emergency care near the end of life by allowing remote system assessment and management [41].

Another promising use of technology in the advanced cancer context lies in symptom management: symptom monitoring devices and communication technologies can facilitate patients' and caregivers' self-management and facilitate communication of worrisome symptoms to providers. For example, the Patient Remote Intervention and Symptom Management System (PRISMS) is a smartphone app designed to track chemotherapy side effects and alert clinic nurses when symptoms exceed preset levels [42]; such tools have helped empower patients and improve patient-provider communication [43]. The use of another self-management intervention, *Webchoice*, was associated with lower symptom distress, anxiety, and depression than usual care [44]. Similar online symptom reporting systems aimed at caregivers have been associated with lower self-reported negative mood for caregivers [45] and symptom improvement for patients [46].

As reflected in the above discussion of palliative care and symptom management interventions, quality of life is a key treatment goal in caring for patients with advanced disease and/or poor prognosis. This is a domain in which technology can support assessment and clinical utilization of patient-reported outcomes on quality of life and psychological distress [44, 47–49]. Moving forward, addressing barriers to patients' adoption and the use of technology will be critical to ensuring that technologies meaningfully contribute to improved patient outcomes, including quality of life. Moreover, we need systems-based clinical trials on the effectiveness of technology-based interventions [50, 51].

Cancer Communication on Social Media: Providing Support Online and Mitigating the Impact of Misinformation

Another domain in which technologic evolutions have affected cancer care and communication occurs in the now ubiquitous social media. Patients, caregivers, and survivors routinely access information about cancer through the Internet and social networking platforms. On the one hand, social media has enabled rapid health information sharing and meaningful support for patients and caregivers, helping to meet their informational and social-emotional needs by connecting with loved ones or others with similar experiences [52]. Patients and survivors connect with other individuals who may have faced similar challenges through online communities. These connections may be useful in improving psychosocial, behavioral, and physical health outcomes [53]. Along with the increased use of social media, more cancer care interventions are being developed through the use of private Facebook pages and other social media platforms—for example, an ongoing study is examining the utility of using social media to support family caregivers caring for seriously ill cancer patients [54]. Such use of social media platforms overcomes geographic and other logistical constraints to enable critical communication among cancer caregivers.

However, the use of social media also introduces growing challenges to patient-centered communication. The online ecosystem may perpetuate the spread of and endorsement of misinformation, including cancer-related myths, falsehoods, and even unproven "miracle cures" [4, 55]. For example, an analysis of breast cancer-related Pinterest pins showed only 22% made a factual claim, whereas 51% of posts were found to have false or inaccurate claims [56]. As another example, misinformation regarding cannabidiol (CBD) and cancer is highly prevalent on the platform GoFundMe, with false claims that CBD is an effective curative therapy for cancer being widely shared and no action taken by the site to stop the spread of misinformation [57]. Unfortunately, many of the automated algorithms used by social media platforms help to create information silos, whereby individual's feeds are curated based on their previous activity, meaning that those exposed to health misinformation may not see alternative content and echo chamber effects are reinforced [5]. As a result, people can easily find information that affirms their biases or emotions and avoid information that challenges incorrect ideas. Furthermore, social media feeds are often emotionally provocative, which contributes to widespread sharing and beliefs that are resistant to rational appeals to address misinformation [58].

Addressing and mitigating the impacts of exposure to false or misleading health information is complicated and requires thoughtful attention beyond simply correcting falsehoods. Surveillance of misinformation and its impacts and development of adaptive and effective interventions to foster health and digital literacy and counter misinformation are critical starting points. Providers and healthcare systems can help patients, and caregivers evaluate the quality of cancer information and reduce the harms of exposure to misinformation [5]. One tangible effort is to reinforce health and science literacy through tools and support systems that help patients navigate the digital environment and assess the quality and trustworthiness of information they encounter. Health/cancer care organizations, clinicians, and scientific experts also have the responsibility of making credible and trustworthy cancer information more accessible. Perhaps the most effective solutions are at the broader systems level: engineering an information ecology that more effectively promotes exposure to credible content (e.g., up-ranking on search engines, providing endorsement to medical and scientific expert entities) and trustworthy sources while diminishing the impact or shareability of non-credible content. These efforts would require social media platforms to partner with researchers and practitioners in developing and implementing policies for curbing misinformation spread. Ultimately, in order to achieve patient-centered communication, we have to go back to the perspectives of the patients and "meet them where they are" by matching accurate and useful cancer information with their preferences and information needs as well as sources they trust.

Cancer Caregiving: Supporting Informal Caregivers Through Communication

Our discussion thus far has focused on the person diagnosed with cancer. However, cancer affects the whole family and social network. Furthermore, for those afflicted with advanced cancer, many responsibilities of day-to-day care and decision-making fall on informal caregivers. The physical and psychosocial-emotional toll on caregivers and disruptions in life are enormous. In 2020, an estimated 48 million US adults provided care and support for an adult facing a serious health condition. Of these individuals, 23% reported caregiving has negatively impacted their health [59]. The number of informal caregivers will continue to grow as an increasing number of individuals face multiple chronic conditions. Cancer caregivers face unique struggles and challenges: they often have to supply intense care in a short time period and are asked to preform highly technical tasks without proper knowledge or support [6]. Moreover, the experiences of cancer patients and their caregivers are often intertwined, and their physical and psychosocial-emotional well-being are often interdependent; the relationship between a cancer patient and their caregiver highlights the importance of communication—between patients and caregivers as well as among patients, caregivers, and healthcare providers—in order to improve patient-centered cancer care. Effective communication can address psychosocial needs, ensure adequate and informed supportive care, and enhance relationships and emotional well-being for both caregivers and patients.

To date, communication interventions have supported caregivers solely or family/couples (dyadic communication)—for example, singular discussions about goals of care or decision aids for treatment options. Multilevel interventions (i.e., communication efforts that target patients, caregivers, as well as the healthcare team) focusing on underserved populations are critically needed. For example, interventions should focus on integrating caregivers into the care delivery system through communication that attends to the needs of both patients and caregivers, assessing caregivers' needs and empowering them to be an active part of the cancer care [6]. However, this is still a nascent area of research and practice, and more practice-based research is needed to integrate all members invested in a patient's care to facilitate communication and improve quality of care.

Precision Oncology: Supporting Patient-Centered, Informed Decision-Making

Cutting-edge cancer research has improved treatment options and efficacy in recent years. In particular, genetics/genomics-informed treatments such as targeted therapies have provided many patients more effective treatment and life-prolonging promises. However, while precision oncology has garnered much excitement in the cancer community, for many patients afflicted with advanced illness and poor prognosis, precision oncology may be unattainable or may even promote false optimism. In some cases, genetic testing or genetically informed or molecularly targeted treatments are not available; in other cases, genetic testing may not yield helpful or conclusive results or provide actionable information to inform treatment plans. For instance, a review of patients who underwent next-generation sequencing for hereditary cancer showed that only 9% of patients had positive results for a pathogenic or likely pathogenic variant [60]. Patient-centered clinical communication is critical in order to ensure patients' informed decision-making and goal-concordant care, whether results of genetic tests are positive, negative, or inconclusive.

One key challenge to patient-centered communication in the practice precision oncology lies in helping patients and caregivers understand and manage uncertainty, such as in making treatment decisions when genetic testing results are inconclusive, or when the utility of targeted therapies is unclear. Furthermore, "tools for tailoring treatment will demand a greater tolerance of uncertainty and greater facility for calculating and interpreting probabilities," [61]. In the case of genetic testing for breast cancer, for example, while testing is becoming more prevalent, hereditary breast cancer accounts for only a small component of breast cancer care, and oftentimes the results of genetic testing can be difficult to interpret or act upon. An estimated of 5–15% of BRAC mutations are classified as variants of uncertainty significance (VUS). For racial/ethnic minority populations such as Hispanics and African Americans, VUS rates are even higher [62, 63]. Receiving VUS results can increase patients' and family members' worries and stress because this result is not considered either pathogenic or benign, with no clear guidance regarding whether or how to act based on these results.

Part of helping patients manage uncertainty entails addressing their understanding of prognosis and care preferences. Unrealistic optimism of one's prognosis is prevalent in patients with advanced diseases, so improved patient-provider communication is critically needed [7]. In fact, research indicates that many patients diagnosed with advanced stages of cancer do not accurately understand their diagnosis and that their prognostic understanding differs from their providers—for example, one study of patients' terminal cancer found that one third believed their cancer to be curable [64]. Similar findings show that although providers believed they had discussed all the key information with their patients, some information was missing or was misunderstood by their patients. Significantly, often providers were found to neglect discussing prognosis [65]. One main reason for this discordant understanding is suboptimal patient-provider communication; for instance, providers often use vague and ambiguous language when discussing prognosis. It is important to highlight that patient-provider communication in the USA is often worse for ethnic and racial minority patients. A study reviewing communications between oncologists and patients self-identifying as Black, African American, or Afro-Caribbean found that, while prognosis and treatment goals were discussed, oncologists were often unclear and used confusing terminology and almost never used survival estimates [7].

Attending to patients' emotions is also critical in the context of genetically informed treatment discussions. Besides the stress and emotional burdens associated with a cancer diagnosis, there are documented psychological impacts of genetic testing and return of genetic results [66–68]. Communication efforts need to ensure patients' psychological needs are met when discussing genetics and in all treatment decisions. Patients must be informed of both the potential benefits and the limitations of treatments [69] so that unrealistic optimism can be minimized.

In implementing precision oncology, additional health literacy and numeracy demand (e.g., understanding and acting upon genetic testing results, managing uncertainty, understanding prognosis, discussing goals of treatment and preferences for end-of-life care) are being placed on patients. Explaining the science will require time and effort on the part of both providers and clinical care systems. Similarly, the implementation of genetically informed precision oncology requires that providers elicit more complex personal information (e.g., family history of cancer) from patients. To date, although precision medicine is frequently articulated in healthcare systems, public knowledge and understanding of this new field is still limited and requires the health systems' attention. Additionally, patient concerns regarding the sharing of genetic information need to be addressed in order to enhance trust and engage patients in promising precision approaches [70]. Precision medicine has the potential to offer many benefits, but it will require strong and evidence-informed communication between patients and their providers.

Challenges of the COVID-19 Pandemic on Advanced Cancer Care

We would be remiss in writing this chapter not to discuss the significant disruptions the 2020 COVID-19 pandemic has caused for patients with advanced cancer and their loved ones. To start, many oncology clinical appointments and even scheduled treatments such as chemotherapy or radiation have been delayed or cancelled, wreaking havoc to care and adding stress. Multiple sources of data point to significant decrease in oncology office visits, increase use of telemedicine, and sharp decline in cancer screening overall in 2020 [71, 72]. Such delays in cancer screening and diagnosis are most likely to increase cancer morbidity and mortality in the near future. When in-person clinical visits do occur, concerns over virus exposure and transmission and adoption of preventive measures (e.g., mask and other PPE wearing, social distancing, inability to have physical touch for comfort or connection) can further disrupt communication by impairing patients' and providers' abilities to read and respond to important nonverbal cues. Symptom tracking and management have also been disrupted as a result of missed or ineffective clinical visits and diagnostic and monitoring tests. While absolutely necessary for community protection against the virus transmission, as the pandemic rages on, the long-term effects of these restrictions, quarantines, and overall isolation are beginning to show in cancer patients. It is important to acknowledge that these conditions will continue to impact cancer care, potentially becoming the "new normal" and deserving careful attention [73].

In addition to the disruptions and restrictions in clinical care, fear and other negative emotional impacts of the pandemic are enormous. For those who are very ill and may be near the end of life, not being able to see loved ones or have fulfilling social and emotional connections in person can be especially difficult, and some may fear dying alone. Caregivers as well as healthcare professionals struggle to support cancer patients as so many traditional means, such as in-person support groupsX, arts therapy in the clinics, prayer and faith-based gatherings, in-person counseling from psychologists, social workers, and chaplains, have all become either unattainable or difficult to carry out.

In this challenging context, achieving patient-centered communication requires multilevel and innovative approaches. New and novel ways of providing health care include telemedicine, use of video conferencing for visits and mobile Apps for symptom tracking and management. Just at the outset of the pandemic alone, according to a report from the Center for Medicare and Medicaid Services, there was a 350-fold increase in the number telehealth visits per week for Medicare beneficiaries, from an estimated 2000 telehealth visits/week in February to 1.28 million in April [74]. Indeed, as in-person medical visits became limited, many started receiving their care via telemedicine which has been greatly enhanced during the pandemic [75]. Telemedicine has rapidly expanded due to the necessity of virtual visits, though concerns about its effectiveness remain. One small silver lining is that telemedicine seems to fulfill some of the objectives of in-person outpatient visits effectively, though, as described above, it is not a replacement for in-person consultation and care [75].

Going forward, and as we begin to improve our management of the pandemic through vaccines and mitigation practices, it is important to continually acknowledge, evaluate, and address the impact of this global crisis on cancer patients, especially those who are most vulnerable due to their socioeconomic and racial/ethnic backgrounds or due to their advanced diseases.

Conclusion

Patient-centered communication is a critical aspect of cancer care. In the context of advanced cancer, and facing evolving challenges in oncology care delivery, a few critical areas warrant special interventions focusing on communication. The growing financial burden of cancer care necessitates better and more integrated cost communication between patients/caregivers and providers. The increasing reliance on technology, from access and use of online patient portals to other means of online interactions, places increasing demand on patients in order to effectively navigate their care. Ensuring patient-centered technology-mediated communication, whereby technology augments interpersonal interactions, instead of replacing or worsening them, is critical, especially for underserved segments of the population, such as those with limited English proficiency, health literacy, or technologic literacy. Outside of clinical care, patients are increasingly accessing cancer information on ubiquitous social media, meaning they are exposed to information of mixed quality and accuracy, including medical misinformation that would negatively affect their knowledge, attitudes, and behavior. Fostering trust in credible sources of cancer information and mitigating the impact of misinformation exposure present another priority in patient-centered communication. As precision oncology gains prominence in cancer care thanks to medical research advances, it is particularly important that communication efforts focused on patients with advanced diseases help them deal with uncertainty, avoid unrealistic optimism, and make informed and goal-concordant care decisions. Finally, 2020 is tragically marked by the historic COVID-19 pandemic and health disparities, and this public health crisis has undermined medicine's ability to provide optimal care for those with advanced cancer. We outlined some opportunities to ensure patients, and their needs remain central to cancer care and communication. In sum, this challenging time calls on communication scientists and practitioners to endeavor on translational work, using social science to inform patient-centered practice and affect change, even in small and incremental ways.

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