Reflection of Help-seeking Behavior in Oncology through Community Engagement

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Abstract

Cancer care is not only about the medical treatments people receive but also about the support that helps them through the journey. In this study, we surveyed twenty-five people (eight patients and 17 supporters) to learn more about the challenges they face when seeking help and the ways they cope during a cancer journey. Patients often talked about difficulties like misinterpreting symptoms or dealing with the impact of COVID-19, while supporters pointed to a need for more information and resources. Both groups highlighted the importance of access to treatment, patient-centered care, and steady emotional and social support. Patients were less comfortable than supporters in raising concerns with oncologists, showing the need for supporters to be the bridge to stronger communication and trust. Many participants described leaning on emotional coping strategies, while also wishing for clearer information and guidance to help them make decisions. These stories show common patterns in how people seek help, what makes them feel supported, and where there are gaps that can be addressed by their community of support. By listening to these voices and reflecting on their responses, we can work with the community to create resources and programs to increase successful outcomes during a cancer journey using community-participatory approaches.

Keywords: Help-seeking behavior, Coping strategies, Cancer care journey, Patient support systems, Patient-provider communication, Community-engaged Research

Introduction

According to the Indiana Cancer Consortium, two out of every five Hoosiers will experience cancer in their lifetime; as of 2019, Indiana's cancer mortality rate (adjusted for age) was 11.4% higher than the national average (Indiana Cancer Consortium, 2021). In 2017, the most reported cancers in Indiana included breast (31.4%), prostate (21.3%), and lung (males: 15.2%; females: 13.6%) (Indiana Cancer Consortium, 2021). Importantly, many factors shape an individual's response to symptoms that may be related to cancer. Childhood trauma, or adverse childhood experiences (ACEs), is associated with co-occurring anxiety and depression, which could influence help-seeking, adherence to treatment, quality of life, and coping (Coupe et al., 2024). Additionally, social needs (i.e., food security, access to healthcare, housing, transportation, etc.), also referred to as social determinants of health (SDH), can influence how a person responds to symptoms and health behavior (Andrejko & Katrichis, 2022). Thus, attending to the individual social, emotional, and mental needs of cancer patients is critical to improving the quality of care and outcomes for all Hoosiers.

Hoosiers from different racial and socioeconomic backgrounds have varying cancer-related beliefs based on ACEs, experiences of medical racism, and more. These beliefs about cancer can influence how individuals respond to symptoms that may be related to cancer. Research suggests that individual differences can shape whether barriers are service-related, emotion-related, or both (Moffat et al., 2016; Oshiro et al., 2022). Service-related barriers include physical barriers to accessing care, such as difficulty getting into an oncologist and a lack of health insurance. Emotion-related barriers, potentially resulting from ACEs or unresolved medical trauma, include fear of being a burden on healthcare staff and difficulty discussing symptoms with the medical team, among others. These emotional and social conditions can affect how easily someone gets care, how quickly they are diagnosed, how they make treatment decisions, how they cope, and their overall outcomes.

Effective patient-provider communication, both verbal and nonverbal, plays a crucial role in the quality of treatment and overall patient satisfaction. Research shows that physician bias based on race and ethnicity exists in cancer care. This bias can be unconscious or intentional and can affect how doctors communicate with and treat patients. Surveys of oncologists suggest that people may be treated differently within the healthcare system depending on their race or ethnicity (Schatz et al., 2022). For example, studies have found that unconscious bias can lead to less supportive communication and poorer pain treatment for Black patients compared to white patients (Fiscella et al., 2021). Patients have also reported that issues impacting communication include a need for increased empathy from oncologists and more personalized treatment information (Anderson et al., 2021). Physician bias can inhibit this essential communication, preventing sensitive, patient-centered interactions and productive help-seeking behavior during the cancer journey.

Study Background

This reflection is based on a small, community-engaged pilot study that explored the challenges people face when seeking help for cancer and how patients and their support networks cope. By listening directly to community members and their experiences, we identified healthcare needs that can guide a larger community-based participatory study in the future.

Methodology

We created separate surveys for patients and support members using Qualtrics, an online platform. The surveys included a mix of closed-ended (i.e., multiple choice, select all that apply) and open-ended (written response) questions drawn from well-established questionnaires about cancer awareness, coping strategies, and patient needs, along with basic background questions. The surveys can be found through Indiana University Indianapolis ScholarWorks (Dimon, A. & Kimble-Hill, A., 2024).

Participants included U.S. citizens who were 18 years of age or older with a history of cancer (for patients only) and who were recruited through social media outreach (LinkedIn and Facebook) and grassroots flyer campaigns on the Indiana University Indianapolis campus, coffee shops, and hospitals in surrounding areas. Emails and targeted social media campaigns were also distributed to religious and cultural organizations to recruit patients and supporters. Providers within the Indiana University Health System were invited to participate via email. This study was approved by the Indiana University Institutional Review Board (protocol #23844) before data were collected in 2024.

Indiana has a lower population of historically underrepresented populations compared to many states in the United States, with the largest of those groups reported in the 2023 census to be Black/African American (10.4%), Hispanic/Latino (8.8%), and two or more races (2.5%) (U.S. Census Bureau). Furthermore, there is a significant socioeconomic challenge where 12.3% of Hoosiers were reported as living in poverty (U.S. Census Bureau). This study was designed to target participants from those populations so we could better understand the challenges underserved people face when accessing cancer care. Furthermore, this study focused on recruiting participants based on cancer diagnosis from Indiana, where 403.7–614.6 out of every 100,000 African Americans (female-male) and 335.8–362.1 out of every 100,000 Hispanic/Latine (female-male) individuals are diagnosed with all types of cancer each year (Swanson et al., 2011). As these communities make up a smaller part of the Central Indiana population, it further limited the potential patient and support participant base thereby limiting this work to being a pilot study.

The final sample consisted of eight patients and 17 support members. Of the 25 respondents, the majority identified as White (68%), followed by Black (24%), Hispanic, Latino, or Spanish (4%), and Asian (4%). Three patients and 11 support members responded to the open-ended questions.

We used SPSS (version 29.2), computer software, to compare closed-ended survey responses across groups. Two members of the research team reviewed written responses and identified common themes. The goal was to better understand the experiences of patients and their support members to better meet patient needs and improve satisfaction and health outcomes.

Summary of Important Findings

Help-seeking Barriers

When asked to select which help-seeking barriers inhibited patients and support members from seeking care, 62% of patients selected ‘other’ compared to 29% of support members. Patients in our sample mentioned “misinterpreting symptoms” and “Covid” as obstacles to seeking cancer care. The Theory of Planned Behavior explains that people make health decisions based on what they believe will happen if they take action, what they think others expect of them, and how confident they feel in their ability to do it (Bosnjak et al., 2020). These patient responses could be due to a lack of cancer-related knowledge to accurately assess the consequences of delaying care or due to medical mistrust around which symptoms will ‘count’ as severe enough to justify seeking help. They also demonstrate how environmental factors can decrease their level of confidence, thereby hindering help-seeking.

Understanding what prevents patients from seeking care is critical to determining the best support to assist them during the cancer journey. Both patients and support members believed it was important for healthcare teams to adopt culturally sensitive, patient-centered care approaches to enhance the quality of care and improve health outcomes for all individuals, especially marginalized Hoosiers. For example, one patient suggested, “Being more watchful of the patient’s symptoms after certain procedures have been conducted.” Picker’s Eight Principles may serve as an effective tool for patients and supporters to evaluate whether the care provided aligns with patient needs. These principles outline factors that influence patient care, including clear patient-provider communication, ensuring continuity of care, encouraging social support, suggesting effective treatment options, considering the social-emotional and physical needs of patients, and engaging in shared decision-making (Picker, 2023). Knowing these principles can help patients and support members advocate for patient needs to receive higher-quality care.

Patient Needs

All participants were asked questions about their perspectives on which social needs are important to discuss during the cancer journey. However, patients and support members were instructed to respond slightly differently, so the frequencies are reported separately for each group. Patients most frequently prioritized discussion about financial concerns (71%) and support systems (43%). Support members also prioritized discussion of the patient's support system (65%) and mental capabilities (65%).

When asked to explain which social needs they felt were important to discuss with healthcare providers during their cancer journey, both groups mentioned having access to resources and treatments as important knowledge for Hoosiers. For example, a support member stated, "I wish there was a handbook that helped you with resources you can take advantage of and general information." The emphasis on resources, access to treatment, financial consideration, and other factors in patient and support responses highlights disparities in access to quality cancer care. Associations between SDH and cancer screening disparities show how the patient's social background guides help-seeking behavior, the quality of care, and health outcomes (Venkataramany & Sutton, 2022). Patients and support members should advocate for resources that remove structural barriers related to patient needs to enhance care quality and health outcomes. Engaging in these efforts has the potential to increase patient engagement in policy reform that goes beyond what physicians can achieve alone. Interventions should address these patients' needs and reduce structural barriers to quality care.

Patient Comfortability

Feeling comfortable with treatment team members can be crucial to patient health outcomes, such as continuity of care (Sharkiya, 2023). When asked which team members, patients, and supporters were most comfortable addressing concerns with, patients (25%) felt significantly less comfortable with oncologists compared to supporters (71%). Research shows how attention to communication practices is critical to improving the comfort of patients with cancer. According to the National Cancer Institute (2025), oncologists should share health-related information using general language, attend to the emotional needs of patients, and involve them in treatment decision-making to enhance patient comfort. Since oncologists play a critical role during the cancer journey, support members and researchers must identify more specific ways to improve patient comfort in addressing concerns with their oncologist, especially among marginalized patients.

With the importance of patient comfortability in mind, we asked patients and support members what makes them feel comfortable with their healthcare team. Both groups discussed that attention to patient care requirements (e.g., avoiding medical jargon and proposing treatment alternatives) made them more comfortable raising concerns with healthcare providers. For instance, one support member remarked, "Able to form a great relationship with the Oncologist -— that still exists." This quote highlights the importance of building rapport with the treatment team to enhance comfort and open communication, leading to stronger relationships and better health-related outcomes.

Factors Influencing the Patient Experience

Patients and support members were asked to select all factors that improved or would have improved their satisfaction with their care. Patients were most likely to associate their satisfaction with having a physician with "a friendly and open demeanor" (50%), who was ""easy to ask questions of" (50%), and who "effectively answers questions" (50%). Support members were also likely to connect their satisfaction with having a care team that is "easy to ask questions of" (52%), but unlike patients, they also prioritized having a care team that "spends time with them" (58%).

Patients and support members were asked to identify what made them feel satisfied with their care. Both patients and supporters felt most satisfied when it was easy to ask their care team questions. Patients felt more strongly that it was important for care members to be able to effectively answer questions, while support members valued when healthcare members spent time with patients. Individual patients and caregivers have particular communication preferences related to target (e.g., provider, peer), content (e.g., emotional support, cancer-related information), style (e.g., language, in-person or virtual), and timing (e.g., prior to treatment, end-of-life) (Li et al., 2022). Understanding the communication preferences of these groups can inform interventions to improve supportive care in the oncology setting, leading to higher patient satisfaction.

In addition to what patients and support members valued about the healthcare team, participants were also asked to explain additional resources that would have eased their cancer journey. Patients mentioned that attention to their needs and social support would have been helpful resources. For example, one patient stated, "A Nurse Navigator who didn't stop responding to my phone calls after the first month would have been nice." Contrarily, support members mentioned that health education and resources (i.e., housing and food vouchers) would have benefited them during the cancer journey. For example, one support member explained, "I don't feel [clinicians] did a good job letting us know about organizations that can help you out. There still may be resources I don't know about." Understanding these different needs can guide the development of coping interventions tailored to each group across the entire care continuum.

Coping Strategies

Understanding coping strategies is critical because they directly influence how patients and supporters manage stress, navigate care, and engage with the healthcare system. Our participants most often described emotion-focused strategies such as seeking emotional support (patient 50%, supporter 53%), looking for something good in what is happening (patient 50%, supporter 41%), and prayer or meditation (patient 50%, supporter 47%). This reflects a general decrease in patterns in which African American, Hispanic, and Indigenous communities relied on religious and community-based coping (Assari, 2014; Culver et al., 2004) that have more recently been overshadowed by other important coping mechanisms such as secular or alternative coping strategies, which could be just as important for younger or less religious subpopulations (Chatters et al., 2008). Careful consideration of these approaches can buffer distress, stigma, mistrust of healthcare, and limited access to accurate information (Conner et al., 2010), but should be a part of a holistic strategy to guide patients to the use of problem-focused strategies during the cancer journey, like strategic planning or seeking information to inform decision making (Carver et al., 1989). More work is necessary to understand the role of strong social support and sensitive patient navigation in addressing cancer patients' mental health as a means to reduce delays in treatment. Therefore, interventions must prioritize coordinated, team-based, and culturally sensitive approaches that incorporate trusted community voices to strengthen positive coping strategies when cancer patients are help-seeking.

Limitations

This study has several limitations. First, it was a small study with uneven participation across groups, which means the findings may not apply to everyone. We also did not work directly with community partners, which may have contributed to lower participation from some racial and ethnic groups. Limited funding meant we could only offer a raffle incentive, which may have reduced the number of people who chose to take part. Finally, patients and support members did not provide the same amount of written feedback, which limited our ability to fully understand each group's experiences.

Conclusions

Before this study, little research had explored barriers to cancer-related help-seeking, and none focused specifically on the experiences of Hoosiers. This study started to address that gap by centering the voices of Hoosiers and highlighting how help-seeking experiences, coping, patient needs, comfort levels, and overall oncology care experiences can vary across patients and support members. The findings point to meaningful differences that can help guide future education and outreach efforts tailored to the needs of each group. Sharing these results in clear and accessible ways may also promote more open conversations and strengthen communication between patients and healthcare providers, particularly in communities that have been historically underserved.

Reflections and Lessons Learned

This study reinforced the importance of listening directly to community members to better understand the challenges they face when seeking cancer-related care. Building on these insights, future studies will use community-participatory approaches that actively involve community partners in shaping research questions, methods, and educational materials. Working alongside communities to co-create resources for patients, support members, and healthcare providers may help encourage better patient-provider communication practices to improve comfortability, coping, and improve cancer health outcomes. Ongoing research should continue to explore how social position, coping tendencies, social determinants of health, past medical experiences, and trust in healthcare systems influence how people seek support and cope during the cancer journey. Together, these efforts can inform practical, community-informed interventions that strengthen supportive care and promote better outcomes for patients and their support members.

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