Chapter 2

Outreach for Unmet Needs in Cancer Care

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ABSTRACT

Despite significant medical advancements leading to personalized cancer treatments, breakthroughs are underutilized due to fragmentation within medical systems and the unmet needs of patients, especially those in rural areas. The founders of Cancer Help Desk (CHD), a non-profit organization, recognized the need for a virtual navigation model to expand patient access to personalized oncology care, regardless of their location within the U.S. CHD created a survey to understand how patients and caregivers perceive their cancer care and validate the need for the CHD virtual navigation model, utilizing oncology nurses, PhD-level molecular scientists, and experts in cancer diagnostics to deliver patient-centered care. The survey was administered by students from Bentley University, who obtained IRB approval. Over 1,000 support group representatives in 50 states received the survey by email, resulting in 139 responses. Respondents expressed unmet needs regarding psycho-emotional challenges, health system issues, communication barriers, and finding credible resources to make informed decisions. The responses validate the urgent need for virtual navigation services to support biomarker testing, clinical trial access, and financial resources for people dealing with cancer. More sustainable navigation models that address disparities and access to quality cancer care should be supported in the future.

DOI: 10.4018/979-8-3693-5400-1.ch002

INTRODUCTION: INDIVIDUALS WITH CANCER HAVE UNMET NEEDS

Over the past few decades, significant advances in early detection and cancer treatment options have helped more people become long-term cancer survivors (Miller et al., 2022; Sakr et al., 2023). Still, a cancer diagnosis can create many challenges for patients and their families as medical interventions and subsequent adverse effects can interfere with quality of life. Proactive support services are needed to address the many difficulties encountered, such as:

- Psycho-emotional needs: e.g., these can be exacerbated by unanswered questions about getting the best care possible.
- Health system needs: e.g., coping with insurance and financial responsibilities.
- Information, communication, and logistical needs: e.g., there can be confusion in understanding testing and treatment options.

The primary goal of any comprehensive oncology care support service is to address the specific needs of patients across health promotion, active treatment phases, survivorship, and palliation. Patient-centered care affects patients' self-efficacy and supports their quality of life (Elkefi & Asan, 2023). In recent years, more attention has been paid to improving care for patients by tracking metrics that are meaningful to support counseling, decision-making, and preparedness for treatments (Ribeiro et al., 2023). A patient-centered approach is needed to offer an effective, customized protocol addressing the circumstances of each patient (Epstein & Street, 2007; Mead et al., 2021)

The initial step towards optimizing tailored supportive cancer care involves identifying patients' and families' most prevalent areas of need (Alsbrook et al., 2022; Maguire et al., 2015). In comparison with the general population, there is an increased perception of unfulfilled needs for mental health care among cancer survivors (Ji et al., 2021). One study asserted that the services that are most lacking are in the psychological and emotional realms, as well as deficiencies in information concerning the healthcare system itself. Certainly, understanding the diagnosis, symptoms, and treatments can lessen the emotional toll (Springer et al., 2024). Survivors also experience psychosocial problems after treatment, such as anxiety, depression, fear of recurrence, and difficulties with employment (Mead et al., 2021; Willems et al., 2016).

Unsurprisingly, patients cannot obtain all the information they need from web-based resources. Confusing medical jargon and terminology remains prevalent online. Most patients without prior knowledge of oncology or biology have concerns about misinformation and seek guidance to determine the credibility and relevance of the information they Google. Also influencing the capacity to assess health information is psychological and physical distress and fatigue. Again, patient-centered interventions are needed to facilitate this emotional and intellectual journey (Hyatt et al., 2022).

Patients in Rural Locations Face Additional Challenges

Only 3% of all medical oncologists practice in rural areas, but 20% of US citizens reside in those provincial regions (Cornelius et al., 2024). Over 70% of all the counties in the US do not have any medical oncologists practicing within their boundaries (Kenamond et al., 2022). Not surprisingly, patients living in urban settings with academically affiliated medical centers are more likely to be enrolled in clinical trials (Ebrahimi et al., 2024). Also, because cancer radiation services often require prolonged

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