
A Parallel Journeys Perspective on Technology-Supported Depression Care for Patients with Cancer

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Abstract

Depression is common but under-treated in patients with cancer. Although support for management of co-morbid cancer and depression has been proposed through integration of psychosocial care into cancer services and through technology to support such care models, challenges remain in designing appropriate and usable technology interventions that meet the needs of the patients and their care team. Because patients with co-morbid cancer and depression struggle to navigate between their cancer care and psychosocial care journeys, traditional psychosocial approaches and mental health technologies need to be adapted to these experiences. In this workshop position paper, we describe our research designing technology to support depression care for patients with co-morbid cancer and depression through use of a *parallel journeys framework*. We propose that the design of mental health technology ecosystems should consider the multiple care journeys that an individual is navigating and present design implications for discussion in this workshop.

Author Keywords

cancer, depression, patient journey, technology

CCS Concepts

•Human-centered computing → Human computer interaction (HCI); •Applied computing → Consumer health;

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Introduction

Depression is a common challenge in patients with cancer, and yet it is severely undertreated. A majority of patients do not receive effective depression treatment, despite depression being associated with higher mortality and with decreased adherence to cancer treatment. Patients in rural areas especially lack adequate access to depression treatment, due to a limited supply of behavioral health providers (BHPs) or psychiatrists to deliver evidence-based treatments and on-site mental health services. Digital behavioral health technologies create new opportunities to improve access to health services and expand the reach of evidence-based practices beyond clinical settings, but standalone patient-facing digital treatments are less effective and have higher attrition when lacking support from BHPs. Although integrated behavioral health care [1] has been recommended and implemented in various health care settings (e.g., cancer, primary care, geriatric), and although several technology solutions have been proposed to extend and enhance such care practices, there remain challenges in designing such technology to be adaptive and personalized to meet the needs of the patients with co-morbid chronic conditions and their care team.

To identify technology design opportunities to support depression care in cancer settings, we conducted interviews with 29 stakeholders (patients, BHPs, medical providers, administrators) and contextual inquiries with 8 BHPs at three different cancer centers. Our qualitative study revealed that patients with cancer and depression experience various phases of a cancer care journey [2] in parallel with their psychosocial care journey. We observed that patients struggle to navigate between these two journeys and that conceptualizing cancer or depression as separate care journeys was insufficient for characterizing this complex care context and thus limiting in the design of

supporting technologies. As a perspective for discussion in this workshop, we propose that the design of mental health technology ecosystems should consider the multiple care journeys that an individual is navigating.

A Parallel Journeys Perspective

Although depression is a common co-morbidity in patients with cancer, *when* and *how* they co-occur varies across patients depending on a patient's cancer diagnosis, treatments and progression, physical and emotional conditions, and their personal and environmental factors surrounding their cancer care journey. Our earlier work [3] introduced the concept of a *parallel journeys framework* as a conceptual design framework for examining two simultaneous care journeys (i.e., a cancer care journey and a depression care journey). Using this framework, we: (1) observed that cancer care journeys and psychosocial care journeys interact and sometimes even compete, and (2) identified challenges unique to this complex care context that occur at the intersection of two journeys.

Patients with cancer hesitated to report depressive symptoms, sometimes to avoid creating a distraction for the care team or sometimes because they felt pressured to appear strong. Patients often deprioritized their depression care and skipped or cancelled their initial appointments with BHPs. Patients undergoing acute cancer treatments may disengage from depression care due to weakened physical condition and due to fatigue from treatment and the strenuous care process. A general lack of documentation of depression treatment plans and assignments also compounded with cognitive impairment brought on by treatment (i.e., "chemo brain") to contribute to decreased adherence and engagement in depression care. Patients who develop depression after active cancer treatment were often required to manage their own depression.

Because cancer places high logistical burdens on patients, BHPs in cancer centers spent much of their time addressing urgent patient navigational needs (e.g., financial, transportation, housing) instead of their underlying depression. Without appropriate screening processes in place for identifying patients at risk for depression, BHPs were often pulled into managing patients in active crisis, a non-ideal situation for thorough psychosocial assessment or for bringing patients into depression care. High demand and added stressors from active cancer treatment present challenges in ongoing depression treatment, requiring BHPs to be flexible and accommodating (e.g., conducting sessions in infusion suites, temporarily disengaging from active depression care). Beyond active cancer treatment, BHPs were under-resourced to provide continued care (e.g., for patients who live far away from the cancer clinic) or to provide appropriate transition plans.

Technology Design Implications

In our research examining this challenging patient population, we identified missed opportunities that allow patients with cancer and depression to fall through the cracks and receive less than ideal or no depression care. Some challenges are addressable through technology, such as remote self-assessments, digitally translated evidence-based psychosocial interventions (EBPIs) and psychoeducation materials, or tools for patient tracking, management, and communication. At a surface-level, these technologies can seem obvious for improving general depression care. However, by taking a *parallel journeys* perspective, we were able to more saliently observe the specific issues encountered by patients with co-morbid cancer and depression. Such observations helped us prioritize and adapt specific functionalities and design opportunities to address the needs of patients

at various phases of a cancer care journey and to reduce cancer-specific barriers to depression care. In this workshop position paper, we highlight two design implications for discussion of technology-supported depression care for patients with cancer.

Supporting changing care contexts

Unlike traditional psychotherapy with regularly scheduled sessions with BHPs, patients with cancer and depression may develop depression and engage in depression care at different phases of their cancer care journey, thus changing the context in which depression care may take place. Patients may have more clinic visits during initial diagnosis and information seeking phases, with sessions with BHPs tacked onto existing oncology visits. Patients in active treatment may receive depression care while receiving chemotherapy in infusion suites or may be too sick from treatment side effects to receive depression treatment. Patients who are sequestered at home to recover from cancer treatment may prefer remote sessions. Remote self-assessments and digitized EBPIs can be helpful when in-person sessions are difficult to arrange or when patients are receiving lengthy treatments, but they can also be used to facilitate and augment in-person sessions. Technology support for depression care should thus be flexible in support for various touch points and care contexts.

Supporting shifting patient priorities and needs

Patients often deprioritize mental health care by normalizing depression as an obvious side effect or by putting off depression care when they are overwhelmed with cancer information, decisions, treatments, or navigational burdens (e.g., finance, transportation, housing). Patient values and goals often shift as they navigate their cancer care journey (e.g., getting through treatment, getting back to normal, rebuilding relationships), as do underlying causes

of depression (e.g., unemployment, end of life planning). Lack of documentation and frequent changes to stressors also distract patients from their original goals and treatment plans, creating additional challenge for BHPs to redirect patients to their ongoing treatment. BHPs must account for these shifting priorities and pull from a repository of tools and techniques (e.g., problem-solving, mood tracking) to meet patient needs while maintaining a steady course of primary depression treatment (e.g., behavioral activation) and monitoring progress towards achieving patient goals and positive outcomes (e.g., reduced PHQ-9). Technology support for depression care should thus track changes in patient values and priorities at various phases of their cancer and depression care journeys. Such support can inform the management or adaptation of appropriate tools and techniques and can monitor progress toward patient goals and in their depression treatment plan.

Discussion

We look forward to workshop discussion of two key topics following from our research.

First, informed by our research with patients with co-morbid cancer and depression, we believe there is an opportunity to apply the parallel journeys perspective to other contexts, such as chronic diseases (e.g., diabetes, arthritis), transitions in life (e.g., pregnancy, developmental stages), or multiple roles (e.g., employee, parent, caregiver). Although we observed well-known barriers to depression care (e.g., stigma), the most notable contributor to deprioritization of depression care was the competing resources demanded by multiple journeys. Instead of technology that only addresses a diagnosed mental health disease, we envision mental health technology that may negotiate an appropriate level of engagement in consideration of an individual's competing demands.

Second, in contrast to a monolithic mental health technology, we believe suites of flexible tools and techniques can provide personalized care and support for patients undergoing multiple care journeys and can help BHPs adapt their care practices. It remains challenging to organize and deliver many piecemeal technology solutions, ranging from online self-guided psychotherapies and mindfulness apps to therapy bots.

We look forward to the CHI 2020 Workshop on Rethinking Mental Health Resources for discussions of our *parallel journeys* perspective, its benefits and limitations, and technology design for depression care.

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