

Informing a Future Clinician-Led Virtual Reality Experience Through Oncology Caregivers' Pre-Treatment Preparation Experiences

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Abstract

Purpose. The purpose of this study was to 1) describe oncology caregivers' pre-treatment preparation experiences, 2) elicit their feedback about approaches to improve the pre-treatment preparation experience, and 3) explore the potential use of visual aids into the pre-treatment education experience that will inform future clinician-led VR experiences. **Methods.** Using a qualitative descriptive design and convenience sampling technique, adult oncology caregivers were recruited to complete anonymous demographic and qualitative surveys posted on social media sites (i.e. American Cancer Society, Facebook, and LinkedIn) and a university supported community research registry (i.e. Pitt + Me). Demographic data were calculated using descriptive analyses (frequency and percentage) and qualitative data were analyzed using an inductive coding approach. **Results.** Participants (N=18) were mostly female (n=13, 72%), white (n=14, 78%), married (n=14, 78%), and had a college degree or higher (n=16, 89%). They categorically ranged in age from 26 years to above 65 years, with the majority (n=11, 61%) between 36-55 years of age. Caregivers described the cancer information as overwhelming and in need of additional side effect information and emotional support. To meet their unmet needs, participants suggested providing additional resources, different approaches to learning, better explanation of processes and procedures, diverse emotional support, and more interactions with the oncology team. **Conclusion.** Clinician created VR experiences designed for and informed by oncology caregivers do not exist yet. VR could provide an alternative pedagogical approach to complement standard oncology treatment preparation. These study findings begin the exploration into innovative preparation approaches that could meet oncology caregivers' unmet emotional and educational needs during a stressful period. **Key Highlights.** There is a dearth of clinicians creating and testing VR experiences for patients, let alone caregivers. Oncology caregivers are the unseen 'backbone' supporting their loved one and providing an innovative modality to support them could improve outcomes. VR has the potential improve outcomes for caregivers, which may improve outcomes for patients.

Introduction and Background

Last recorded in 2020, 53 million Americans identified as being an unpaid caregiver.¹ Of those caregivers, 45% experienced a financial impact from their caregiving role and 61% were female.¹ A caregiver is defined as an individual who supports the needs of another person due to illness, injury, or disability.² Specific to oncology caregivers, these individuals tend to be women (58%), middle-aged ($M=53$ years), and related to the person they are caring for.³ Their caregiving experiences tend to be episodic, intense, and short-term (approximately two years) in comparison to non-cancer caregivers.³

Caregivers are a hidden workforce tackling important responsibilities with limited formal training.⁴ Because caregivers typically are thrust into these roles with little training, they experience reduced quality of life,^{1,4,5} especially when their diverse needs are not prioritized.⁶ In healthcare, caregivers typically receive limited support options compared to patients, despite requiring assistance themselves.^{7,8}

Prior studies confirm caregivers have varied unmet needs that should be addressed to improve their outcomes. For example, Denham, et al.'s cross-sectional study⁹ assessed the frequency of caregivers' (N= 457) self-reported unmet needs across five domains and demographic factors. Key findings highlighted younger caregivers, age 18-45, have moderate to high unmet needs ($p < .05$) and caregivers in this sample required self-care support. Recommendations for future interventions should target coordination among caregivers and health care providers, age appropriate programs, especially for younger caregivers, and accessible resources. Denham, et al., concluded increasing healthcare providers' awareness of caregivers' unmet needs and resources to support them is critical to meet their needs.

Wang, et al.'s systematic review¹⁰ identified non-oncology patients' and their informal caregivers' unmet care needs. Patients identified their most critical unmet needs related to psychological, physical, and healthcare service and information. Informal caregivers priority unmet needs were illness and treatment information, and care related information. Wang, et al., concluded both patients and their caregivers' unmet care needs should be evaluated as a whole unit to address their issues.¹⁰

Specific to oncology caregivers, Weaver, et al explored the unmet needs of oncology caregivers caring for patients treated for sarcoma through semi-structured interviews.¹¹ Results revealed four key themes: support with medical aspects of caregiving, support for self, informational needs about the patient, and financial support.¹¹ In this study, oncology caregivers recognized the need for diverse support, yet they were apprehensive to prioritize their needs over their loved one. They reflected they would benefit from connecting with fellow oncology caregivers who could empathize with their experiences.

Despite research acknowledging increased psychological distress and poorer quality of life among caregivers of patients with cancer, targeted interventions must take into account their distinct unmet needs.^{4,12} Virtual reality (VR) could be an innovative intervention to support oncology caregivers' unmet needs through an immersive experience. VR technology combines three-dimensional computer-generated graphics with motion trackers and audio in head-mounted displays to create immersive and interactive environments.¹³ This technology could be an effective interventional tool to communicate information that requires an immersive environment¹⁰ such as patient education,¹⁴ psychological therapy,¹⁵⁻¹⁷ and pain distraction.^{18,19} In addition, immersive VR has demonstrated the ability to improve recall.²⁰

Identifying caregivers' multifaceted and complex unmet needs and deficiencies in services can inform future interventions.⁴ Tailoring these interventions to address caregivers' needs may reduce their distress and improve their quality of life.¹² Currently, there is a dearth of literature exploring oncology caregivers' pre-treatment preparation needs and innovative interventions to support those needs during a stressful period of time. Therefore, the purpose of this study was to 1) describe oncology caregivers' pre-treatment preparation experiences, 2) elicit feedback to improve their pre-treatment preparation experience, and 3) elicit feedback to incorporate visual

aids into the pre-treatment education that will inform future nurse-led VR experiences tailored to their needs.

Methods

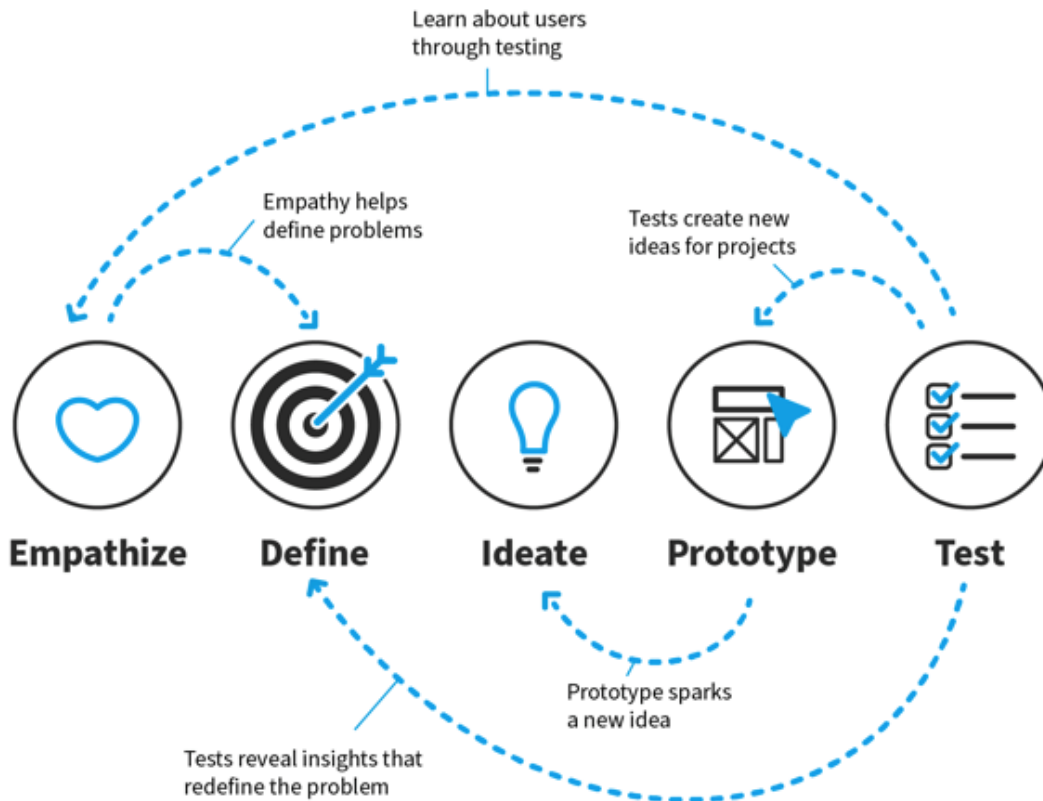
Study Design and Sample

This study employed a qualitative descriptive design to explore the initial ‘empathize’ construct in the Design Thinking Framework (Figure 1).²¹ The emphasize construct was used describe unmet needs and pain point²¹ to inform a future VR intervention for oncology caregivers. After receiving Institutional Review Board approval and permission to post, from July, 2021 – October, 2021, adult oncology caregivers, 18 years or older, were recruited to respond to anonymous demographic and qualitative surveys posted on social media sites (Facebook and LinkedIn), a national oncology forum (National Cancer Society), and a university supported community research registry (Pitt + Me). Using a convenience sampling technique, participation was open to adult caregivers who 1) supported an individual who received oncology treatment within the last two years, and 2) had the ability to read, write, and speak English.

Figure 1. Design Thinking Framework²¹



Design Thinking: a Non-Linear Process



Study Procedures and Data Collection

Prior to participant recruitment, the Institutional Review Board approved the study. Study flyers were posted on the American Cancer Society, Facebook, and LinkedIn social media sites, as well as Pitt + Me research registry. The Pitt + Me registry is a community of patients, volunteers, and researchers partnering together in research and clinical trials. Consent was not required to collect anonymous data; however, interested participants could read through the research introduction explaining the goal of the study, surveys, and time commitment before accessing the surveys. Survey data was collected through the secure and encrypted REDCap data management system. In addition to demographic questions, these semi-structured open-ended surveys aimed to elicit caregivers' pre-treatment experiences and whether visual aids (i.e., video, model) could enhance these experiences. Data were collected until saturation occurred.

Data Analysis

Demographic data were calculated using descriptive analyses (frequency and percentage) using SPSS version 27 and qualitative data were analyzed using NVIVO version 12 software with a content analysis approach.²² Qualitative experience responses were initially coded, related codes

were categorized and then, clustered to identify themes.²³ Coding accuracy was assured through faculty review and themes were discussed with the research team to ensure agreement and trustworthiness of results.

Results

Eighteen adult caregiver participants responded to the anonymous demographic and qualitative surveys (see Table 1). Participants were mostly female (n=13, 72%), white (n=14, 78%), married (n=14, 78%), and had a college degree or higher (n=16, 89%). They categorically ranged in age from 26 years to above 65 years, with the majority (n=11, 61%) between 36-55 years of age. In addition to demographic results, three prominent themes emerged: 1) feeling of preparation to care for a loved one, 2) perspectives to improve preparation of the oncology caregiving experience, and 3) visual aids to support oncology caregivers.

Table 1. Participant Characteristics (N=18)

Age	n (%)
18-25 years	1 (5)
26-35 years	2 (11)
36-45 years	5 (28)
46-55 years	6 (33)
56-65 years	1 (6)
Greater than 65 years	3 (17)
Gender	
Male	5 (28)
Female	13 (72)
Race	
Black or African American	2 (11)
Hispanic or Latino	1 (6)
White	14 (78)
Prefer not to answer	1 (5)
Marital Status	
Single	2 (11)
Married	14 (78)

Widowed	2 (11)
Educational Level	
High school graduate	1 (6)
Some college	1 (6)
College graduate	5 (27)
Graduate school or higher	11 (61)

Theme 1: Feelings of Preparation to Care for Loved One

Many caregivers described their preparation experiences as fraught with many emotions and difficult to manage because they felt overwhelmed and underprepared (see Table 2). For example, one participant stated, “The emotional rollercoaster is huge, trying to make sense of and understand what’s happening feels impossible.” Another participant stated, “I felt prepared from an educational standpoint but not at all from an emotional standpoint.” From participants’ descriptions, pre-treatment education appeared to be focused on the patients’ treatment plan and less about the emotional aspects of being a caregiver. For example, “education helped to feel prepared, but the emotional and mental aspects are what drain you the most after you’re already physically drained from care for them. That’s something I don’t think you could ever be prepared for.”

Table 2. Caregivers’ Feelings of Being Prepared to Support Loved One (N=18)

Themes	n (%)	Codebook Description
Emotional dimensions related to caring for a loved one	11 (65)	Feeling scared, grateful, unprepared, and difficulty watching loved one suffer
Felt unprepared	7 (41)	Feeling unprepared to manage side effects, emotional aspects of caregiving and/or full-time caregiving
Felt prepared	6 (35)	Felt prepared because of education given and/or background of medical knowledge
Education was important	4 (24)	Education helped to feel prepared
Able to ask questions	1 (6)	Be able to ask oncology team questions about treatments
Was a forced caregiver	1 (6)	Did not want to be a caregiver to a loved one

Theme 2: Perspectives to Improve Preparation of Oncology Caregiving Experience

Several caregivers described the emotional toll preparing for treatment with their loved one and how they wished they better understood different aspects of the cancer journey (see Table 3). For

example, the fear of the unknown and feeling helpless was expressed by several participants. Other participants felt they needed more information to adequately manage their loved one’s side effects. For instance, one participant stated, “How other people handle chemo with a similar diagnosis to hers. The doctors were always careful to explain that everyone is different but I don’t think it was ever communicated to us just how hard chemo can be on a person’s body and loved ones.” Many caregivers were unable to articulate one could better prepare for the caregiving experience related to the unknown. For example, one participant stated, “Not sure. Nothing can adequately prepare a person for the unknown...”

Table 3. Caregivers’ Perspectives to Better Prepare for the Oncology Caregiving Experience (N=18)

Themes	n (%)	Codebook Description
How to manage emotional aspect of caregiving	6 (35)	Feeling unheard, fear of the unknown, difficulty watching a loved one suffer or difficulty dealing with loved ones’ emotional responses
How to help manage side effects	5 (29)	Need more information and guidance to manage side effects associated with treatments.
Unsure or nothing	4 (24)	Pertaining to being unsure what they wish they better understand or not having suggestions for what they wished they better understood
Information was overwhelming	2 (12)	Feelings of being overwhelmed when discussing treatment plan with medical team
Amount of work to provide care	1 (6)	Requirement of caregiver to support love one through treatment
Better understanding of procedures and steps	1 (6)	The need to understand all the procedures, processes, and step involved in cancer treatments
COVID caused separation	1 (6)	Perception the pandemic created a situation with less than ideal contact with providers
Wish I knew loved one was ill	1 (6)	Loved one not disclosing illness

Theme 3: Visual Aids to Support Oncology Caregivers

Participants suggested visual aids could improve their pre-treatment experiences by facilitating a better understanding of various procedures, assisting them with the organization of information, and creating a reduction of paperwork (see Table 4). Participants stated, “A calendar with when to take meds on which days of treatment cycle, what meds should be discontinued/on hold before treatments and after treatment...” and “A checklist for each office visit to ensure we had the needed lab/testing orders, prescriptions/refills, consult orders/communication etc.” Another stated, “An explanation of what will happen, for how long, and in what order.”

Table 4. Improving the Caregiver Experience With Visual Aids (N=18)

Themes	n (%)	Codebook Description
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Unsure or nothing	8 (47)	Not having additional feedback to suggest
Comprehension of procedures or steps of the process	7 (41)	In need of knowing what to expect from beginning to end, treatment information, and medication management.
Organization of all treatment aspects	3 (18)	In need of more organization throughout the treatment process such as explaining the timing of treatments, having a checklist, and using a calendar.
Forming connection to others	2 (12)	Connecting with clinicians and/or having personal connections
Reducing paperwork	1 (6)	Having too much paperwork to manage
Using an app	1 (6)	Having an app to access information
Having bigger fonts	1 (6)	Written material is in need of larger font sizes

Discussion

Guided by the empathize construct in the Design Thinking Framework,²¹ this study described adult caregivers' experiences to prepare oncology treatments and their suggestions to improve these experiences. Eighteen adult caregiver participants responded to social media, oncology forum advertisements, and a regional university supported research registry to anonymously share their pre-treatment experiences. The participants were mostly white, educated, females who described their pre-treatment experience as affecting different emotions related to preparation for their caregiving journey. Study sample demographics are consistent with existing national caregiving demographics in which caregivers tend to be white females¹; however, inconsistent with national oncology caregiving demographics, this subgroup of caregivers typically do not have a college degree.³

Perceptions of level of preparation affected participants' emotions. Preparing for oncology treatments is an emotionally charged period of time with a steep learning curve for both patients and their caregivers.²⁴ Emotional aspects may not be addressed during this pre-treatment period as the technical aspects of oncology treatments are typically discussed. In addition, the short interval between diagnosis and treatment may not provide enough time for caregivers to learn how to best support their loved one.¹¹

To improve feelings of preparation, participants identified the need for emotional support, better understanding of the procedures, and connecting to others like them. Often, pre-treatment preparation is not tailored to caregivers who must acquire information and skills needed to support themselves and individuals with cancer before, during, and after treatment.^{11,24} Consistent with existing literature, caregivers would benefit from having a support system of people who can empathize with their experiences.¹¹

Caregivers also identified the addition of visual aids could help them better understand procedures and processes. VR, in particular, could be an innovative visual aid to deliver immersive educational content that would complement standard written and verbal oncology treatment preparation.²⁵ Further, immersing caregivers in a safe virtual environment could

provide an additional opportunity to explore processes and procedures they do not fully comprehend through verbal and written explanations alone.

Limitations

Because this study was designed to describe oncology caregivers' pre-treatment preparation experiences while simultaneously exploring opportunities to leverage future VR experiences for oncology caregivers, limitations were present. A qualitative descriptive design limits the depth of data collected, as this approach re-presents data.²² Further, a convenience sampling technique was employed to remotely reach eligible participants. In addition, the sample consisted of self-selected white, educated female participants. The sampling technique and sample could contribute to selection bias and limited understanding of diverse pre-treatment preparation experiences potentially impacting the accuracy of a future VR caregiving experience.

Implications for Public Health

Caregivers are often not considered or even included when deploying technology in the healthcare setting or in the community despite evidence demonstrating they are often inextricably linked to patient outcomes.²⁶ This gap enables clinicians to design and create a VR solution for caregivers that delivers and reinforces customized oncology information through a visually informative 3-dimensional mechanism. Further, incorporating VR technology could offer a robust and enhanced approach to supporting caregivers during a heightened emotional time.

VR experiences specifically designed for and informed by oncology caregivers do not exist. Clinicians creating VR experiences explicitly for them could lead to better outcomes not only for caregivers, but possibly for the patients they support.²⁶ Creating VR experiences in the future could address some of these unmet preparation needs expressed by oncology caregivers, such as different approaches to learning and explanation of processes and procedures. These study findings begin the exploration into different innovative approaches to meet oncology caregivers' unmet needs.

Conclusions

Virtual reality (VR) could be an innovative intervention to support oncology caregivers' unmet needs in preparation to support a loved one during cancer treatment; however, this type of support is not widely used in the healthcare setting or in the community. Preparation is personal during the pre-treatment period and no two oncology caregivers are alike nor are their needs.²⁴ Thus, clinicians creating virtual reality (VR) experiences designed for caregivers could offer innovative, enhanced preparation leading to less anxiety, uncertainty, and fear.²⁷ Conclusions drawn from this study demonstrated an opportunity for nurses to create meaningful VR experiences to support oncology preparation for caregivers. Creating VR experiences exclusively for oncology caregivers would be a novel clinician-led approach that is currently not in existence. Current VR research focuses on delivering experiences for patients with cancer and not caregivers who support them.²⁸ Therefore, at this current state of the science, oncology clinicians and researchers can be on the forefront of incorporating cutting-edge technologies to support caregivers whether in the hospital or community settings.

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