

Clinical Trials

Understanding patient perspectives and beliefs about treatment

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BACKGROUND: Understanding the experiences of patients with solid tumors who are in phase 1 clinical trials can help nurses to provide optimal care.

OBJECTIVES: The purpose of this article is to describe patient perspectives of participating in a phase 1 trial and understanding their disease status and treatment options. In addition, the authors describe the impact of the disease and clinical trial participation on quality of life.

METHODS: 30 patients were interviewed and audio recorded; the interviews were transcribed and content analysis methods were used to identify common themes.

FINDINGS: Patients reported participating in the phase 1 clinical trial because their doctors informed and encouraged them, they had no other treatment options if they wanted to live longer, or they wanted to help future patients with cancer. Most believed that participation would improve or stabilize their illness and quality of life. They believed that, when the clinical trial ended, there would be new treatments. Participants reported that healthcare providers and family members provided support, and that compassion, cultural awareness, spiritual support, and the need for individual attention were important.

KEYWORDS

phase 1 clinical trial; patient perspective; quality of life; new treatment options

DIGITAL OBJECT IDENTIFIER

10.1188/19.CJON.592-598

ADVANCES IN THE TREATMENT OF CANCER ARE LARGELY DEPENDENT on clinical trials to evaluate new treatment options. The oncology literature has explored numerous factors related to participation in clinical trials, including patient understanding of treatment options, motivations for participation in trials, and expectations of treatments (Atherton, Szydlo, Erlichman, & Sloan, 2015; Beernaert et al., 2016; Jenkins et al., 2011, 2013; Mack et al., 2015; Nielsen & Berthelsen, 2019; Sanders, Seda, & Kardinal, 2013; Sun et al., 2014). Several studies have identified unrealistic expectations of early-stage agents by patients who believe that these new treatments offer hope for cure (Bell & Balneaves, 2015; Godskesen, Nygren, Nordin, Hansson, & Kihlbom, 2013; Haynes-Maslow et al., 2014). In addition, prior studies have shown that patients rarely understood the information presented to them about results and greatly overestimated their chance of response (Sulmasy et al., 2010), believing that anticancer agents could kill cancer cells (Agrawal et al., 2006).

Substantial advances in cancer treatment have occurred, including the development of immunotherapy, targeted agents, and genetic testing. Many new agents offer advantages such as oral delivery and fewer adverse effects. These advances have enhanced trial participation. The benefits, however, exist within the reality that early-phase treatments are experimental, particularly in phase 1 clinical trials, where the goal is most often to determine doses and initial tumor response (Sun et al., 2014). Phase 1 trials test a drug's dosage and safety, and phase 2 trials extend the research to a larger population. Phase 3 trials are generally randomized studies in large populations based on the experience of the phase 1 trial in refining doses (National Cancer Institute, 2016).

Cancer treatment advances have occurred at a time when major advances have been made in the integration of palliative care in cancer. Palliative care has emphasized the importance of communication of treatment options, realistic discussions about patient goals of care, and honest conversations about prognosis (Anwar et al., 2017; Cassel et al., 2016; Dias, Chao, Lee, Wu, & Kloecker, 2016; Ferrell et al., 2017; National Consensus Project for Quality Palliative Care, 2018). Considering only disease-focused treatment may delay hospice or palliative care referral, despite a patient's advancing disease, symptoms, and other quality-of-life concerns. Oncology nurses play an important role in supporting patients as they consider treatment options and difficult decisions (Anwar et al., 2017; Ethier, Paramsothy, You, Fowler, & Gandhi, 2018; Jang, Krzyzanowska, Zimmerman, Taback, & Alibhai, 2015; Mollica et al., 2018; Treasure et al., 2018).

This qualitative study explored the perspectives and needs of patients with solid tumors who were participating in phase 1 trials. The aims of the