

Hodgkin Lymphoma Survivor Wellness

Development of a web-based intervention

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BACKGROUND: Informational and supportive care resources are needed for Hodgkin lymphoma (HL) survivors.

OBJECTIVES: The aim of this article is to adapt and evaluate a previously developed survivorship care website for HL survivors.

METHODS: A mixed-methods, user-centered design, including one-time focus groups, was followed by iterative web design and user testing. Transcripts were content analyzed, and survey responses were summarized.

FINDINGS: HL survivors need survivorship care education and support. Tailored web-based resources may be an effective adjunct to clinical care. The Survivor Wellness website is a usable web-based resource for HL survivors that may facilitate survivorship care.

KEYWORDS

user experience; web-based intervention; Hodgkin lymphoma; cancer survivors

DIGITAL OBJECT IDENTIFIER

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SURVIVAL RATES FOR HODGKIN LYMPHOMA (HL) have improved due, in large part, to advances in treatment during the past 30 years (Patel et al., 2018). The five-year survival rate for those diagnosed with HL is 78%–93%, varying with stage of disease (American Cancer Society [ACS], 2018). Despite the success of living longer, treatment for HL—often with anthracyclines or radiation therapy—is not without consequences. Many survivors are left to live with the risk of late and long-term effects from their cancer and cancer treatments, as well as the emotional and psychosocial implications of being a cancer survivor (ACS, 2018; Ng, 2014). The consequences of HL treatment include the development of secondary malignancies, cardiopulmonary disease, and endocrinopathies (ACS, 2018; Ng, 2014). In addition, survivors may face fear of recurrence, worry, or emotional changes while adjusting to cancer survivorship (Raphael et al., 2017).

Because of the impact of HL and its treatment, survivors are instructed to seek routine medical care for screening, prevention, and monitoring that is different from that recommended to the general population. These recommendations are tailored to survivors based on the type of treatment received and can include increased breast cancer screening, lung cancer screening, cardiac monitoring, and emotional and psychosocial support, as well as a host of other recommendations related to health and well-being (Sanft et al., 2019). HL survivorship care includes providing specialized care and addressing unmet needs (Cox et al., 2016). This context of care may be influenced by social, economic, and geographic factors. A large retrospective study of nearly 4,000 cancer survivors found that only 43% accessed a survivorship clinic for care, and this outcome was affected by survivors' geographic location in comparison to the clinic (Nathan et al., 2016).

When HL survivors have access to resources associated with survivorship and follow-up medical care, their clinical care improves (Kvale et al., 2016). Web-based resources are available to cancer survivors and HL survivors through organizations such as the American Society of Clinical Oncology,