

Unmet Needs in Survivors On and Off Cancer Treatment: A Comparative Survey

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Survivors require a range of resources to keep up with the demands of their treatments and side effects, and can have many unmet needs. A survey of patients at one cancer center identified significant differences in the needs of survivors on treatment and off treatment, with a higher number of unmet physical needs beyond functional status for those currently receiving treatment. Unmet emotional needs were high in both groups, suggesting that more resources and education may be of benefit to patients in understanding the role of cancer in their lives.

AT A GLANCE

- Survivors on and off cancer treatment have many unmet physical needs, suggesting more attention to side effects is required.
- Survivors often have spiritual and emotional needs related to understanding cancer, in addition to managing the impact of cancer on their lives, work, and relationships.
- Many survivors identify lack of awareness of resources as their largest barrier to accessing help.

KEYWORDS

needs assessment; continuity of care; neoplasms; survivorship; unmet needs

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Individuals navigating the complex healthcare system need a wide range of resources, particularly in the context of frequent treatments and life changes resulting from cancer. Survivors, defined as individuals from the time of diagnosis, including during and after the treatment process, often struggle to keep up with the complex physical and emotional demands of their condition, and as a result experience many unmet needs (Denlinger et al., 2014; Götze et al., 2018; Leach et al., 2014; Lisy et al., 2019; Mazor et al., 2019; Shakeel et al., 2020). These needs exist within the physical, psychosocial, and supportive care domains (Lisy, 2019; National Coalition for Cancer Survivorship, 2021).

Although psychosocial distress screening has been recommended by the American College of Surgeons Commission on Cancer (CoC), implementation has been inconsistent (American College of Surgeons, 2021; Ehlers et al., 2019; Jacobsen & Norton, 2019). CoC survivorship standard 4.8 requires that “the survivorship program team determines a list of services and programs, offered on-site or by referral, that address the needs of cancer survivors” (American College of Surgeons, 2021, p. 36). However, many of these efforts focus narrowly on the treatment phase of the cancer continuum (Götze et al., 2018; Leach et al., 2014; Shakeel et al., 2020).

To identify potential areas of clinical need and to meet the CoC standards, a group of survivors was surveyed using validated measures to identify unmet needs, symptom burdens, and satisfaction with clinician communication. Survivors who were either on or off treatment were randomly selected from the electronic health record of visits in the previous calendar year. The information derived from this survey was then used to evaluate resources offered at the authors’ institution.

Methods

This study evaluated the overall levels of unmet needs between survivors who were on treatment and off treatment, using the Cancer Survivors’ Unmet Needs measure (CaSUN) (Geller et al., 2014; Hodgkinson et al., 2007). This self-report questionnaire consists of 53 questions about needs across the following five domains: access to care (7 items); access to information (10 items); emotional, social, and spiritual issues (19 items); physical needs (8 items); and economic and legal issues (9 items). Each question has a three-point scale with the options (a) no need, or need is not applicable; (b) have need, but it is being met; and (c) need is currently unmet. Domain