

Supportive care needs of hematological cancer survivors: A critical review of the literature

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Abstract

The purpose of this review was to determine the perceived supportive care needs of hematological cancer survivors, and the patient characteristics associated with higher levels of need. Medline, PsychInfo, CINAHL, EMBASE and PsycEXTRA, were searched for eligible articles published between 1979 and 2011. Ten full-text articles were identified. Extensive variation among study populations, methodologies

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and needs assessment measures used, made it difficult to synthesize results. Consequently, we could not confidently determine the most prevalent perceived needs of hematological cancer survivors. However, the limited data loosely suggests that concerns surrounding cancer recurrence and survival may be predominant needs experienced by hematological cancer survivors. Younger survivors were also identified by several studies as reporting higher levels of several areas of need. Future research is needed to assess the supportive care needs of large heterogeneous, population-based samples of hematological cancer survivors, utilizing valid, reliable and standardized measures of supportive care needs.

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1. Introduction

Hematological cancers are a diverse group of cancers that develop in the blood or bone marrow [1–3]. There are over 60 sub-types [4,5], that are often classified into three main disease groups: myeloma, leukemia and lymphoma [1,3]. Collectively, hematological cancers have been estimated to be the fourth most common cancer types diagnosed in both men and women in the economically developed world [6]. Improvements in survival rates for a number of hematological cancers have been noted in several different countries, including Europe [7], Australia [8] and the United States [9]. The *National Cancer Institute* in the United States considers a cancer survivor, as someone “from the time of diagnosis through the balance of his or her life” [10]. The number of hematological cancer survivors is rising, partly due to an increase in the aging population, increasing incidence and improvement in cancer treatment and some survival rates [3].

Hematological cancers are a unique group of cancers. There is considerable variability among the types and sub-types of hematological cancers and their treatment [3,11]. For some, the disease is aggressive, requiring treatment that is often extensive and debilitating, and sometimes involving long periods of inpatient care (e.g. bone marrow transplant and chemotherapy) [3,12,13]. Other forms are chronic in nature with frequent relapsing requiring active treatment and management for a number of years [3,11].

Similar to other cancers, hematological cancers affect many aspects of a person's life. Physical effects may include fatigue [14,15], reduced role function, insomnia, pain and dyspnea [15]. Longer-term effects may include fatigue [16,17] and poorer self-reported physical health [18]. Several reviews have also established associations between some hematological cancers and employment related outcomes [19,20]. Given the significant impact of cancer, it is vital that hematological cancer survivors are provided with health care that is patient-centered and focused on addressing their unique and specific concerns.

Assessing the supportive care needs of cancer patients is recognized as an important step in providing optimal patient-centered care [21,22]. Supportive care needs include the physical, informational, emotional, psychological, social, spiritual and practical concerns [23], which patients require support in addressing [23,24]. Assessing the supportive care needs of hematological cancer survivors provides an

opportunity to identify the most pressing issues survivors wish to receive help with [25,26]. Such information can guide resource allocation, care planning and patient referrals [26,27]. Identifying patient, demographic, disease and treatment characteristics associated with higher levels of perceived needs may also assist in targeting support to sub-groups of survivors who are at increased risk of experiencing difficulty [28].

Several reviews have investigated the experiences of hematological cancer patients or survivors [29–31]; however these have largely included studies focusing on quality of life [29–31], with few studies included specifically assessing supportive care needs. While important, quality of life does not provide information on patients' perceptions of the level of assistance required to address their concerns [24,25]. A review focusing on the perceived supportive care needs of hematological cancer survivors will provide important information on what areas survivors specifically feel they need help with, what sub-group of survivors may be at risk of requiring additional support and provide direction for future research in this important area. In turn, such information could be used by clinicians and researchers in determining support, services and research initiatives that may be most appropriate for this population. This review aimed to investigate the perceived supportive care needs of hematological cancer survivors, with an overall objective to identify: (i) the most prevalent perceived supportive care needs of adult hematological cancer survivors; and (ii) the sociodemographic, disease, physical, treatment and care characteristics associated with high levels of needs.

2. Methods

2.1. Literature search

A hematological cancer survivor was defined as an individual diagnosed with any type of hematological cancer from time of diagnosis to the end of life [10]. The databases, Medline, PsychInfo, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase and Psychextra were searched using the following combination of terms: (needs assessment or unmet needs or perceived need* or supportive care need* or unmet need* or needs) AND (Multiple Myeloma or multiple myeloma* or leukemia or leukemia,

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