
ISSUES IN ADULT BLOOD CANCER SURVIVORSHIP CARE

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OBJECTIVES: *To describe the current literature and future directions of survivorship care for the adult blood cancer population including unique features, identification of needs, practice guidelines, care models and the implications for nursing.*

DATA SOURCES: *Peer reviewed literature, government and national advocacy organization reports, professional organization guidelines.*

CONCLUSION: *Adult blood cancer survivors are a heterogeneous population that often receives complicated treatments to live a longer life. Survivorship needs among this population are often unmet throughout the cancer care continuum. The limited research literature and guidelines point to survivorship care strategies from the day of diagnosis to enhance long-term outcomes and improve quality of life.*

IMPLICATIONS FOR NURSING PRACTICE: *Nurses are experts in symptom management and central to preventing, detecting, measuring, educating, and treating the effects of cancer and its treatment. Moreover, nurses are key to implementing strategies to support blood cancer survivors, families, and caregivers from the day of diagnosis to the last day of life.*

KEY WORDS: *Cancer survivorship, survivorship care planning, hematologic malignancies, blood cancers, nursing care, supportive care, blood cancer survivors*

HEMATOLOGIC malignancies, sometimes referred to as *blood cancers*, account for 9.5% of all cancers.¹ Sixty subtypes of hematologic malignancies arising from the myeloid and lymphoid cell lines are mainly classified as lymphoma, leukemia, and myeloma.² Standard treatment often consists of ‘watchful waiting,’ symptom management,

intensive therapy including chemotherapy, immunotherapy, surgery, radiation therapy, and hematopoietic cell transplant (HCT), or a combination of approaches over time.

Five-year survival rates for hematologic malignancies continue to rise: 71% of people with lymphoma, 59% of people with leukemia, and 45% of people with myeloma are alive 5 or more years after

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diagnosis.³ Despite increasing longevity among survivors of hematologic malignancies, there is limited literature, inadequate identification, and few guidelines to address the needs of this population.

DEFINITIONS

The descriptive terms of cancer survivor and cancer survivorship care are varied. There is a complexity of meaning of survivorship among people who experience cancer and institutions providing their care. Cancer survivorship is commonly conceptualized as starting at diagnosis.^{4,5} Cancer survivorship care is typically provided during the post-treatment phase, including psychosocial and physical recovery, adjustment to changes, maintaining general health, and reintegration into normal daily life.⁶

The conceptual difference between the phase of survivorship beginning at the time of diagnosis and survivorship following curative treatment creates conflict in defining the best time and way to provide survivorship care, especially to people who are challenged by an incurable cancer. Survivors of chronic leukemia, indolent lymphoma and multiple myeloma often balance the hope of remission with the knowledge that they may not be cured of their cancer and face survivorship issues while on chronic therapy. Survivors of acute leukemia, Hodgkin lymphoma, and aggressive forms of lymphoma can have complex, combination therapy including hematologic cell transplant with curative intent, resulting in prolonged recovery and substantial long-term and late effects. Myelodysplastic syndrome is considered a malignancy,⁷ but many who live with it do not consider themselves to have cancer.

Perhaps, the diverse nature of hematologic malignancies and its treatment contributes to the wide range of feelings and beliefs adult blood cancer survivors express about the term *cancer survivor*. Based on their individual interpretations of the term and its relevance to their identity, these survivors may reject or embrace the title.⁸ The question remains, how best to describe the experience of living with and beyond cancer and provide the supportive care necessary for optimal quality of life.⁸

SURVIVOR NEEDS

Some specific needs of adult blood cancer survivors have been described in the literature. These

include psychosocial needs, financial needs, and physical needs.

Psychosocial Needs

A systematic review of 17 studies to determine unmet psychosocial needs of people with blood cancer identified psychological and information needs, most notably fear of recurrence throughout the course of illness.⁹ Survivors in these studies desired more information and more positive relationships with family members and the health care professionals involved in their care. Information and psychological needs were greatest at the time of diagnosis and during treatment, including treatment effectiveness, effects on family, ability to have children, and concerns about paying for care. The number of needs was lower after treatment. However, more of these needs were unmet. A single unmet need in the post-treatment setting, like fatigue or anxiety, was hypothesized to be more likely to cause distress.^{9,10}

In a cross-sectional population-based comparative study to assess the needs of adult blood cancer survivors living in Australia and Canada, the most prevalent concern (18%) reported by 437 survivors was 'dealing with feeling tired.'² There was no statistical difference between countries, cancer type, age, or time since diagnosis.

In a survey of 718 long-term acute leukemia, Hodgkin, and non-Hodgkin lymphoma survivors, 5 to 40 years from diagnosis treated at a single institution, 18% reported high levels of fatigue and 10% of participants had moderate to severe impairment in functioning.¹¹ There were no statistically significant differences in fatigue levels or levels of functioning between cancer types. The authors found a decline in the negative impact of cancer among long-term survivors, perhaps because of changed expectations and social roles.¹¹

Among younger adults treated for non-Hodgkin lymphoma, three studies reported higher levels of sexuality and/or fertility needs¹²⁻¹⁴ and one study found 61% wanted more information about fertility.¹³

Financial Needs

Financial concerns are a recurring theme in the limited literature about the unmet needs of adult blood cancer survivors. A survey study of 268 adult blood cancer survivors diagnosed in the previous 3 years in Australia showed health care-related expenses were a concern, particularly the

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