



The psychosocial outcomes of individuals with hematological cancers: Are we doing enough high quality research, and what is it telling us?



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ARTICLE INFO

Article history:

Received 17 August 2015

Received in revised form

27 November 2015

Accepted 25 February 2016

ABSTRACT

This systematic review assessed the quantity and quality of research examining the psychosocial outcomes among hematological cancer patients. Studies were categorised as either measurement, descriptive or intervention. Intervention studies were further assessed according to Effective Practice and Organisation of Care (EPOC) methodological criteria. A total of 261 eligible papers were identified.

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Keywords:
 Psychosocial
 Adjustment
 Hematological cancer
 Systematic review

The number of publications increased by 8.8% each year (95% CI = 7.5–10.2%; $p < 0.0001$). The majority of studies were descriptive ($n = 232$; 89%), with few measurement ($n = 8$; 3%) and intervention ($n = 21$; 8%) studies identified. Ten intervention studies met EPOC design criteria, however only two interventions, one targeted at individuals with Hodgkin's or Non-Hodgkin's lymphoma and one targeted at individuals with leukaemia, lymphoma or myelomatosis were successful in improving patients' psychosocial outcomes. Despite an increasing volume of research examining psychosocial outcomes of hematological cancer patients, there is a need for robust measurement and methodologically rigorous intervention research in this area.

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1. Introduction

1.1. Hematological cancers are associated with sub-optimal psychosocial outcomes

Hematological cancers are a diverse group of cancers that primarily affect the blood and bone marrow. They are typically categorised into three main disease groups: leukemias, lymphomas and myeloma (National Institute for Clinical Excellence, 2003). Within each of these disease groups there are a range of different sub-types, each differing in their presentation, progression and treatments. Some forms are acute and highly aggressive, requiring urgent and intensive treatments, which often results in long periods of hospitalisation and a number of debilitating side effects (National Institute for Clinical Excellence, 2003). While other forms are slow growing and chronic, which may only require monitoring or less intensive treatments (National Institute for Clinical Excellence, 2003).

As a result of a diagnosis of hematological cancer and the resulting treatment, patients and their families experience a range of psychological, social and emotional challenges. Prevalence of psychosocial distress, anxiety and depression among hematological cancer patients and survivors has been found to be higher than that reported by survivors of some other cancer types (Boyes et al., 2011; Carlson et al., 2004). A recent study by Linden and colleagues (Linden et al., 2012) found that rates of clinical and sub-clinical anxiety among hematological cancer patients were 48% and 23% respectively, and rates of clinical and sub-clinical depression were 38% and 17% respectively. In another large study of non-Hodgkin's lymphoma survivors, 39% of those surveyed reported at least one cluster of cancer-related symptoms of post-traumatic distress, 8% reported all three possible clusters of post-traumatic stress disorder symptoms (Smith et al., 2008) and 37% reported persistent or worsening symptoms five years later (Smith et al., 2011). Similar to survivors of other cancer types (Simard et al., 2013), fear of cancer recurrence and uncertainty has been identified as common concerns of hematological cancer survivors (Black and White, 2005; Grundy and Ghazi, 2009). Many hematological cancer survivors also experience a range of social consequences as a result of their cancer, including taking time off work; decreased income; missing family events, children's activities, social or religious activities; difficulty paying bills and using up savings (Paul et al., 2013). The psychosocial wellbeing of individuals affected by cancer is important because of its association with poorer quality of life, more intense physical symptoms, increased functional impairment and poor treatment adherence (Skarstein et al., 2000; Fann et al., 2008).

1.2. The contribution of research in reducing the psychosocial impact of hematological cancer

To improve important health outcomes and develop the best possible evidence for addressing psychosocial outcomes for

hematological cancer survivors, there is a need for methodologically rigorous research. As measurement research is key to accurately assessing the extent and nature of a problem, research should firstly focus on developing sound, psychometrically robust psychosocial outcomes measures. Once valid and reliable measures are available, research should focus on undertaking well-designed descriptive studies to provide an understanding of the prevalence and factors associated with the problem of interest. Such descriptive research can also provide information to assist in determining areas amenable to intervention. Finally, rigorous intervention studies should then be conducted to provide causal evidence about the most effective strategies for delivering best practice healthcare. However, intervention studies must meet minimum standards of scientific quality to ensure adequate internal and external validity.

In order to reduce the adverse impact of cancer on individuals who are diagnosed with a hematological cancer, there is a need for knowledge about the prevalence and causes of sub-optimal psychosocial outcomes, and effective strategies that can be implemented to improve them. Examining the number and type of measurement, descriptive and intervention publications in a particular field over time provides a broad indication of research capacity (Crisp et al., 2000; Cooke, 2005). Such examination in other fields of research has found a lack of intervention research comparative to descriptive research. Further, assessing the methodological quality and effectiveness of interventions provides an indication of the strength of evidence available and identify strategies that may be successfully implemented to improve psychosocial outcomes in this population (Bailey et al., 2010; Sanson-Fisher et al., 2010). Despite the significant psychosocial burden associated with hematological cancer, the volume, scope and quality of research output related to psychosocial outcomes among hematological cancer patients is unknown. Understanding the current state of research in this area will help to determine current research gaps, and to prioritise the type of research required for improving the psychosocial outcomes of this unique and growing population.

1.3. Aims

This systematic review aims to examine:

1. The volume of data-based publications examining psychosocial outcomes among hematological cancer patients at any phase of the cancer trajectory from diagnosis to end of life.
2. The proportion of measurement, descriptive and intervention research that has been carried out.
3. The methodological quality of intervention research according to the Effective Practice and Organisation of Care (EPOC) (Group CEPaOoCR, 2015) methodological criteria.
4. The effectiveness of interventions in improving psychosocial outcomes for hematological cancer patients.

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