



Myeloma patients' experiences of haematopoietic stem cell transplant: A qualitative thematic synthesis

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ABSTRACT

Purpose: The aim of this study was to synthesise all qualitative evidence on the experiences of myeloma patients undergoing haematopoietic stem cell transplant (HSCT).

Method: A systematic search strategy was developed and a rigorous search of the literature was undertaken searching six databases (CINAHL, Embase, Medline, Psych Info, Ethos and Proquest). The software for systematic reviews www.covidence.org was used to blind screen for eligible papers. Quality appraisal of each study was undertaken using the Critical Appraisal Skills Programme (CASP). Confidence in each finding was assessed using Confidence in the Evidence from Reviews of Qualitative research (CERQual).

Results: Eight qualitative studies (reported in eleven papers and including seventy six myeloma patients) were selected in the final sample for evidence synthesis. Four themes were identified relating to patients' feeling 'dead', disconnecting and isolating themselves, cognitive impairment and engagement with exercise and its benefits in recovery.

Conclusions: The burden of cognitive functioning among myeloma patients was often under detected. Nurses should ask patients regularly about their memory and any challenges they may be experiencing to their concentration and recall. Exercise during the transplant process can help improve patients' recovery, both physically and psychologically. A structured exercise programme developed by a physiotherapist to suit the needs of each patient should be standard practice in the transplant process.

1. Introduction

Multiple myeloma (also referred to as Myeloma) is a malignancy of plasma cells that originate from the B-cell lineage. It is characterised by the excess production of a monoclonal protein that subsequently results in different forms of end organ damage and the following symptoms; anaemia, renal insufficiency, hypercalcaemia and bone loss or destruction (Munshi and Anderson, 2013). Although consistent improvements in progression-free survival (PFS) and overall survival (OS) have been made in the last decade, myeloma remains an incurable condition (McEllistrim et al., 2017). Administration of more intensive regimes such as haematopoietic stem cell transplant (HSCT) and the introduction of novel agents, has resulted in significant improvements seen in life expectancy and extended the median survival in all age groups by 50% with more significant improvement in the younger patient population (under 60 years) and predicted five and ten year survival estimates of more than 50% and 30% respectively (Boland et al., 2013).

Since the late 1990's high dose melphalan treatment (200mg/m²)

followed by autologous haematopoietic stem cell transplant (autoHSCT) (donor and recipient are the same person) has become the standard treatment for patients with myeloma aged less than sixty five years (Wang et al., 2014; Stettlar et al., 2017). While there has been some support for the use of allogeneic HSCT in patients with multiple myeloma, this treatment option remains controversial with conflicting views on its role in the management of multiple myeloma (Koniarczyk et al., 2017).

The process of autoHSCT occurs over three phases: pre-transplant, transplant to engraftment and post-transplant (Koniarczyk et al., 2017). In the pre-transplant phase, mobilisation (e.g. using a granulocyte-colony stimulating factor) and collection of the patient's haematopoietic stem cells occurs (HSCs). After high dose chemotherapy, the patient receives an infusion of their previously harvested HSCs. Toxicities experienced are due to high-dose melphalan which affects the gastrointestinal tract, bone marrow and hair follicles and requires intensive supportive care and psychological care (Koniarczyk et al., 2017).

Our understanding of the associated symptoms and treatment

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related toxicities with transplant among myeloma patients is limited (Ramsenthaler et al., 2016). There are many issues associated with autoHSCT that patients both fear and encounter. Although the risk of mortality with autologous transplant is low, it has a high emotional and physical morbidity with psychological and physical consequences that may last for months and even years and negatively impacts on their quality of life (QOL) and overall functioning (El-Jawahri et al., 2015). In a recent longitudinal study examining patient reported symptom burden during the 3–9 month period post autologous HSCT (Wang et al., 2015), it was found that 35% of patients consistently reported high burden symptoms of fatigue, pain, numbness, bone aches and muscle weakness up to nine months post autoHSCT.

Nurses play a pivotal role in educating, advocating and supporting patients and pre-empting potential co-morbid conditions associated with transplant in order to initiate early intervention to minimise side effects and associated distress (Bilotti et al., 2011). In order to care comprehensively for myeloma patients undergoing transplant, a deep insight into their experiences is also required. A recent qualitative systematic review focuses on myeloma patients' experiences (Hauksdóttir et al., 2017), however, it does not focus specifically on myeloma patients' experiences undergoing transplant. This study is therefore timely and is the only know qualitative evidence synthesis focusing specifically on myeloma patients undergoing transplantation.

2. Methods

The aim of this study was to describe the experiences of myeloma patients undergoing auto haematopoietic stem cell transplant (HSCT). Thematic synthesis of the qualitative literature as outlined by Thomas and Harden (2008) was the guiding methodology. This methodology facilitates synthesis of findings across selected studies by the examination of the 'results' or 'findings' through coding by a line-by-line approach, following which descriptive themes and analytic themes are generated.

2.1. Search strategy

A systematic search was undertaken using all possible combinations of the study's key words which included "myeloma patients", "haematopoietic stem cell transplant", "experience" and "qualitative" (Table 1). Six databases were searched (CINAHL, Embase, Medline, Psych Info, Ethos and Proquest). Year parameters were not set in order to capture all relevant literature. Grey matter such as unpublished material, e.g. PhD thesis and conference abstracts relevant to the question were also examined to avoid publication bias (Evidence for Policy and Practice Information and Co-ordinating Centre, 2010). The initial search retrieved 1256 references.

2.2. Screening

Papers were included if they met the following inclusion criteria:

1. Patients with a diagnosis of myeloma who had undergone

Table 1

Search Terms. Terms used for search strategy across databases using elements of review question. PICO (Population, Phenomenon of Interest, Context).

Population	Context	Phenomena of interest	
Myeloma patients	Haematopoietic stem cell transplant	Experience	Qualitative
Myeloma* or myeloma or plasma cell leukaemia or plasma cell leukemia or multiple myeloma* or plasma cell myeloma* or plasma cell myeloma* or kahler	Stem cell* or bone marrow or autologous or peripheral blood cell* or transplant* or Haematopoietic Stem Cell Transplantation	Experience*	"Qualitative Research + " or "Interviews" or " Surveys and Questionnaires" OR "Self Report" OR "Focus Groups" or qualitative or phenomenolog* or focus group* or interview* or grounded theor* or mixed methods or ethnograph* or survey* or questionnaire or hermeneutic*

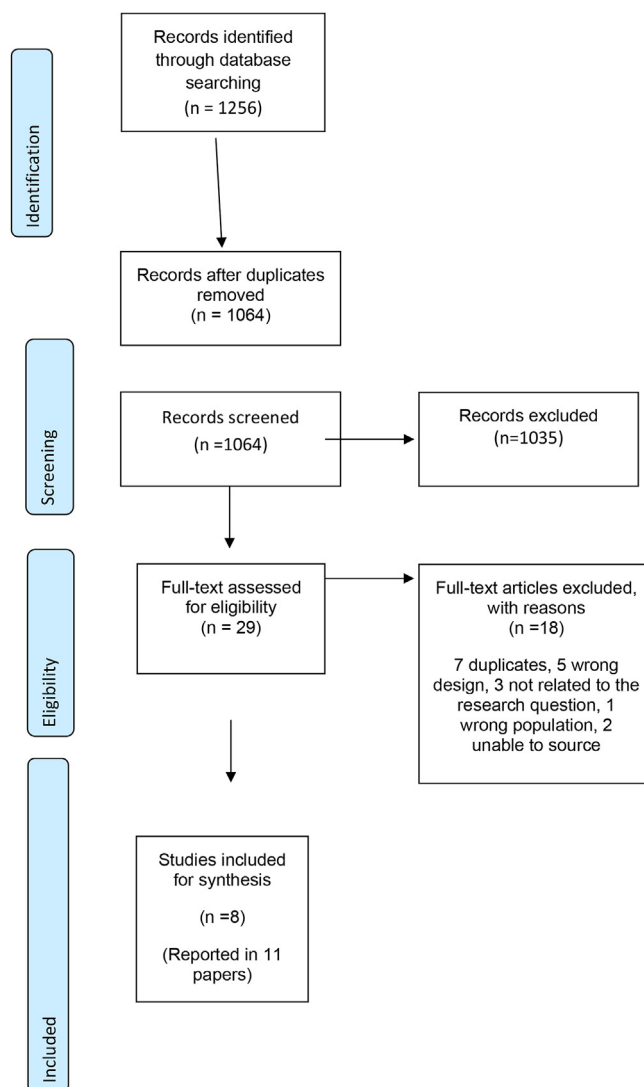


Fig. 1. Prisma results.

1. haematopoietic stem cell transplant.
2. Qualitative studies to include phenomenology, ethnography, grounded theory, generic qualitative or mixed methods which examine patients' experiences.
3. Adult patients over 18 years of age
4. English language.

Following removal of duplicates, the title and abstract of all 1064 remaining papers were screened blindly by two reviewers (the first and last authors) in Covidence®, a software for systematic reviews (www.covidence.org). Conflicts were resolved by discussion and in some instances a third reviewer (an experienced oncology nurse) was consulted

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