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My time; your time; the time of living with myeloma

Abstract

Abstract of a poster presentation presented at the Joint Meeting of the COSA 39th Annual Scientific Meeting and IPOS 14th World Congress of Psycho-Oncology, 13-15 November 2012, Brisbane Convention and Exhibition Centre.

Keywords

your, time, myeloma, my, living

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MY TIME; YOUR TIME; THE TIME OF LIVING WITH MYELOMA

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Introduction: Improvements in treatment of myeloma have led to a significant increase in the median duration of survival. Management of the disease often requires onerous and complex regimens involving multi-disciplinary support and treatment from a number of different modalities. This requires significant input of effort from both health care professionals and from patients and their carers.

Methods: Ten patients, with myeloma and attending one of three hospitals, were recruited together with a lay carer. Participants were interviewed on three occasions over 14 months. A total of 47 interviews were generated. These data have been analysed using the constant comparative method of Grounded Theory. Interviews were digitally recorded and transcribed verbatim. Data were managed using NVIVO software.

Results: Living with myeloma requires effort, planning and organisation and thus, is work. Participants also put effort into managing complications and side effects of myeloma and its treatment and into integrating them into how they live with myeloma. Living with myeloma requires organisational skills, physical and emotional effort and is undertaken by both patients and significant others.

Conclusion: The constellation of activities that require toil and effort by those living with myeloma have been conceptualised as work as it takes effort to live day to day with myeloma. Understanding this notion is important for healthcare professionals in working with people with myeloma and other cancers. Understanding commonalities and differences between the kinds of work patients and healthcare professionals undertake may assist with working together with patients in their own work and thus enhancing supportive care.