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## Disease isolation: The challenges faced by mothers living with multiple myeloma in rural and regional Australia



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### A B S T R A C T

#### Keywords:

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Isolation  
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Women  
Mothers  
Rural and regional

**Purpose:** To explore the interrelationship of two challenging aspects of the cancer experience: the diagnosis and experience of younger women living with multiple myeloma, and their geographical disadvantage.

**Method:** A cross-sectional retrospective qualitative methodology was employed. Five women with dependent children and a diagnosis of myeloma, living in rural and regional Australia, were interviewed using a semi-structured technique. Interpretative phenomenological analysis provided the foundation for the data analysis and interpretation.

**Results:** The central concept of disease isolation emerged from the data and captured the interrelationship of the experience of living with a rare cancer, while living in a rural and regional area of Australia. Three strong themes emerged: 1) isolation due to living with a rare cancer, 2) isolation within the myeloma population, and 3) isolation due to the disease effects and treatment. In the context of these results, isolation depicted the sense of being alone or separated, both physically and psychologically, from potential sources of support, and of being different from others (both patients with cancer and patients with myeloma), which presented barriers to accessing support.

**Conclusion:** The interrelationship of geographical isolation and living with multiple myeloma underpins the core issues relating to the main themes. Understanding the issues confronting younger women with myeloma living in rural and regional of Australia may assist health professionals to improve support for women in this situation.

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### Introduction

Multiple Myeloma, a relatively rare haematological cancer accounting for 1.2% of cancer's diagnosed in Australia (Australian Institute of Health and Welfare, and Australasian Association of Cancer Registries, 2012), receives limited media attention and has been scantily studied through qualitative methods; consequently little is known about the experience of living with this incurable disease. Existing research suggests that, among people with haematological malignancies, patients with myeloma have the lowest quality of life and highest level of symptoms due to the added distress of bone pain, pathological fractures and recurrent infections (Johnsen et al., 2009). Studies specifically investigating the

experiences (Kelly and Dowling, 2011; Molassiotis et al., 2011a; Potrata et al., 2011) and quality of life (Molassiotis et al., 2011b; Mols et al., 2012) of patients living with myeloma reveal low performance on health-related quality of life (HRQOL) sub-scales, including global quality of life, physical functioning, role functioning, and social and cognitive functioning. Psychologically, high levels of depression were found in myeloma patients, with a direct relationship between unmet needs and both depression and anxiety (Molassiotis et al., 2011b). Qualitative studies investigating patients' experience with myeloma have similarly revealed that patients living with myeloma face a multitude of physical (Kelly and Dowling, 2011; Molassiotis et al., 2011a; Potrata et al., 2011) and emotional factors (Kelly and Dowling, 2011; Molassiotis et al., 2011a), while the impact of living with an 'unknown future' was the only theme that was explicitly reported within all the studies (Kelly and Dowling, 2011; Molassiotis et al., 2011a; Potrata et al., 2011). While these studies provide valuable insight into the quality of life and experience of myeloma, they typically involve older patients, as myeloma is a disease more prevalent in the older age

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ranges. Consequently, there is little known about the experiences of younger patients with myeloma and, in particular, those from rural and regional areas, who face the additional challenges of relocation for treatment, separation from their family and disruption to parenting and vocational roles.

From the few studies conducted with haematological cancers in rural environments the evidence suggests that such patients face significant challenges, particularly in the areas of accessing appropriate medical care in their local environment, receiving emotional support (McGrath, 2001), work and financial concerns (Bray et al., 2011; McGrath, 2001), and the demands of travelling for treatment (McGrath, 2001). For example, McGrath (2001) found that some participants described being “very scared” and “under confident” due to a perceived lack of qualified doctors in their local area and that, in some instances, the local doctor and/or hospital weren't informed about their disease or treatment (McGrath, 2000, 2001). Furthermore, participants indicated that there was a need to have contact with other people going through a similar situation and social outlets, as they were “lonely and bored” (McGrath, 2001). However, there is emerging evidence to suggest that the employment of Cancer Care Coordinators in rural and regional areas has reduced some of the challenges experienced by patients returning home from a specialist metropolitan hospital, giving subsequent rise to perceived wellbeing (Bray et al., 2011; Drury and Inma, 2010).

Examining the wider literature on cancer patients in rural settings, findings suggest that the demands of travel for treatment (Baldwin and Usher, 2008; Hegney et al., 2005), isolation from family and support networks (Baldwin and Usher, 2008; Hegney et al., 2005) and age (DiSipio et al., 2009; Girgis et al., 2000) may have profound impacts on the quality of life and needs of rural cancer patients. Specifically, Girgis et al. (2000) found that younger women with breast cancer are three times more likely to report some need for help compared to older women. Furthermore, Baldwin and Usher (2008) found that women with gynaecological cancers reported difficulties accessing local support services and challenges regarding relocation for treatment.

In the light of the lack of literature on younger women with multiple myeloma living in rural and regional areas, and the consistent findings that myeloma patients face significant challenges to their quality of life that are potentially compounded by the distance from treatment centres, the current study aimed to gain greater insight into the experiences of rural women living with myeloma in rural Australia. The study specifically examined the experiences of mothers living with myeloma in rural and regional Australia, with the current paper reporting on issues regarding the impact of rurality and isolation.

## Methodology

### Research design and analysis

A cross-sectional retrospective qualitative methodology was employed in the current study. Data was gathered through semi-structured interviews, and subjected to interpretative phenomenological analysis. This approach allowed for a greater understanding of the internal world of the participants through the meaning of their lived experience (Hayes, 2000; Starks and Brown Trinidad, 2007).

### Participants

Participants were recruited through promotion of the study by the Leukaemia Foundation National Myeloma Coordinator and the ‘Myeloma’ newsletter. Interested participants contacted the first author directly and their eligibility for the study was assessed.

Eligible participants were women who: (1) had a diagnosis of myeloma, (2) had travelled and had treatment in a specialist metropolitan hospital for a period exceeding one week, in the last seven years, (3) were mothers<sup>1</sup> of dependent children living at home, (4) living in a rural and regional area. Women, who had been diagnosed in the previous 12 months, were undergoing intensive treatment, or receiving palliative care were excluded from the study. Five women with a mean age of 48 years at the time of diagnosis participated in the study, with the average age of their children being 15 years. The average post-diagnosis period was 5.2 years. The distance travelled by a participant to a specialist hospital ranged from 140 to 3000 km, and the time spent away from home for treatment ranged between one and five months. All participants had at least one stem cell transplant.

### Procedure

Prior to the study's commencement, it received approval from the Charles Sturt University Human Research Ethics Committee. After screening for eligibility was conducted by the first author, participants were provided with an information sheet and consent form, and a time was arranged for the interview. Interviews were conducted either face to face or via the telephone, and lasted approximately 60–75 min. All interviews were recorded and transcribed verbatim by the first author, with participants being assigned a pseudonym.

### Data analysis and interpretation

The data was analysed in four stages in accordance with interpretative phenomenological guidelines (IPA) (Smith and Osbourne, 2008; Willig, 2001). The first author was responsible for the primary analysis of the data, and three of the five (60%) transcripts were independently coded by the second author with emerging themes discussed and checked between the first two authors to ensure rigour within the interpretation. Revisits to the transcripts were made to ensure contextual consistency. An integration of cases followed the fourth stage, and a master list of themes was created, unearthing the participants' shared experience of the phenomenon.

## Results

The concept of disease isolation captures the core essence underpinning the interrelationship of the experience of living with a rare cancer with living in a rural and regional area of Australia. Three themes emerged: 1) isolation due to living with a rare cancer, 2) isolation within the myeloma population, and 3) isolation due to the disease effects and treatment. In the context of these results, isolation is defined as a sense of being alone or separated, both physically and psychologically, from potential sources of support, and of being different from others, which presented barriers to accessing support.

### Isolation due to living with a rare cancer

The significance and consequences resulting from the diagnosis of a rare or ‘unknown’ cancer has received limited qualitative attention within the field of cancer research. However, it surfaced as a core issue within the current study. Three of the five participants were unaware of the disease at the time of diagnosis, delaying the realisation of the severity of their situation. For example, Elizabeth stated: “no I had never heard of it. And even initially I thought “oh I've got

<sup>1</sup> A broad definition of mother was used, encompassing women with dependent children, therefore allowing for situations such as women with disabled adult children in their care, or women who are responsible for the care of grandchildren.

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