

# Deborah Thompson

Florence Nightingale Grants and Award Recipient Report

## Patient and carer experiences with multiple myeloma and myelodysplastic syndrome in regional Australia

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### Background

Multiple myeloma (MM) and myelodysplastic syndrome (MDS) are treatable but incurable conditions that can impose substantial symptomatic and side effect burdens on patients, with impacts on quality of life and experience for patients and carers. We sought to understand these impacts on life participation for patients and carers living in Tasmania, a regional area of Australia.

### Methods

Patients in Southern Tasmania were recruited by a myeloma nurse and invited to participate in focus groups. Focus groups were held online and face-to-face in 2022. Thematic analysis was used for focus group data.

### Results

A total of ten focus groups were held with 48 participants (n=23 with MM, n=9 with MDS, n=16 carers). Key themes arising from patient focus groups included Relationships (presence or absence of partner; bidirectional caring; communicating about their condition); Positivity; Perception of condition (own and others'); and Symptoms and Comorbidities (including presence of comorbidities; impact of symptoms; communication and management of symptoms). Not all patients had carers and some carers had health conditions, necessitating the patient with MM or MDS to take on a caring role (bidirectional caring). Some patients had other health conditions and could not always disentangle side effects/symptoms across conditions. Key themes arising from carer focus groups included Relationships (carer/patient relationship; carer as part of the caring team; carer relationship with friends/family); Change (negative and positive changes to the carer/patient relationship; change in carer activities; new role for carer; changes in the patient); and Needs (information; practical/instrumental; emotional). Not all carers experienced negative changes, or viewed their caring role as burdensome.

### Conclusions

Support for patients and carers is important, particularly if patients do not have a carer or may be acting both as a carer and care recipient. Although support for carers is important, consideration of the positive aspects of the caring role is likewise important for developing appropriate interventions and supports.