

Deborah Thompson

Florence Nightingale Grants and Award Recipient Report

Patient and carer experiences with relapsed/refractory multiple myeloma and myelodysplastic syndrome

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The Returned Sisters Memorial Grant provided me with funds to organise and run focus groups over a period of six months as part of the project. It also allowed time for regular meetings between myself and other project members.

Ten focus groups were held, with a total of forty-eight participants. For patients, the meetings focused on how they managed and talked about/communicated their symptoms, particularly with health professionals and family, plus how their everyday life had been affected. For carers, we focused on the difficulties and challenges of caring for someone living with relapsed/refractory multiple myeloma (RRMM) and myelodysplastic syndrome (MDS), as well as what was most rewarding.

Information was gathered from participants regarding their thoughts about remote symptom monitoring and completing a questionnaire whether online or written, for example about their health and care satisfaction. Including more patient-reported outcome evaluations in a patient's treatment pathway may uncover symptoms and assess quality of life issues not voiced.

Establishing and running the focus groups turned out to be more time-consuming than I had predicted. Due to Covid and also due to peoples' geographical locations we offered online meetings via Zoom as well as face-to-face. Having a predominantly elderly cohort, using email and Zoom was not easy for some. A Zoom test run was offered a couple of days before the meeting which proved helpful. Face-to-face groups were managed in the Cancer Support Centre at the Royal Hobart Hospital.

The groups were extremely successful. Participants mostly spoke freely and were very open with their thoughts and feelings. Fatigue was already a known symptom among patients with RRMM and MDS and this was confirmed repeatedly by participants. In one of the gatherings, a carer, a very private person, had not spoken to anyone previously about how they were coping. However, through meeting others, they opened up and engaged with another carer in particular and was encouraged to reach out to them following the meeting.

Holding these groups clearly helped patients and carers by talking with one another. They also helped me, as a practitioner, to have a greater understanding of symptom burden. I am very thankful to have received this grant and to have been given the opportunity to participate in the project. As a result of my experiences, I have seen the value of forming a Partners & Carers Group through my role as a Myeloma Support Nurse.