

Changes in Health-Related Quality of Life During Multiple Myeloma Treatment: A Qualitative Interview Study

Lise Sonsby, MD, Josephine Rahbæk Dueholm, MD, Dorthe Boe Danbjørg, RN, PhD,
Niels Abildgaard, MD, DMSc, and Lene Kongsgaard Nielsen, MD, PhD

PURPOSE: To explore whether patients with multiple myeloma changed their construct of health-related quality of life during treatment.

PARTICIPANTS & SETTING: 14 participants were selected from 10 hematology-oncology departments in Denmark.

METHODOLOGIC APPROACH: This interview study used a prospective, longitudinal, exploratory design. Semistructured interviews were conducted while participants were undergoing active treatment for multiple myeloma and six months after the baseline interview. Interviews were analyzed using systematic text condensation.

FINDINGS: The overall theme at baseline was insecurity, and the overall theme at six months was coping. The following subthemes were also identified based on participants' description of their health-related quality of life: concerns about having a meaningful life, dealing with everyday limitations, and maintaining social networks; adjusting expectations to abilities; expanding social networks; and exploring a meaningful life.

IMPLICATIONS FOR NURSING: Patients' ability to use coping strategies should be considered when screening for rehabilitation needs. During systematic in-depth symptom screening, unmet rehabilitation needs (e.g., physical functioning, fatigue, pain) may become apparent.

KEYWORDS health-related quality of life; multiple myeloma; patient-reported outcomes; response shift
ONF, 50(5), 635-645.
DOI 10.1188/23.ONF.635-645

Multiple myeloma (MM) is the second most common hematologic cancer, with an incidence of 7 in 100,000 people per year (Padala et al., 2021). However, the use of high-dose chemotherapy with autologous stem cell transplantation and novel therapeutics has improved survival (Rajkumar, 2020). Clinical presentation of MM can include bone lesions, renal insufficiency, anemia, hypercalcemia, and immunodeficiency, which can lead to infection (Kyle et al., 2003). Most patients with MM present with a high symptom burden and report lower health-related quality of life (HRQOL) compared to patients with other hematologic cancers (Baz et al., 2015; Boland et al., 2013; Johnsen et al., 2009; Jordan et al., 2014). HRQOL is defined as a multidimensional construct that encompasses perceptions of the positive and negative aspects of dimensions produced by disease or its treatment (Osoba, 1994).

Results from HRQOL measures are increasingly being used in healthcare decision-making, including in oncology drug development, patient care, organizational policies, and healthcare politics (Kluetz et al., 2018). Changes in HRQOL in patients with MM have mostly been investigated using patient-reported outcome measures (PROMs), such as the European Organisation for Research and Treatment of Cancer Quality-of-Life Questionnaire-Core 30 (EORTC QLQ-C30) and EORTC QLQ-Multiple Myeloma Questionnaire (EORTC QLQ-MY20) (Aaronson et al., 1993; Cocks et al., 2007; Nielsen et al., 2017). One concern with using longitudinal PROMs is that patients may understand items and response categories differently as they go through new life experiences, making comparisons between scores difficult (Edwards et al., 2018; Sommer et al., 2020). Measurement invariance is an important component of a PROM instrument