

Patient preferences for treatment decisions in relapsed/refractory multiple myeloma (RRMM) treatment: results of the PARTNER-project

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Background Over the past decade, treatment options for multiple myeloma have increased substantially. To find the best therapy for each individual patient, patient preferences should be taken into account whenever a decision regarding relapsed/refractory multiple myeloma (RRMM) treatment has to be made. Shared decision making is one of the keys to person-centered care. However, it is unclear how this is currently performed in practice, and how patients with RRMM experience decisions regarding their treatment.

Purpose The aim of this study is to investigate how RRMM patients and their carers can be involved in decisions related to medication, and to design tools to support shared decision making as well as training for HCPs. The ultimate goal is to contribute to a person-centered approach in RRMM care.

Method To get insight into patients' experiences and expected level of involvement, semi-structured interviews with RRMM patients and their carers were conducted. Besides, interviews with HCPs (hematologists, nurses, onco-coaches and pharmacists) have been performed to get insight into HCPs' experiences and perceived opportunities for patient and carer involvement. A convenience sampling technique was used to recruit participants from five different hospitals. Interview guides were based on a thorough review of the literature. Interviews were audio-taped and transcribed verbatim. An iterative inductive approach was used to analyze the findings. Interviews were conducted until data saturation. The protocol was approved by the ethical commission EC Research UZ/KU Leuven and the local committees in the participating hospitals.

Findings By mid-November, 43 interviews had been conducted, 17 with HCPs and 26 with patients / carers. Oncologists mentioned that, when different treatment options are available, the decision is based on preferences of patients and patient specific factors. For patients, however, it was unclear that they could participate in the decision regarding their treatment. Patients and carers felt their needs were insufficiently explored and asked for more in-depth conversations about their expectations and hesitations regarding the treatment. Although HCPs confirmed they were available for answering questions of patients, most patients experienced a threshold to contact HCPs for information. HCPs defined patient involvement as valuable and acknowledge it will contribute to an improved care for RRMM patients.

Conclusion HCPs claim that treatment decisions are based on specific factors, but this is not openly discussed with patients. Patients and carers will benefit of an open conversation with active listening and an in-depth exploration of the need for involvement. In a next phase of this project, tools to support HCPs and patients in shared decision making (e.g. question prompt list) will be developed using experience-based co-design, with the aim to contribute to a higher level of patient participation.