



The Myeloma Patient Outcome Scale (MyPOS) German Version

Gerlach C^{1,2}, Ramsenthaler C^{3,4}, Munder M^{2,5}, Weber M^{1,2}

¹ University Medical Center of the Johannes Gutenberg University of Mainz, Interdisciplinary Palliative Care Unit, ² uct, University Center for Tumours Mainz, Germany,

³ University Medical Center of the Ludwig Maximilians University of Munich, Department of Palliative Medicine, Munich, Germany

⁴ King's College London, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, London, United Kingdom,

⁵ University Medical Center of the Johannes Gutenberg University of Mainz, III. Medical Clinic and Polyclinic, Mainz, Germany

Introduction

- Multiple Myeloma is characterized by high symptom burden and impaired quality of life (QoL).
- Today 60% of MM patients belong to the fast growing segment of the population of over 65 years, 'baby boomers' are approaching.
- Medical progress results in prolonged survival of myeloma patients.
- Palliative care is accessible only for a minority of myeloma patients.
- No German standard measure of Myeloma QoL exists.

AIM: This project aims to provide a valid and reliable QoL and palliative needs instrument for MM with an emphasis on patient-centered aspects for clinical use in Germany. For this purpose the MyPOS was culturally adapted to the German context.

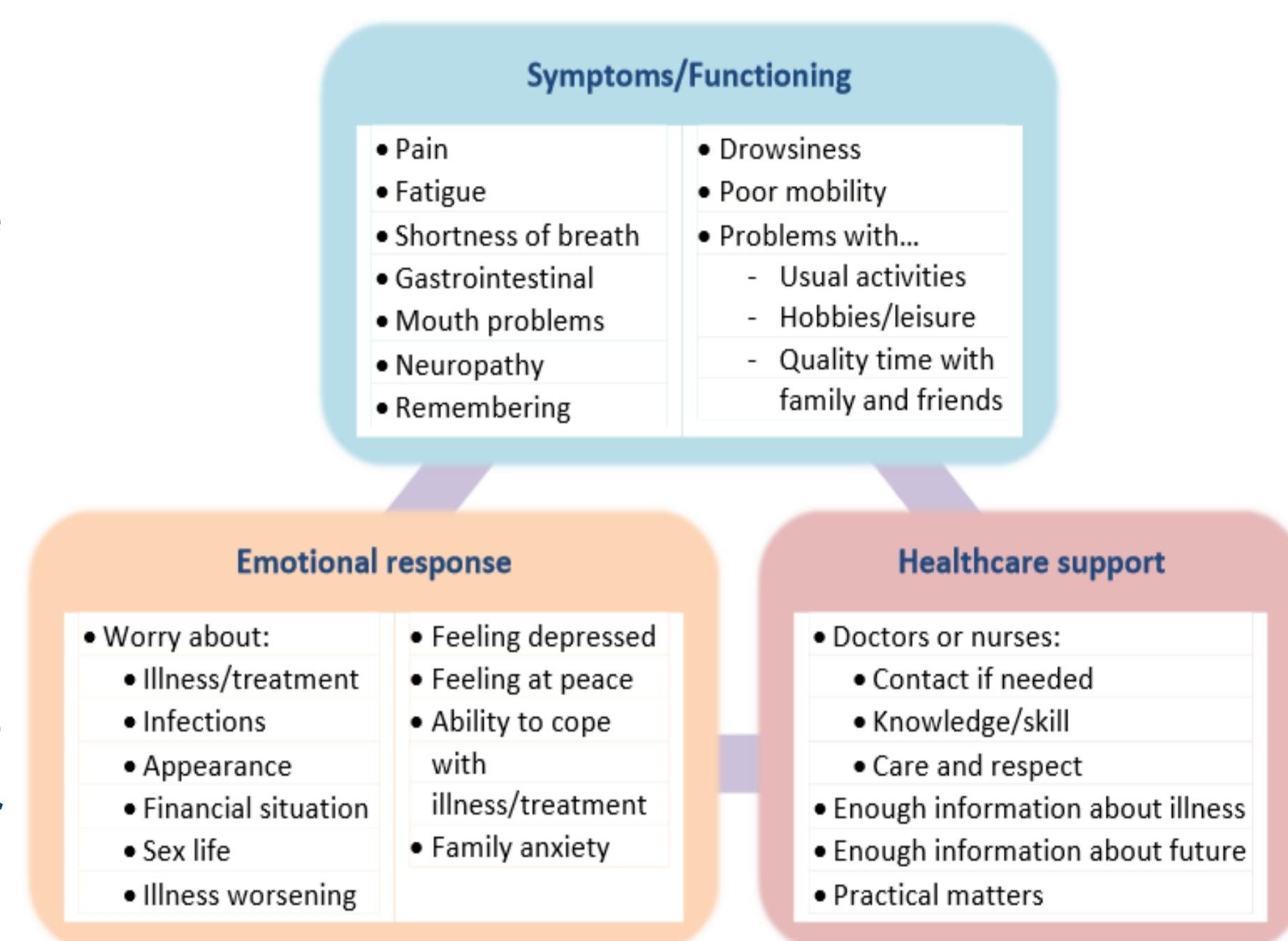
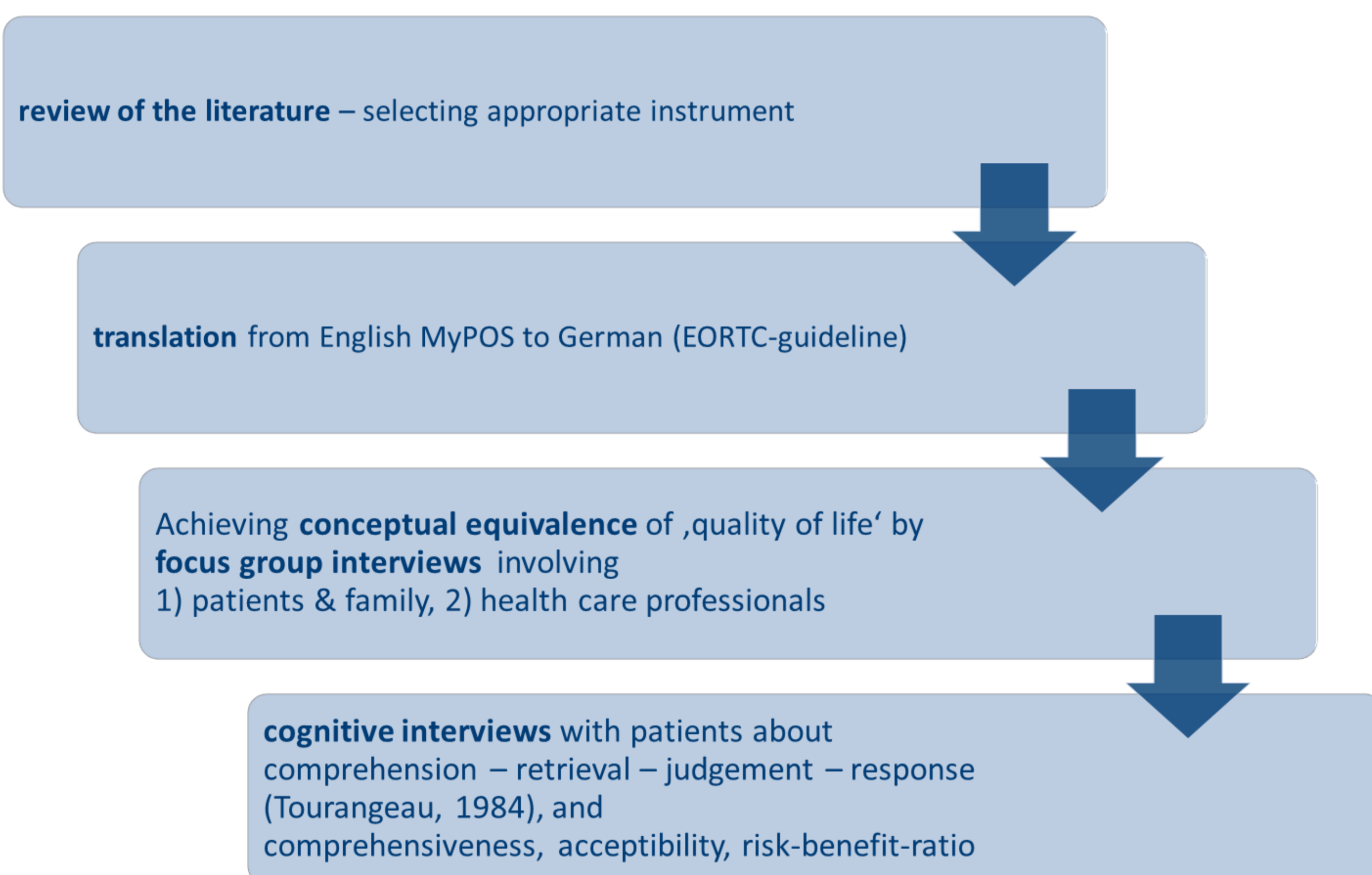


Fig. MyPOS as validated in the U.K. consists of 33 items with 3 subscales based on a QoL model with the dimensions symptoms, emotional response, and healthcare support.

Methods



participant	N	role	purposive sampling
focus group patient & family	5	patient, relative	role gender age ≥ 65/ < 65 J. remission/ stable disease/ progressive disease
focus group health care professionals	6	profession	physician, community care, nurse in hospital, psycho-oncologist, social worker
cognitive interviews	9	patient	gender age ≥ 65/ < 65 J. Karnofsky performance score, phase of illness socio-economic background

Conclusions

Integration of palliative care aspects seems to be required and welcomed by patients with MM. The MyPOS-German might be a valuable instrument to support haemato-oncologists in this respect. Testing models for its implementation is the next step. The patients' call for a caregiver version is an important research implication.

Please contact: christina.gerlach@unimedizin-mainz.de

Results

- Approved German translation and cultural adaptation of MyPOS
- Patients suggested a stronger focus on caregiver burden, to incorporate the wider patient support system
- Participants in Germany suggested more elaborate answer options regarding information needs, incorporating respect for the patient's possible wishes and right for less information:

	Umfassend informiert - ich weiß, dass ich jederzeit nachfragen kann	Habe Informationen erhalten, aber nicht immer verstanden	Wurde auf Nachfrage informiert - hätte aber gern mehr erfahren	Wurde sehr wenig informiert - einige Fragen wurden vermieden	Überhaupt nicht
8. Haben Sie so viele Informationen erhalten, wie Sie wollten?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

- Clarification of items in favour of more direct language:

	Keine Probleme	ein wenig	mäßig	stark	sehr stark
9. Wünschen Sie sich Unterstützung bei praktischen Problemen, die Folge Ihrer Erkrankung sind (z.B. finanzieller oder persönlicher Art)?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

- Careful consideration of issues which are not regularly addressed but important for patients:

Beantworten Sie bitte die folgende Frage unabhängig davon, ob Sie zurzeit sexuell aktiv sind.

Wenn Sie die Frage lieber nicht beantworten möchten, kreuzen Sie das nebenstehende Kästchen an und fahren Sie mit dem nächsten Abschnitt fort.

	Gar nicht	Selten	Manchmal	Meistens	Immer
13. Haben Sie sich in der vergangenen Woche Gedanken um Ihr Sexualeben gemacht?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

- Removal of health care satisfaction items because of their association with fear of unjustified criticism of staff and social desirability bias or non-response bias
- Content validity: Comprehensive QoL coverage of MyPOS confirmed
- Confidential treatment of MyPOS information important !
- Patients want the issues raised by MyPOS discussed with their doctor, and MyPOS may help to direct and focus conversations.

F20. Haben Sie den Eindruck, dass sich das ärztliche und das Pflegepersonal gut mit Ihrer Erkrankung auskennt und Sie kompetent behandelt?

F21. Werden Sie vom ärztlichen und Pflegepersonal sorgfältig und mit Respekt behandelt?