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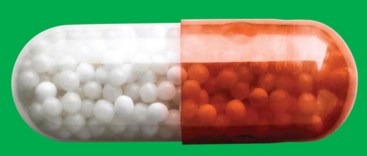

Needs and experiences of patients and healthcare professionals towards shared decision making in multiple myeloma clinical practice: A qualitative study in Europe

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BACKGROUND & OBJECTIVE

The inclusion of patient preferences in treatment decision making via **shared decision making (SDM)** is increasingly considered important in oncology. On such setting is **multiple myeloma (MM)**, in which complex trade-offs must be made. However, views about SDM **in MM clinical practice remain unknown**.

Objective: To identify the needs and experiences of stakeholders regarding SDM in MM clinical practice.

METHODS

Semi-structured interviews with patients (n=39) and healthcare professionals (HPCs) (n=20) including hematologists, oncology nurses, and trajectory counselors (guide patients throughout their disease trajectory).

DETAILED INFORMATION

- Participants:
- Analysis: framework method
- Patients and HCPs were involved as researchers and provided substantial input throughout the different steps of the study

RESULTS

Knowledge about SDM

Different levels of notions and conceptualizations regarding the term and application of SDM.

PATIENTS: Lack of knowledge regarding the term SDM

HCPs: Difficulties providing definition consistent with literature although being familiar with concept

Need for SDM

Ideal level of involvement is different for each patient:

Minimal involvement ⟷ Final decision making

- Stem cell transplantation
- Participation in clinical trials
- Possibility to refuse treatment at end-of-life stage (palliative care)

HOWEVER: all patients wanted to receive lay-language information regarding their disease and treatment (to different extents)

Implementation of SDM

Steps of SDM according to the OPTION instrument (Elwyn *et al.*) are applied depending on:

- Patients' personal characteristics
- Treating HCP
- Patients' country including national guidelines

Commonly raised barriers and facilitators

Barriers	Facilitators
1. ADOPTER LEVEL (= influencing factors related to the individuals who use the innovation which is the SDM process)	
− Cognitive impairment of patients − Low health literacy of patients − Language barriers − Poor communication skills of HCPs	+ Good communication skills and use of tailored information + Education of patients, which will result in patient empowerment + Professional translators
2. INNOVATION LEVEL (= influencing factors related to the SDM process or the collaborative decision-making approach)	
− Insufficient patient-centered information − Low conviction about SDM effectiveness − Lack of knowledge and skills in SDM	+ Education about SDM + Development of patient decision aids
3. DECISION LEVEL (= influencing factors related to the decision itself or that are antecedent to the SDM process)	
− Quick decisions (acute settings) − Small decisions − Perceived lack of treatment options	+ Important decisions
4. RELATIONAL LEVEL (= influencing factors related to the interpersonal interactions during the SDM process)	
− Fear of disagreeing with HCP − Bad patient-clinician relationship − Multiple doctors treating the same patient − Lack of openness of HCPs to involve patients	+ Trust between the patient and the clinician + Recognizing there are 2 experts in the clinical encounter + Patients accepting responsibility to be involved in decision-making
5. ENVIRONMENTAL LEVEL (= influencing factors related to practice environment and clinical setting)	
− Time constraints − Interruptions during consultations	+ Supportive policy on a national level and/or on the level of the hospital + Inclusion of SDM in clinical guidelines

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CONCLUSION

- **SDM should be applied in a patient-individualized way** considering that not all MM patients have a desire to be involved in the SDM process.
- **Patient organizations** can have an important role in **creating awareness** about SDM among patients and in **stimulating patient empowerment**.
- **Specific** guidelines regarding the concrete application **for SDM in MM should be developed**.
- Further **quantitative research** would be useful **to complement this study and determine associations** between patient characteristics and patients' ideal level of involvement.