

Shared or guided decision-making in the clinical immunology practice? A matter of personalization!

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Background

The rheumatology, dermatology, and gastroenterology departments at the Medical Centre Leeuwarden initiated a project to improve supportive care for immunological treatments. The aim is to enhance quality of care and increase patient engagement by identifying patients' needs and suitable supportive measures based on qualitative research.

The foundational model for this study is the 'Subjective Health Experience' (SHE) model by Bloem and Stalpers (Figure 1). Patients are categorized into four segments based on disease acceptance and perceived control, assessed through six questions. Each segment specifies patients' needs that form the base for the type of support that is required.

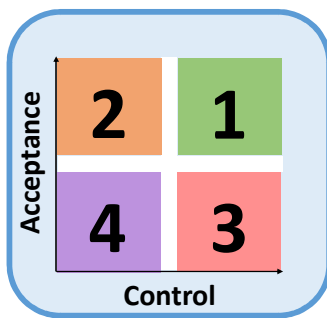


Figure 1: segments of the SHE-model: 1 High acceptance and control, 2 High acceptance and low control, 3 Low acceptance and high control, 4 Low acceptance and control

Aim

Enhance the quality of care for patients with immunological disorders by increasing patient engagement and determining which individuals benefit most from shared decision-making versus guided decision-making approaches.

Guide to tailor care interventions with the SHE-model, to align with patient preferences and needs

Methods

Semi-structured group discussions and individual interviews, moderated by an experienced facilitator:

- Healthcare professionals
- Patients with immunological conditions (rheumatoid arthritis/spondylarthritis, inflammatory bowel disease, or psoriasis/hidradenitis suppurativa).

Participants were asked to:

- Describe segment in behaviors, questions, and needs
- Outline the support provided by MCL to patients and the type of support suitable for each segment.
- Share thoughts on own condition and health (patients)

The results were analysed using the Matrix method (Groenland)

Conclusion

The SHE-model offers practical tools for personalizing supportive care for individuals with immunological conditions.

The model can be used for identifying suitable candidates for 'shared or guided decision-making'.

The key elements of supportive care are attention, acknowledgement, and active listening.

Results

WHAT

- Contact with healthcare professional**
- Consultation with healthcare professional**
- Information transfer and instructions**
- Mode and frequency of contact**
- Support from third parties** (e.g., family, caregivers, or other professionals)
- Digital support**
- Promoting lifestyle and therapy adherence**

Figure 2: Based on the discussions with patients and healthcare professionals it was determined **WHAT** types of supportive care can be offered to immunological patients

Segment 2

Characteristics

- Seeks guidance to better cope with the condition
- Attempts to prepare for consultations
- Consults multiple healthcare professionals
- Open attitude towards the treatment team

HOW

- Providing an overview when necessary
Continuously emphasizing that help and support are available
- Shared decision-making on the treatment plan
Structuring
- Orally: more concise explanation
Print/digital information: overview
- Less remote: phone (video call), email
Contact limited, as the situation demands
- Written referrals to other professionals
- Offering digital apps
- Mentioning, automate (new) behaviour by offering rules and programs

Segment 1

Characteristics

- Attaches a great importance to factual information
- Keeps up with new developments regarding the condition
- Prepares for healthcare visits
- Copes easily with setbacks

HOW

- The individual knows how they feel and takes the initiative on what to do
Offering affirmation: "Keep it up"
- Shared decision-making on the treatment plan
- Orally: more concise explanation
Digital information: new developments
- More remote: e-mail
Contact limited, as the situation demands
- Written referrals to other professionals
- Offering digital apps
- Highlighting importance and providing an overview of rules and programs

Segment 4

Characteristics

- Let's everything (preferably) sink in for a moment
- Can not decide treatment options, but does want help
- Asks a lot of attention from healthcare professionals
- Blames other people

HOW

- Sketching a clear timeline regarding the progression of treatment and support
Taking complaints seriously and invest time
- Guided decision-making on the treatment plan
Extra focus on mental aspects alongside physical aspects (early referrals)
- Orally: Step-by-step explanation, repeating
Print information: Aftercare, follow-up calls
- Direct contact: face-to-face (video call, phone)
Contact intensive
- Oral referrals to other professionals
Actively involve family/caregiver
- Discussing digital apps (along with caregiver)
- Explicitly guiding and offering aftercare of programs

Segment 3

Characteristics

- Questions why this happens to them specifically
- Wants to keep things the way they are
- Tends to blame themselves
- Struggles with shame for their illness

HOW

- Assistance in acceptance and in relearning one's body and mind
Being open, showing understanding
- Guided decision-making on the treatment plan
Extra focus on mental aspects alongside physical aspects
- Orally: More detailed explanation
Print information: information in sections
- More direct contact: hybrid phone/ face-to-face
Contact intensive
- Written referrals to other professionals
Actively involve family/caregiver
- Discussing digital apps (along with caregiver)
- Providing and explicitly discussing rules and programs

Figure 3: Based on the discussions with patient and healthcare professionals, characteristics of the four SHE-segments were determined. In addition, it was determined **HOW** the different types of supportive care (**WHAT**) should be offered

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