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RESEARCH ARTICLE

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Values clarification as part of shared decision-making with patients with limited health literacy in general practice

Laura Vriese^a , Jesse Jansen^a , Bart Knottnerus^b , Jany Rademakers^{a,b}  and Trudy van der Weijden^a 

^aDepartment of Family Medicine, Care and Public Health Research Institute - CAPHRI, Maastricht University, Maastricht, The Netherlands; ^bNivel - Netherlands Institute for Health Services Research, Utrecht, The Netherlands

ABSTRACT

Background: One-third of the Dutch population has limited health literacy (LHL), making it difficult for them to access, understand, appraise, and apply health information. Patients with LHL often adopt a more passive role in shared decision-making (SDM), relying on their doctor to make decisions. A key element of SDM is values clarification: understanding what matters to the patient including their values, preferences, and circumstances. Values clarification remains under-implemented in healthcare settings, despite its relevance to patients with LHL.

Aims: This study aimed to explore SDM in general practice consultations, focusing on values clarification, as observed by researchers and perceived by general practitioners (GPs) and patients with LHL and multimorbidity.

Methods: We video-recorded consultations between 20 GPs and 55 patients with LHL and multimorbidity. Subsequently, GPs and patients independently rated perceived SDM using SDM-Q-9. We used OPTION⁵ to quantitatively measure observed SDM. We qualitatively analyzed how and when values clarification occurred during consultations.

Results: The observed average SDM performance (OPTION⁵, range 0–100) was 10.6 (SD 8.2). GPs rated their SDM performance at 64.7, while patients rated it at 88.9 (SDM-Q-9, range 0–100). Qualitative analysis showed that values clarification was about multiple types of preferences, goals, and concerns. GPs typically initiated values clarification by proposing a treatment option and checking if the patient agreed, rather than deliberating collaboratively. This sample of patients with LHL rarely initiated values clarification, but if they did, it mostly occurred early in the consultation when they shared their reason for encounter.

Discussion: Observed SDM was low. We saw discrepancies between observed and experienced SDM, possibly due to the difference in how instruments measure SDM, or clinicians overestimating their SDM behavior. Patients reported even higher SDM levels than GPs, suggesting differing understandings or social desirability. Shared understanding of the problem seems an important requirement for values clarification. Values clarification was mainly initiated by GPs, but often resembling a paternalistic approach. Asking more open-ended questions may improve values clarification. Future research into perspectives and needs of GPs and patients with LHL could improve values clarification and SDM in general practice.

PLAIN LANGUAGE SUMMARY

People with LHL often struggle to understand health information and to take part in healthcare decisions. We studied SDM in general practice consultations with patients with LHL, focusing on values clarification: understanding what matters to patients, using video-recorded consultations and questionnaires. Detailed SDM and values clarification were limited. Commonly, GPs initiated values clarification, often using a directive approach with closed-ended questions; patients rarely initiated values clarification. Using open-ended questions and stimulating patients to reflect on what matters to them prior to the consultation may support values clarification.

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CONTACT Laura Vriese  Laura.vriese@maastrichtuniversity.nl  Department of Family Medicine, Care and Public Health Research Institute -CAPHRI, Maastricht University, PO Box 616, 6229 HA Maastricht, The Netherlands.

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Introduction

One in three Dutch people has inadequate or limited health literacy (LHL) (Heijmans et al., 2024). Health literacy entails people's knowledge, motivation, and competence to access, understand, appraise, and apply health information to make informed health decisions (Sørensen et al., 2012). LHL is more common among people with lower education, lower socioeconomic status (SES), older age, and multimorbidity (having two or more [chronic] health conditions) (Heijmans et al., 2019; Johnston et al., 2019; Pedersen et al., 2021; Skou et al., 2022; Sørensen et al., 2015). LHL is associated with poorer health outcomes and increased healthcare use (Allen-Meares et al., 2020; Berkman et al., 2011).

Shared decision-making (SDM) has been shown to improve outcomes, particularly for patients with LHL and multimorbidity (Durand et al., 2014; Ng et al., 2019). SDM is defined as “the process of clinician and patient jointly participating in a health decision after discussing the options, the benefits and harms, and considering the patient's values, preferences, and circumstances” (Hoffmann et al., 2014). Effective participation in SDM requires patients to understand complex health information, weigh alternatives, communicate with clinicians, and express what matters to them (Muscat et al., 2019). These abilities span the full spectrum of health literacy skills: from basic reading and writing (functional), to applying information and engaging in dialogue (interactive), to critically appraising options and asserting preferences (critical) (Muscat et al., 2019; Nutbeam, 2000). Many patients with LHL struggle with these tasks (Pel-Littel et al., 2024; Rademakers & Heijmans, 2018). They often find it difficult to articulate their symptoms and values (Bjørland & Brekke, 2015; Murugesu et al., 2022), and may defer decisions to their doctor, believing that “the doctor knows what is best” (Louizou et al., 2024; Roodbeen et al., 2020; Spronk et al., 2018). These barriers to SDM are often amplified in the context of multimorbidity, where trade-offs between treatments and values are more complex (Moffat & Mercer, 2015; Pel-Littel et al., 2019).

While SDM is increasingly promoted across care settings, much of the conceptual and empirical work has been developed primarily in hospital settings, focused on single-disease decision points (van der Weijden et al., 2017). In contrast, general practice often involves multiple, interconnected health issues, limited consultation time, and decisions embedded in a long-term relationship between patient and general practitioner (GP) (Pereira Gray et al., 2016; Silvério Rodrigues et al., 2019). As a result, structured SDM models, such as the three-step model by Elwyn et al. (2012), may not fully reflect how SDM unfolds in general practice. Nevertheless, a shared aim of SDM across settings and models is to make decisions align with what matters to the patient.

Clarifying what matters to the patient is central to SDM. This process is described in SDM models as *goal talk* (Elwyn et al., 2013; Elwyn & Vermunt, 2020) and *preference talk* (Elwyn et al., 2013; van der Weijden et al., 2017), and in patient decision aid literature as *values clarification* (Witteman et al., 2021). While these terms overlap, subtle differences exist: *goals* most commonly refer to desired (health) outcomes, *preferences* to choices among options, and *values* to the broader beliefs and life context that shape decisions (Pieterse & Stiggelbout, 2016). In this study, we adopt the term *values clarification* as an umbrella concept that encompasses these dimensions. It refers to the process of identifying what matters to a patient relevant to a health decision, including preferences, concerns (e.g., concerns about changes in health status), and other issues related to the patient context (Hoffmann et al., 2014; Witteman et al., 2021).

Values clarification is especially relevant, and often more challenging, for patients with LHL and multimorbidity (Oedekoven et al., 2019; Peinado et al., 2020). Yet, when this process is overlooked or insufficiently supported, decisions may fail to align with what matters to the patient, increasing the risks of over- or undertreatment (Mulley et al., 2012), non-adherence to treatment plans (Swift et al., 2021), and decisional regret (Joseph-Williams et al., 2011). For patients with LHL and multimorbidity, GPs play a key role in facilitating values clarification (Légaré & Witteman, 2013; Marteau et al., 2001), by actively helping patients to explore and articulate what matters to them. This enables more tailored, effective, and patient-centered decision-making (Murugesu et al., 2023; Muscat et al., 2019).

Despite its importance, values clarification remains one of the least studied and implemented components of SDM (Rake et al., 2022; Savelberg et al., 2020). Little is known about how it unfolds in routine general practice with patients with LHL and multimorbidity, even though it is precisely

the group for whom it may be most critical. This study addresses this gap by exploring how and when values clarification occurs in real-world GP consultations with patients with LHL and multimorbidity. We had two research questions: (1) To what extent does SDM with patients with LHL and multimorbidity occur in general practice, as observed by researchers and perceived by GPs and patients using validated instruments? and (2) How and when during these consultations does values clarification occur, as examined through qualitative analysis?

Methods

Study design

We performed an explorative observational study using a mixed-method approach. Real-life consultations between GPs and patients with LHL and multimorbidity were video-recorded, and both GPs and patients completed questionnaires. Video-recording is a reliable method for analyzing doctor-patient interactions with minimal impact on participant behavior (Arborelius & Timpka, 1990). Ideally, we would follow patients over time to capture the longitudinal nature of SDM in general practice; however, for practical reasons, we focused on single consultations. This study has been approved by the Research Ethics Committee of Maastricht University (FHML-REC/2022/094).

Participants

GPs

We recruited GPs from low SES areas across the Netherlands, to facilitate the inclusion of patients with LHL (Heijmans et al., 2019), aiming for variation in geography and work experience. GPs were contacted by phone or email by the researcher (LV), with a reminder after 2–7 days. They knew the study focused on SDM with patients with LHL but were unaware of specific measures (except the SDM-Q-Doc), or the focus on values clarification. Participating GPs received €100 as compensation.

Patients

GPs were asked to select three patients with presumed LHL and multimorbidity from their appointment list 1–2 days prior to the research day. Exclusion criteria were age under 18 or follow-up consultations that would not involve decision-making. GPs identified LHL based on proxy indicators including low education, language barriers, difficulty with understanding the GP and with expressing complaints and values, wanting to leave decisions to the GP, and a general passive attitude. Although relying on GP judgement introduces potential sampling bias, prior research shows that patients' health literacy is often overestimated and rarely underestimated, making it more likely that patients with LHL were correctly identified (Hedelund Lausen et al., 2018; Kelly & Haidet, 2007; Storms et al., 2019). Initially, the eligibility criterion multimorbidity was defined as multiple chronic conditions. However, we received feedback from participating GPs that this hampered recruitment. We therefore broadened the definition of multimorbidity to multiple (not necessarily chronic) conditions. This adjustment was implemented from the sixth included GP onward. Patients received a €20 gift card as compensation.

Procedure

Before the first consultation, GPs gave written informed consent to participate in the study and completed a demographic questionnaire. GPs were asked to invite eligible patients ten minutes before their appointment, during which the researcher explained the study privately and obtained the patient's written informed consent. The researcher accompanied the patient to the consultation room, started the video recording, and left the consultation room. For privacy, the patient was filmed from behind and the GP from the front. Immediately after the consultation, the GP turned off the camera and completed a questionnaire about their perceived SDM performance, while the patient completed a

similar questionnaire verbally with the researcher. We repeated this procedure throughout the research day, aiming for three patients per GP. The researcher requested an anonymized copy of the SOAP (Subjective, Objective, Assessment, Plan) notes for each consultation.

Measures

Background characteristics

GP and practice characteristics, as reported in the demographic questionnaire, are shown in [Table 1](#) in the results. The researcher also recorded the urbanization level (CBS, 2023a) and SES-WOA score (CBS, 2022) (socioeconomic score of neighborhoods based on wealth, educational level, and labor market participation) of the practice location.

Patient characteristics are also presented in [Table 1](#). We did not directly assess LHL, as comprehensive health literacy measurement is time-consuming and impractical in clinical practice (Dijkman et al., 2023). No simple tool captures all aspects of health literacy. Therefore, we used the widely adopted Set of Brief Screening Questions (SBSQ) to assess *functional* health literacy (i.e., difficulty with basic reading and writing). This three-item tool uses a 5-point Likert scale (0–4); an average score of ≤ 2 indicates low functional health literacy (Chew et al., 2004; Fransen et al., 2011).

Observed SDM performance (OPTION⁵)

Observed SDM performance was measured by analyzing the video-recordings using the validated Observing Patient Involvement (OPTION⁵) tool (Barr et al., 2015; Elwyn et al., 2013). This five-item tool ([Table 2](#) in results) uses a 5-point Likert scale (0: no effort – 4: exemplary effort), converted to a 0–20 scale for a total score of 0–100. Higher scores indicate higher SDM performance. Although an OPTION tool exists for patients with multimorbidity (Pel-Littel et al., 2019), we used the general version to allow comparison with the broader SDM literature, including studies among groups with low education or older age.

Perceived SDM performance (SDM-Q-Doc and SDM-Q-9)

Perceived SDM performance of both GPs and patients, was measured using the validated well-accepted Shared Decision-Making Questionnaire (SDM-Q-9), which includes nine statements rated on a six-point scale (0: completely disagree – 5 completely agree) (Kriston et al., 2010; Rodenburg-Vandenbussche et al., 2015). GPs completed the clinician version (SDM-Q-Doc). Patients completed the SDM-Q-9 verbally with the researcher. While most items concern treatment decisions, responses about other types of decisions (e.g., care assistance) were also approved. Following the SDM-Q-9 protocol, questionnaires with more than two missing responses were excluded from analysis. As only item 6 of the SDM-Q-9 addresses values clarification, we added two items for patients (Kunneman et al., 2023; Meakin & Weinman, 2002), and one for both GPs and patients (Agha et al., 2009) to explore this aspect more thoroughly. These were based on relevant literature, but not yet validated. All original and additional items are shown in [Table 3](#) in the results. Although the SDM-Q-9 is not specifically validated for patients with LHL, we tested it with an individual with LHL. To aid comprehension, we simplified verbal language when necessary and we used visual response options, displaying a scale with thumbs (Van Rooijen et al., 2021) ([Figure 1](#)), as visual aids help patients with LHL (Richter et al., 2023).



Figure 1. Visual scale for SDM-Q-9 for patients.

Data analysis

Quantitative analyses

Observed SDM performance (OPTION⁵). Two researchers (LV, MT) were trained using the OPTION⁵ tool via the OPTION⁵ manual (Elwyn et al., 2018), independently scoring five video-recorded consultations from a separate study (with permission). They compared ratings, resolved discrepancies, and repeated this process with additional consultations until they achieved an intraclass correlation coefficient >0.6, ensuring a shared interpretation of the items. After training, both researchers scored all consultations from our study. Differences in scoring were resolved by averaging their scores. When multiple decisions occurred, the main decision was scored, clarified with SOAP notes if needed. We calculated means, SDs, and ranges for each OPTION⁵ item, converting each to a 0–20 scale for a total score of 0–100.

Perceived SDM performance (SDM-Q-Doc and SDM-Q-9). The questionnaires that measured perceived SDM were analyzed using descriptive statistics. We added the scores of the original statements and converted these to a scale of 0–100, with no total score being calculated when more than two answers were missing (Kriston et al., 2010). Means of scores per statement were compared between the GPs and patients. We analyzed the additional statements similarly.

Qualitative data analysis

We used the Framework Analysis method to analyze our video-recorded consultations, combining inductive and deductive approaches, using five steps (Gale et al., 2013): (1) Familiarization with the data: LV and MT independently transcribed and coded all consultation segments related to values clarification (preferences, concerns, and contextual issues), including verbal and nonverbal (e.g., nervousness or embarrassment) communication and field notes. Coding was initially guided by the interview guide (inductive) and iteratively supplemented with codes derived from existing frameworks (deductive). (2) Creating a thematic framework: Data were grouped into categories (LV, MT, JJ, BK, TvdW). During this process, we noticed similarities with preexisting frameworks. Specifically, we used Elwyn & Vermunt's framework to classify different types of goals (Elwyn & Vermunt, 2020) and Rocque et al.'s framework to categorize strategies for values clarification (Rocque et al., 2020). (3) Applying the framework: The framework was applied to all data, with continuous adjustments. A second coder (MT) independently analyzed 10% of the consultations ($n=6$), randomly selected across tertiles. Inter-coder reliability was 0.82. Minor discrepancies were reviewed by the first coder (LV) and resolved through discussion, with consensus easily reached. (4) Charting: Quotes of each transcript were organized in the framework (LV, MT). (5) Interpretation: LV and JJ interpreted the data and discussed findings with research team (LV, JJ, BK, TvdW, JR). Coding was performed by nonclinical researchers. To ensure clinical relevance and validity, coding and interpretations were regularly discussed with team members including a GP (BK). The final coding tree is provided in [Supplementary File A](#).

Results

Of the 134 general practices approached, thirteen agreed to participate (9.7%), resulting in 20 GPs (ranging 1–3 GPs per practice) participating in our study. Practices mostly indicated lack of time as reason for non-participation. Through purposive sampling across the Netherlands, we obtained a diverse population in terms of geographic location and work experience of the GP, while focusing on low SES areas ([Table 1](#)). Most GPs (90%) believed their practice had above-average patients with LHL. Of the 64 selected patients, 58 agreed to participate (90.6%). We excluded three patients; two were under eighteen years old, and one patient did not have LHL (modified by GP after consultation). This resulted in 55 participating patients who varied in age, background, and functional health literacy (basic reading and writing skills).

Table 1. Characteristics of consultations, GPs, and their practices and patients.

Characteristics consultations (<i>n</i> = 55)			
Mean duration [range]		14 Minutes and 55 seconds [6–29 minutes]	
Discussed decisions (%)			
	Medication	28	(51%)
	Referral for tests in secondary care	11	(20%)
	Information and advice	7	(13%)
	Tests in primary care	4	(7%)
	Referral to another primary care professional (e.g., physiotherapy, speech therapy)	4	(7%)
	Lifestyle	1	(2%)
Characteristics GPs (<i>n</i> = 20)		<i>n</i> (%)	
Sex			
	Male	6	(30%)
	Female	14	(70%)
Age (years)			
	Mean [range]	46.8	[28–64]
	18–39 (<i>n</i> (%))	5	(25%)
	40–64	15	(75%)
	≥65	0	(0%)
Mean number of years working as GP [range]		15.0	[0–29]
Type of GP			
	Practice owner	13	(65%)
	Employed by a health center	2	(10%)
	Locum GP	3	(15%)
	GP in training (final year)	2	(10%)
Previous training in SDM		6	(30%)
Previous training in health literacy		3	(15%)
Characteristics general practices of the 20 GPs		<i>n</i> (%)	
General practice type ^a			
	Solo practice	6	(30%)
	Duo practice	5	(25%)
	Group practice	7	(35%)
	Health center	2	(10%)
Employed other physicians in practice			
	Assistant practitioner	20	(100%)
	Nursing specialist	7	(35%)
	Physician assistant	1	(5%)
	Care consultant in foreign language	3	(15%)
Degree of urbanization of location of practice (CBS, 2023a)			
	Extremely urbanized	4	(20%)
	Strongly urbanized	12	(60%)
	Moderately urbanized	0	(0%)
	Hardly urbanized	4	(20%)
	Not urbanized	0	(0%)
SES-WOA score of location of practice [range] ^b		–0.231	[–0.567 – 0.102]
Characteristics patients with LHL and multimorbidity (<i>n</i> = 55)		<i>n</i> (%)	
Sex			
	Male	24	(44%)
	Female	31	(56%)
Age (years)			
	Mean [range]	55.3	[19–85]
	18–39	11	(20%)
	40–64	26	(47%)
	≥65	18	(33%)
Migration background			
	None	26	(47%)
	Non-Western migration background	7	(13%)
	Western migration background	22	(40%)
Educational level regarding SOI 2021 (CBS, 2023b)			
	No education	6	(11%)
	Low education	32	(58%)
	Secondary education	15	(27%)
	High education	2	(4%)
Marital status			
	Unmarried, no partner	25	(46%)
	Having a partner, living alone	3	(6%)
	Having a partner, living together	7	(13%)
	Married	20	(36%)
Functional health literacy (basic reading and writing skills)			
	Inadequate functional health literacy (SBSQ ≤ 2)	15	(27%)
	Adequate functional health literacy (SBSQ > 2)	40	(73%)

^aGPs could choose multiple options (e.g., duo practice in a health center).^bSocioeconomic score of neighborhoods based on wealth, educational level, and labor market participation (Higher score reflects higher socioeconomic status. The average score in the Netherlands is about 0) (CBS, 2022).

Level of SDM performance

Observed SDM performance (OPTION⁵)

The inter-rater reliability on the total OPTION⁵ score was 74.5% (intraclass correlation coefficient = 0.76). OPTION⁵ scores ranged from 0 to 35 (on a scale of 0–100), with a mean score of 10.6 (SD 8.2), implying on average no to minimal effort in SDM performance (Table 2). Five consultations had a total score of 0.

Table 2. Observed SDM performance scores using OPTION⁵.

OPTION ⁵	n = 55		
	Mean	SD	Range
Item 1. Choice talk (scale 0–20 ^a) For the health issue being discussed, the clinician draws attention to or confirms that alternate treatment or management options exist or that the need for a decision exists. If the patient rather than the clinician draws attention to the availability of options, the clinician responds by agreeing that the options need deliberation.	2.2	2.4	0–7.5
Item 2. Deliberation (scale 0–20 ^a) The clinician reassures the patient or re-affirms that the clinician will support the patient to become informed or deliberate about the options. If the patient states that they have sought or obtained information prior to the encounter, the clinician supports such a deliberation process.	0.4	1.3	0–7.5
Item 3. Option talk (scale 0–20 ^a) The clinician gives information or checks understanding about the options that are considered reasonable (this can include taking no action), to support the patient in comparing alternatives. If the patient requests clarification, the clinician supports the process.	3.0	2.9	0–10
Item 4. Preference talk (scale 0–20 ^a) The clinician tries to elicit the patient's preferences in response to the options that have been described. If the patient declares their preference(s), the clinician is supportive.	3.3	3.1	0–10
Item 5. Decision talk (scale 0–20 ^a) The clinician tries to integrate the patient's elicited preferences as decisions are made. If the patient indicates how best to integrate their preferences as decisions are made, the clinician tries to do so.	1.6	2.6	0–10
Overall score (scale 0–100)	10.6	8.2	0–35

^aScore on a scale of 0–4, calculated to a scale of 0–20 (0=no effort, 1=minimal effort, 2=moderate effort, 3=skilled effort, 4=exemplary effort).

Perceived SDM performance (SDM-Q-9)

Questionnaires from five patients (and their corresponding GP questionnaires) were excluded due to more than two missing values, in line with the SDM-Q-9 protocol. Four of them found the statements too difficult to answer, and one deemed them not applicable. In total, we had complete data for 50 consultations (Table 3). In the nine original SDM-Q-9 statements, GPs rated SDM much lower than patients: 64.7 and 88.9 (on a scale of 0–100), respectively, with an absolute difference of 24.2. The difference was even larger for additional statements focused on values clarification, with an absolute difference of 30.5).

Qualitative analysis

We found three themes: SDM on problem definition, types of values, and strategies for values clarification. Illustrative quotes regarding these themes are described in Table 4.

SDM on problem definition

At the start of the consultation, before discussing treatment options or values, the GP and patient often needed to explore the reason for the visit. We identified two ways in which patients presented their reasons for encounter, often requiring a joint effort to define the primary problem.

1. *The patient asks directly for treatment or referral.* Some patients began consultations by requesting specific treatments (e.g., antibiotics) or tests (e.g., ultrasound or X-ray), often based on online information, advice from others, or past experiences with similar complaints or treatments. In response to these requests, GPs often explored the underlying problem together with the patient.

Table 3. Results of perceived SDM performance (extended SDM-Q-9) ($n=50$ consultations).

		Mean [range] GPs	Mean [range] patients
Original SDM-Q-9 statements^a			
Mean of original 9 statements		64.7	88.9
Statement 1	My doctor made clear that a decision needs to be made.	65.0 [0–100]	90.7 [0–100]
Statement 2	My doctor wanted to know exactly how I want to be involved in making the decision.	60.2 [0–100]	88.8 [0–100]
Statement 3	My doctor told me that there are different options for treating my medical condition.	59.7 [0–100]	84.0 [0–100]
Statement 4	My doctor precisely explained the advantages and disadvantages of the treatment options.	55.3 [0–83]	80.1 [0–100]
Statement 5	My doctor helped me understand all the information.	73.7 [17–100]	94.3 [0–100]
Statement 6	My doctor asked me which treatment option I prefer.	67.0 [0–100]	85.1 [0–100]
Statement 7	My doctor and I thoroughly weighed the different treatment options.	53.4 [0–83]	87.5 [0–100]
Statement 8	My doctor and I selected a treatment option together.	68.7 [17–100]	94.0 [33–100]
Statement 9	My doctor and I reached an agreement on how to proceed.	79.7 [17–100]	95.2 [33–100]
Additional statements^a			
Mean of additional statements		65.7	96.2
Statement 10	My doctor made me feel like I could ask or say anything.	–	95.7 [50–100]
Statement 11	My doctor took me seriously.	–	98.0 [67–100]
Statement 12	My doctor and I decided together what issues surrounding my illness and treatment were most important to me.	65.7 [0–100]	94.8 [0–100]

^aScore on a scale of 0–5, calculated to a scale of 0–100 (0=totally disagree, 1=strongly disagree, 2=somewhat disagree, 3=somewhat agree, 4=strongly agree, 5= totally agree).

2. *The patient tells a story without defining a problem.* Some patients told a long story with many different complaints and elements, where the GP summarizes the story and verifies that the most frequently mentioned or worst complaint is what the patient wants to discuss during the consultation.

Types of values

Once the problem definition is clear, SDM can be continued with a discussion of what matters to the patient. As described in the introduction, we use the term “values clarification” to refer to this process. GPs and patients clarified a range of values, including preferences, concerns, and goals:

1. *Treatment-specific preferences* included preferences for a specific treatment option (e.g., an injection, physical therapy, or increased pain relief for a patient with symptoms of bursitis).
2. *Practical preferences* included preferences for location (e.g., a blood test at home versus in the hospital, or collection versus delivery of medication) and preferences for follow-up (e.g., if and when a follow-up appointment will be scheduled).
3. *Preference to not decide.* In some cases, patients did not express preferences and redirected the question back to the GP, sometimes showing signs of discomfort such as hesitant responses or nervous behavior.
4. *Concerns* of the patient were often discussed. GPs commonly addressed concerns by discussing them and by reassuring the patient.
5. *Goals.* Three types of goals were differentiated. Most mentioned were fundamental goals, which relate to the patient’s values and life priorities. Less mentioned were functional and symptomatic goals, which relate to maintain or improve daily activities and independence, and manage or reduce specific symptoms or concerns, respectively. Although most conversations focused on improving symptoms, this was often not explicitly framed as a goal, for example, “*But that hip has gotten worse and it really hurts.*” (Patient-52), to which the GP responds: “*Okay, should I prescribe paracetamol, do you want that?*” (GP-20).

Strategies for values clarification

Theme 3 shows five strategies how values clarification has been applied.

1. *Invited by GP (close-ended).* GPs often initiated values clarification in a closed, more paternalistic manner, suggesting options (e.g., medication) and allowing limited space for patient input.

At times, this left little room for objection, resembling a form of informed consent (e.g., “*Do you think that’s a good idea? That we do a blood test and stool analysis?*” (GP-2)).

2. *Invited by GP (open-ended).* In some consultations, GPs explained options, incidentally using an option grid (one-page decision aid), followed by an open-ended question asking what the patient thought of the option(s). Sometimes, GPs asked patients about their values without explaining options first (e.g., “*What would you like?*” (GP-10)).
3. *Initiated by patient.* In some consultations, patients-initiated values clarification, mostly at the beginning of the consultation, by requesting a specific treatment or tests. Patients often referenced online information, advice from others, or past experiences with similar complaints or treatments when requesting treatments or tests. As noted earlier, this often led to the GP and patient to first clarify the problem together.
4. *Initiated by patient’s caregiver.* When patients brought someone with them to the consultation, often this person expressed values on behalf of the patient or helped the patient to clarify their values. Again, it was then often the case that first a problem had to be defined together.
5. *Extra attention and time.* A few GPs explicitly addressed functional health literacy by asking if the patient could read. Furthermore, in seven consultations, patient values were more extensively clarified. These consultations were on average longer (mean 21 min and 23 s) than the average of all consultations (14 min and 55 s).

Discussion

This study explored SDM, particularly values clarification, in consultations between GPs and patients with LHL and multimorbidity. We found that observed SDM performance was generally low, while perceived SDM, especially of patients, was much higher. Detailed SDM and values clarification were rare. A shared understanding of the problem appeared necessary for values clarification. Values clarification included preferences, concerns, and goals. GPs typically initiated these discussions after explaining treatment options, but often recommending a preferred treatment option and checking for agreement, rather than actively exploring what mattered to patients and aligning care accordingly.

Our observer-rated SDM performance (OPTION⁵) was low, especially compared to studies in cancer and palliative care (Roodbeen et al., 2021; Stubenrouch et al., 2016), where consultations tend to be longer and contextual knowledge of the patient’s values may be less available than in general practice, where long-term patient-provider relationship may span decades (Caverly & Hayward, 2020). While a study linked lower education to lower OPTION⁵ scores (Dillon et al., 2017), our scores were even lower. Similarly low scores were found in a study with older patients (Muscat et al., 2019). Since both lower education and older age are associated with LHL, this may explain our results. As in previous research (Baghus et al., 2024; Diendéré et al., 2021; Scholl et al., 2015), observer-rated SDM (OPTION⁵) was much lower than perceived SDM performance (SDM-Q-9), possibly due to socially desirable answers of patients (Harbisetar et al., 2019), clinicians overestimating their SDM behavior (Légaré & Thompson-Leduc, 2014), or because the difference in how instruments measure SDM: OPTION⁵ captures observable SDM behaviors (e.g., eliciting preferences), while SDM-Q-9 may also reflect relational and interpersonal experiences (Brito et al., 2015; Kasper et al., 2011; Pieterse et al., 2018).

In our study, GPs reported lower levels of experienced SDM than patients (SDM-Q-9). Few explorative studies have used this instrument with both GPs and patients. Nevertheless, one study found similar results, with GP residents experiencing less SDM than patients (Baghus et al., 2024), while another found no significant differences between GPs and patients (Den Ouden et al., 2022). These studies, however, focused on general and type 2 diabetes patients, not those with LHL. Research suggests that patients, especially those with LHL, may interpret SDM differently than clinicians, emphasizing relational over procedural elements, and valuing friendliness and attentiveness as indicators of involvement (Entwistle & Watt, 2006; Ho et al., 2024; Muscat et al., 2016). Since no SDM measurement tool is validated especially for people with LHL, we used the original SDM-Q-9 with additional explanations when needed. However, we are aware that patients with LHL might nevertheless have misunderstood some statements. Lastly, patients, particularly those with LHL, may be

Table 4. Themes and quotes qualitative analysis.

Themes	Illustrative quotes
1. SDM on problem definition	
a. The patient asks directly for treatment or referral	
Asking for treatment	Patient-16: <i>"I just think I really have an infection, that it just needs to be killed, with antibiotics or something."</i>
Asking for tests	Patient-32: <i>"I personally think the problem is my liver, I don't think it's doing well. Maybe I need to go to the hospital or get checked out. Yes, I'm afraid my liver might be damaged."</i>
b. The patient tells a story without defining a problem	(Patient-5 mentions various complaints in a long story, including pressure and pain in the sinuses, broken nights, getting less air, frequent colds, migraines, pressure from glasses, quality of life and headaches, and she mentions often that she snores, after which GP-6 summarizes patient's story and verifies if snoring is the main problem) GP-6: <i>"Because snoring is the most important thing I hear from you especially?"</i> (Patient-5 nods) (Patient-8 mentions various complaints in a long story, including pain in the right hand, and also in the fingers of the left hand, waking up at night, having the flu, asthma, shortness of breath, coughing, and after that again a lot about the pain in the right hand) GP-8: <i>"And is your question to me whether another injection is allowed or what uhm..."</i> Patient-8 (nods) <i>"Yes."</i>
2. Types of values	
a. Treatment-specific preferences	(GP-1 explains different options to a patient with most likely bursitis: an injection, physical therapy, or increased pain relief) Patient-2: <i>"I choose the injection" [...] "I've done physical therapy once, and it made me sore for two days, and then I had to go again, so that's not really an option for me."</i> GP-4: <i>"We have the replacement therapy, so the nicotine replacement therapy. Do you want to try, or do you want to do it without?"</i> Patient-15: <i>"No I want to try it, and if I... later, with more easy, I will leave it. But for the beginning I prefer to start with it."</i> Patient-42: <i>"I'm not really into taking medicine right away, I'd rather try something else first."</i>
b. Practical preferences	
Preferences for location	(GP says the lab can also do blood sampling at home) GP-2: <i>"Would you like that, or would you rather go to the hospital?"</i> [...] Patient-38: <i>"Yes well, then just let them [caregivers who take blood samples] come."</i> (Patient is prescribed medication) GP-2: <i>"Do you want it to be delivered?"</i> (Patient wants to pick it up directly, but that's not possible) Patient-38: <i>"No just have it delivered then."</i>
Preferences for follow-up	(GP and patient want to make a new appointment) GP-12: <i>"Should I go ahead and schedule something for a month from now? Does that work for you? Or not? Or would you prefer to call yourself?" (Makes a phone gesture)</i> Patient-21: <i>"Uh... Just do it this time, I'll call myself."</i>
c. Preference to not decide	(GP-1 asks patient about preference whether or not to supplement bronchitis treatment with a bronchodilator) Patient-3 (sits uncomfortably) <i>"May I ask something? What do you advise me, which is best?"</i> (Patient still does not want to choose after this, GP finally makes decision to add bronchodilator)
d. Concerns	(Patient-1 is concerned if spots on tongue could possibly be cancer) GP-1: <i>"I am always honest with you, this is not cancer." [...] "Are you reassured now, or do you need anything else from me to feel more at ease?"</i> (Patient-55 asks the GP to measure his blood sugar value) GP-9: <i>"Are you worried about that or not?"</i>
e. Goals ^a	
Fundamental goals	Patient-24: <i>"I don't want to stay here, because that house is quite big" [...] "Well ideally I would like to move one more time to a smaller house, maybe an assisted living facility. At least something big enough for me to live in."</i>
Functional goals	Patient-33: <i>"I just want to be able to talk clearer and, uh, articulate better."</i>
Symptomatic goals	Patient-25: <i>"I want less pain. But only for uh..."</i> (patient cannot find the word, but scratches the skin) GP-13: <i>"Itching?"</i> Patient: <i>"Yes, itching."</i>
3. Strategies for values clarification^a	
a. Invited by GP (close-ended)	GP-17: <i>"To be more certain that there is no infection, we can sometimes check with a blood test if there's an infection. Would you like that? If so, we can do it today."</i> GP-16: <i>"And would it be an idea, if they can't remove the wart this way, for you to go to the dermatologist?"</i>
b. Invited by GP (open-ended)	
Explaining options and clarify values	(GP explains that she thinks antibiotics can calm the abscesses) GP-8: <i>"So what would you think of that? To try that first?"</i> GP-5: <i>"What do you think about us giving you some tablets?"</i> GP-4: <i>"I'm going to show you the stop smoking- the options that we have to stop smoking."</i> (GP explains options to stop smoking with option grid) Patient-15: <i>"But can I have that option and also do come here and tell how I feel and all that?"</i>

(Continued)

Table 4. Continued.

Themes	Illustrative quotes
Asking what patient would like without first discussing options	GP-10: <i>"What would you like to do with that?"</i> GP-17: <i>"Did you have any ideas yourself?"</i>
c. Initiated by patient	Patient-13: <i>"I'd like to get blood drawn because sometimes I'm... I'm standing, or sitting in the car, or it doesn't matter what I'm doing... I'm kind of... I just don't feel really present."</i> Patient-55: <i>"I see, uh, blood sugar value, would you want to measure that sometime? I've never, uh."</i>
d. Initiated by the patient's caregiver	
Caregiver states values	Daughter patient-49: <i>"He needs help, someone to cook for him, and clean for him, and take care of him, and talk to him, that's what he- my father needs"</i>
Caregiver helps with values clarification	(GP indicates good pain relief is important, daughter patient helps with values clarification with patient) Daughter patient-20: <i>"Yes, diclofenac, she doesn't have diclofenac at home. Does that require a prescription?"</i> GP-11: <i>"Uh, diclofenac requires a prescription if you want it in 50 milligrams."</i> Daughter patient-20 (to patient-20): <i>"Would you like that?"</i> (Patient-20 nods)
e. Extra attention and time	
Extra attention for functional health literacy	GP-17: <i>"We've got info on nerve pain, but for a lot of people, it's quite difficult to read in Dutch. How is that for you?"</i> Patient-43: <i>"Read it out loud?"</i> GP-17: <i>"Well, are you able to read a text? Can you manage that?"</i> Patient-43: (nods) <i>"Yes."</i> (GP explains about medicine what he wrote down and verifies patient can read it) GP-12: <i>"Can you read well?"</i> Patient-16: <i>"Yes."</i> (laughs a little) GP-12: <i>"Well, I'm just asking, not everyone can."</i> Patient-16: <i>"No, I read it all just fine."</i>

^aWe used existing frameworks where appropriate, see data-analysis in methods for more information

more inclined to give socially desirable answers out of concern for damaging their relationship with their GP, despite assurances of confidentiality (Harbishettar et al., 2019; Tarrant et al., 2010).

We found that establishing a shared understanding of the patient's primary problem was often necessary before discussing options and values. Patients typically presented their reason for encounter in two ways, both requiring collaborative interpretation. Some requested specific treatments or tests early, often based on online information, advice from others, or prior experience. Given the prevalence of misinformation, filtering accurate information can be challenging, especially for patients with LHL (Carletto et al., 2025; Schulz & Nakamoto, 2022). GPs needed to redirect these requests into meaningful conversations addressing underlying values and misconceptions (Breivold et al., 2022; Southwell et al., 2023). Others struggled to articulate their concerns clearly, a common issue in general practice with patients with LHL (Murugesu et al., 2022; van der Weijden et al., 2017), requiring GPs to summarize and clarify. To address these challenges, incorporating a "step 0" to the SDM model, focused on shared problem understanding or "goal talk" (Elwyn et al., 2013; Elwyn & Vermunt, 2020), as suggested in prior research (Noordman et al., 2022; van de Pol et al., 2016), may be especially beneficial for this group (Noordman et al., 2022).

We found that values clarification was mostly initiated by GPs after explaining (treatment) options, but often by recommending the option they deemed most suitable. This aligns with previous research showing that GPs frequently adopt directive styles when communicating with patients with LHL (Arthur et al., 2009; Carvajal et al., 2023). Some GPs in our study used open-ended questions. While this is known to reduce misunderstandings (Garcia et al., 2010), and uncover broader patient values (Rocque et al., 2020), some patients seemed uncomfortable with this approach and redirected such questions back to their GP. This may reflect limited understanding or a preference for the GP to decide, which, especially under time pressure, may reduce GPs' willingness to explore patient values and reinforce a more directive style (Driever et al., 2022; Noordman et al., 2022). Moreover, ambiguity remains around when SDM is considered appropriate. Previous research shows that even similar clinical scenarios have been used to argue both for and against the use of SDM, reflecting differences in how SDM is understood across contexts and authors (van der Horst et al., 2023). GPs may therefore not always view a decision as preference-sensitive and thus may not perceive a need for SDM. Prior research further suggests that clinicians often conflate SDM with informed consent or offering choice only when guidelines are lacking (Driever et al., 2022). While a directive style can feel

supportive to some patients, it may unintentionally undermine autonomy and trust (Cribb & Entwistle, 2011; Hirsch, 2023).

Lastly, we observed that patients sometimes relied on caregivers to express values. While caregivers can support SDM and help articulate values (Bogaerts et al., 2023; Roydhouse et al., 2020), they may also complicate the process by imposing their own values, which may not align with the patient's (Ayalon et al., 2012; Marks & Arkes, 2008). This dual role of caregivers, as both supporters and potential influencers, requires careful attention from GPs to ensure that the patient's own values remain central in decision-making.

Strengths and limitations

Our study had several strengths. First, we measured SDM from three perspectives (observer, GP, and patient), providing a comprehensive understanding of the SDM performance including differences in perspectives (Gärtner et al., 2018). Second, using videos instead of audio allowed analysis of nonverbal communication, which might be particularly relevant with patients with LHL (Coleman, 2020; Wittenberg et al., 2018). Third, the diverse distribution of GP practices across urban and nonurban areas in the Netherlands enhances transferability.

Our study also had some limitations. First, selection bias may have occurred, as more enthusiastic GPs might have participated, and LHL and multimorbidity were not objectively confirmed (Hernán et al., 2004). Relying on GP judgement without formal health literacy assessment may have led to misclassification, though literature suggests GPs rarely underestimate health literacy (Hedelund Lausen et al., 2018; Kelly & Haidet, 2007; Storms et al., 2019). While we targeted patients with both LHL and multimorbidity, the communication challenges observed mostly relate to LHL, making findings relevant beyond the multimorbidity context. Second, we considered the Hawthorne effect, since GPs knew we were studying SDM and completed the SDM-Q-9-doc between consultations (Goodwin et al., 2017). To limit this, we did not mention our focus on values clarification. We opted to have the SDM-Q-9-doc completed immediately after each consultation rather than at the end of the day to avoid memory errors (Spencer et al., 2017, 2017). Third, although we used a visual response scale with thumbs in the SDM-Q-9 to aid comprehension, this may have introduced interpretation bias, as patients might have seen them as value judgements (good versus bad). Fourth, for practical reasons, our analysis did not account for the longitudinal GP-patient relationship or their history, which is a key aspect of general practice. Lastly, we did not compare our patient group to the general population. However, our study aimed to explore within-group dynamics rather than between-group differences.

Implications

Supporting values clarification in consultations with patients with LHL may benefit from practical adjustments. Using more open-ended questions can help patients articulate their values. However, as some patients with LHL may find open-ended questions difficult to answer, questions should be adapted to the individual's communication needs, for instance by tailoring questions to the patient's context (Muscat et al., 2021). Communication training may support GPs in this. Patients could also be encouraged to reflect on their values before consultations. This may help strengthen patient autonomy, even when consultation time is limited.

We recommend a mixed-methods approach for exploratory research in patient-provider communication, as combining quantitative and qualitative data provides deeper insights (Wasti et al., 2022). Further qualitative work, such as interviews, may be needed to fully understand GP and patient experiences and needs regarding values clarification, with the ultimate aim to develop health-literacy-friendly care in general practice.

Conclusion

Our study found low observed SDM and revealed a discrepancy between observed and experienced SDM in general practice. Patients with LHL and multimorbidity reported higher experienced SDM

than GPs, possibly due to differing interpretations or social desirability. It was often needed to first establish a shared understanding of the patient's primary problem. Values clarification included preferences, concerns, and goals, and was typically initiated by GPs through closed-ended questions or suggestions, resembling a paternalistic approach, while patients rarely initiated it. Using more open-ended, easy-to-understand questions could help in values clarification. Future research on experiences of GPs and patients with LHL and multimorbidity could help improve values clarification and SDM in general practice.

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Authors' contribution

CRedit: **Laura Vriese** (PhD candidate female, health scientist, expertise: health education and promotion): Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Visualization, Writing – original draft; **Jesse Jansen** (PhD, female, psychologist, expertise: medical decision-making): Conceptualization, Formal analysis, Funding acquisition, Methodology, Supervision, Writing – review & editing; **Bart Knottnerus** (PhD, male, GP, and researcher): Conceptualization, Formal analysis, Funding acquisition, Methodology, Supervision, Writing – review & editing; **Jany Rademakers** (PhD, female, psychologist, expertise: health literacy): Conceptualization, Funding acquisition, Supervision, Writing – review & editing; **Trudy van der Weijden** (PhD, female, trained as doctor, epidemiologist, expertise: implementation of shared decision-making): Conceptualization, Funding acquisition, Methodology, Supervision, Writing – review & editing.

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ORCID

Laura Vriese  <http://orcid.org/0009-0006-6870-7872>
 Jesse Jansen  <http://orcid.org/0000-0002-7739-0049>
 Bart Knottnerus  <http://orcid.org/0000-0001-7266-1746>
 Jany Rademakers  <http://orcid.org/0000-0003-2742-4543>
 Trudy van der Weijden  <http://orcid.org/0000-0002-7469-3781>

Data availability statement

The data that support the findings of this study are available from the corresponding author (LV) upon reasonable request.

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