

Shared Decision Making in Practice and the Perspectives of Health Care Professionals on Video-Recorded Consultations With Patients With Low Health Literacy in the Palliative Phase of Their Disease

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Abstract

Introduction. An important goal of palliative care is improving the quality of life of patients and their partners/families. To attain this goal, requirements and preferences of patients need to be discussed, preferably through shared decision making (SDM). This enhances patient autonomy and patient-centeredness, requiring active participation by patients. This is demanding for palliative patients, and even more so for patients with limited health literacy (LHL). This study aimed to examine SDM in practice and assess health care professionals' perspectives on their own SDM. **Methods.** An explanatory sequential mixed methods design was used. Video recordings were gathered cross-sectionally of palliative care consultations with LHL patients ($n = 36$) conducted by specialized palliative care clinicians and professionals integrating a palliative approach. The consultations were observed for SDM using the OPTION⁵ instrument. Potential determinants of SDM were examined using multilevel analysis. Sequentially, stimulated recall interviews were conducted assessing the perspectives of professionals on their SDM ($n = 19$). Interviews were examined using deductive thematic content analysis. **Results.** The average SDM score in practice was moderate, varying greatly between professionals, as shown by the multilevel analysis and by varying degrees of perceived patient involvement in SDM mentioned in the interviews. To improve this, professionals recommended 1) continuously discussing all options with patients, 2) allowing time for patients to talk, and 3) using strategic timing for involving patients in SDM. **Discussion.** The implementation of SDM for people with LHL in palliative care varies in quality and needs improvement. SDM needs to be enhanced in this care domain because decisions are complex and demanding for LHL patients. Future research is needed that focuses on supporting strategies for comprehensible SDM, best practices, and organizational adaptations.

Keywords

communication, decision making, limited health literacy, observational study, palliative care, stimulated recall, video recording

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Introduction

Around 20 million people a year need palliative care worldwide; in the Netherlands, in 2017, over 100,000 people went through a palliative phase before they

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died.^{1,2} The World Health Organization (WHO) defined palliative care as “an approach that improves quality of life of patients and their families who are facing problems associated with life-threatening illness.”³ Addressing the needs of patients and their partners/family is an important goal of palliative care. The recommended approach for making decisions in which the needs of patients and their partners/families are addressed is shared decision making (SDM).^{4–6} In SDM, health care professionals and patients decide the best treatment and care option together after discussing all available options, their pros and cons and personal preferences, and the circumstances of the patient.^{4–6} In the Netherlands, professionals are required by law to fully inform patients about all available options, risks and consequences, and become aware of the patient’s situation, personal needs, and invite the patient to ask questions.^{7,8}

SDM in palliative care can be complicated and challenging. Patients in the palliative phase of their disease sometimes receive inpatient or outpatient hospital care, which is highly complex and preference-sensitive.⁹ Additionally, emotional and psychological distress, the prospect of death, and cognitive abilities of patients (as a result of advanced age, illness, or educational level)^{10–12} result in patients having problems processing information.^{11,13} The complex and preference-sensitive care and difficulties with processing information in palliative care could lead to reduced communication and, in turn, hampered SDM.¹⁴ Attention to SDM is therefore warranted for all patients in palliative care.

Bearing in mind the complexity of decision making in palliative care for all patients, SDM is an even bigger challenge with and for patients with limited health literacy (LHL).^{15,16} LHL is defined as “the limited ability to access, understand, appraise, and apply health information to make judgments and make decisions in

everyday life concerning healthcare.”^{15–18} In Europe, almost 48% of the population experience these difficulties.¹⁹ The estimated proportion of adults with LHL in the Netherlands is 29%.²⁰ Groups most at risk of LHL are semiliterate people (2.5 million in the Netherlands), people with 10 years or less of formal education, the elderly, people with low socioeconomic status (SES), chronically ill people, and first-generation migrant workers with little formal education and low SES.^{20–22} Nevertheless, LHL is also found in people with medium or high levels of education, indicating that LHL is determined by more factors or situational elements than only the number of educational years, and can be seen as both a trait or a state.^{23,24} Because of the difficulties LHL people have with health and health care information, this complicates communication in health care and, in turn, hinders SDM.^{25,26} As a consequence, patients with LHL are involved in SDM less often, have less favorable health outcomes, spend more time in the hospital, and have a lower medication and treatment compliance.¹²

Health literacy is increasingly gaining attention in health care practice. The WHO considers it as one of the central determinants of inequality in health care.²⁷ Communication strategies that aim to improve communication between professionals and LHL patients include the teach-back method, chunk and check, and the use of pictures and illustrations.^{18,28–31} In palliative care, limited research has been carried out focusing on SDM and LHL.²⁹ We do know that SDM is not always used in Dutch clinical practice.^{32–34} Professionals want more time to communicate with LHL patients in palliative care because, in their view, time is the most important aspect for resolving the current barriers.^{35,36} We also know that palliative patients want to engage in SDM³⁷ and value good communication with their professional highly.³⁸ This study aimed to examine SDM in palliative care for LHL patients conducted by specialized palliative care clinicians and professionals integrating a palliative approach, and to assess these professionals’ perspectives on their own SDM.

Methods

Study Design

An explanatory sequential mixed methods design was used, in which fragments from the video-recorded consultations were used in interviews to further understand quantitative observations of SDM. Cross-sectional, video-recorded consultations were gathered. Video recordings of consultations are a valid method for examining communication between health care professionals

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and patients.³⁹ SDM was investigated by measuring the extent to which professionals involved patients in SDM, using the “Observing Patient Involvement in Decision-Making” (OPTION)⁵ instrument.^{40–42} Sequentially, the professionals reflected on their own SDM behavior and how they thought they had involved their patients in SDM during “stimulated recall interviews.”^{43–46} Video-recorded consultations were used to stimulate the professionals’ recall of the outpatient consultation and to discuss the professional’s thoughts, meanings, and subjective reactions elicited by it.^{44,45}

Setting and Procedure

Consultations in oncology, radiation oncology, pulmonary disease, and specialized palliative care departments were the setting for this study, including professionals integrating a palliative approach and specialized palliative care clinicians. These clinical areas were chosen because of the clear correlation between LHL and poorer health: asthma and chronic obstructive pulmonary disease (COPD), diabetes, cancer, cardiovascular disease, and psychological problems are significantly more common in people with LHL in the Netherlands.¹⁶ Data were collected between April and October 2018 (RR and WvdH) as part of a larger project called “A Basic Understanding,” which aims to improve information provision and decision making with LHL patients in secondary palliative care (Appendixes 1 and 2). Four Dutch hospitals participated, located in different regions of the Netherlands (three academic hospitals and one general hospital). To protect the privacy of participants, recordings were anonymized by deleting all data that could reveal the identity of the participants. In video recordings, when expressions of names that could reveal the identity of participants were audible, the audio was deleted. The study protocol was evaluated by the Medical Ethics Committee of the Radboud University Medical Center, which exempted the study from formal ethical approval (File Number CMO: 2017-3623).

Participating hospitals appointed an employee as the local project manager—in two cases a specialized nurse and in two cases a medical specialist—functioning as the contact point for the researchers. These local project managers invited professionals in the hospital to participate. Eligible patients were preselected by the local project manager based on inclusion criteria^{47,48} and convenience sampling, and were informed by phone by the project manager or researcher approximately a week before the planned visit to the hospital. At that moment, the patients also received information explaining the background of the study,

the purpose of the video recordings and the procedures, and contact details of the researchers.

Patients who expressed interest were approached by a researcher in the waiting room before seeing their health care professional. If patients decided to participate, inclusion criteria were checked in a private room at the hospital using a short questionnaire. The researcher asked the questions and registered the answers. Furthermore, the patients and professionals signed an informed consent form (IC) before the video recording of the consultation. To make sure that LHL patients could fully understand the patient information form and IC forms, tailored versions were created using plain language. Both were tested by a panel of the Dutch ABC Foundation (low literacy volunteers who regularly assess the understandability and applicability of texts). An unmanned video camera was installed in the consulting room, pointing at the professional, making them visible and audible on video; patients (and partners/family) were only audible. Patients received a gift voucher between 10 and 30 euros, depending on the amount of participation in the project. The video recordings were stored in a secured and locked room at Nivel; only researchers had access to them. Four to 8 weeks after the initial recording, professionals looked back at carefully selected fragments of their own consultations about SDM with a researcher (RR or WvdH). These stimulated recall interviews were conducted at their workplace.

Participating Patients and Professionals

LHL patients in this study are defined as per the definition given earlier in the introductory paragraph.¹⁵ They are aged ≥ 18 , have been diagnosed with cancer or COPD, and are in the palliative phase of their disease. The assessment of the palliative phase of patients for both cancer and COPD was conducted by the local project manager or professional of the participating hospital, always someone with a medical background capable of making this assessment. In this assessment, they adhered to the definition of palliative care given in the introduction.³ The assessment of the level of health literacy of the patient was checked and determined by using a short questionnaire, asking the educational background of the patient and asking three questions indicating health literacy: “Many people find it difficult to read hospital leaflets—how about you?” “Many people find forms and filling them out difficult—how about you?” and “Do you need help filling out forms or reading leaflets?”^{47,48} An educational background at or lower than vocational level or less than 10 years of formal schooling, and

affirmative answers to at least one of three health literacy questions indicated LHL. Patients were also included when professionals considered them to be LHL (expert opinion). This consideration prevailed the educational background and the “three question assessment” of LHL, because LHL is also found in people with medium or high levels of education and patients often hide that they do not understand health information.^{16,31} Therefore, patients could easily circumvent our assessment in the questionnaire. Patients were excluded from participating if they 1) did not speak the Dutch language, 2) were in the terminal phase of their disease, 3) had a severe intellectual disability, or 4) had a psychiatric problem or dementia. The professionals included were physicians and nurses who regularly conduct consultations with patients with cancer and/or COPD and discuss palliative care and/or treatment options.

Instrument and Analyses

*Option*⁵. The OPTION⁵ instrument is a reliable and valid method for investigating SDM.⁴⁰⁻⁴² Five SDM items are coded on a 5-point Likert-type scale, ranging from 0 = “zero effort observed” to 4 = “exemplary effort,” as presented in Table 1. The OPTION⁵ instrument includes the rating of communication by professionals and patients in the consultation related to prior conversations.⁴⁹ This means that, for instance, if a professional or patient refers to a prior establishment of goals, preferences, or decisions, this is included in the assessment of SDM. Coding was conducted using BORIS software.⁵⁰ All 40 video-recorded consultations were initially checked by one main observer (RR) on whether SDM was conducted and if SDM could be measured using OPTION⁵. Thirty-six consultations were observed by the main observer, and 25% (10 consultations) were also reviewed by a second observer (JN) to ensure reliability. Both observers had been trained to use the OPTION⁵ instrument. When multiple decision-requiring issues (or index problems, as referred to in OPTION⁵)⁴⁹ were discussed in one consultation, the main observer selected one of the issues for observations. These issues were selected for observation when a decision was needed in the relevant consultation, or when patients addressed the issue to be solved. The selected issues were communicated to the second observer. Interrater reliability between observers was calculated using Cohen’s kappa (0.80), indicating a substantial interrater agreement.⁵¹

The total OPTION⁵ score is generated by converting the scores to a 0 to 100 scale and then calculating the

average. The higher the score, the higher the level of SDM. Potential determinants for applying SDM by professionals (type of disease, sex of patients and professionals, age of patients, consultation duration and the type of consultation) were analyzed using multilevel analysis [with professionals as Level 1]. All variables were added to allow an explorative analysis of any possible associations with SDM.⁵²⁻⁵⁵ Because of the explorative nature of our analysis, every item in the OPTION⁵ instrument was additionally calculated independently. Data was analyzed using Stata version 15.⁵⁶

Stimulated Recall Interviews. Before conducting the interviews, the video-fragments used in the interviews were selected individually by two researchers (RR and WvdH), focusing on three types of occurrences in the videos: 1) the expressions of emotion by the patient, 2) potential manifestations of misunderstandings between patient and professional, and 3) elements of SDM (using the OPTION⁵ protocol^{40,41,49}). After selecting fragments, the researchers compared their findings, in which differences were resolved through discussion, leading to a maximum of three fragments to be viewed and discussed in the interviews. Interviews took place 4 to 8 weeks after the initial recording. The professionals were asked to recall the consultation and give their perspectives on communication, SDM, and other aspects that could facilitate or hinder communication with LHL patients.⁵⁷ The topic list (Appendix 3) used during the interviews was developed based on literature and experience from previous research⁵⁸ (JN, SvD). Feedback was provided on initial versions of this topic list by researchers with ample experience in researching LHL (JN, SvD, GB, RR). All the interviews were audio-recorded and transcribed verbatim (RR and WvdH). To increase credibility, all professionals conducted a member check, that is, to check the completeness of the transcripts. Participants did not provide feedback on the results of our study.

The interview transcripts were analyzed using deductive thematic content analysis.⁵⁹ All transcripts were read carefully and parts in which elements of SDM were mentioned were selected (RR). Initial codings were applied to these segments independently by one researcher (RR). These codings were reviewed and complemented by a second researcher (JN). Discrepancies between researchers were resolved through discussion, and modifications to the initial categories were made when necessary (RR, JN). All categories and patterns that emerged during analysis are illustrated by multiple quotes that were translated into English and edited, increasing readability without losing meaning or context.

Table 1 Observations of Palliative Care Consultations With LHL Patients Using the OPTION⁵ Instrument, per Item and Corresponding Scores

Items	Scores ^a				
	0	1	2	3	4
1. For the health issue being discussed, the clinician draws attention to or confirms the fact that there are alternate treatment or management options or that a decision needs to be made. If the patient rather than the clinician draws attention to the availability of options, the clinician responds by agreeing that the options need deliberation.	4	8	10	6	8
2. The clinician reassures the patient or reaffirms that they will support the patient in informing them or deliberating the options. If the patient states that they have sought or obtained information before the meeting, the clinician supports the deliberation process.	12	11	6	7	0
3. 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.	2	7	16	10	1
4. The clinician makes an effort to elicit the patient's preferences in response to the options that have been described. When the patient states their preference, the clinician is supportive.	11	10	11	3	1
5. The clinician makes an effort 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 makes an effort to do so.	9	11	12	3	1
Total number of OPTION ⁵ observations per score	38	47	55	29	11

OPTION⁵, observing patient involvement in decision-making instrument.

^aScore description: 0 = No effort (zero effort observed in the video-recorded consultation); 1 = Minimal effort (effort to communicate could be implied or interpreted in the video-recorded consultation); 2 = Moderate effort (basic phrases or sentences used in the video-recorded consultation); 3 = Skilled effort (substantive phrases or sentences used in the video-recorded consultation); 4 = Exemplary effort (clear, accurate communication methods used in the video-recorded consultation).

Results

Sample Characteristics

Table 2 provides an overview of the medical and demographic characteristics of participating patients and professionals. Forty consultations were video-recorded, SDM was assessed in 36. Four videos were excluded, because consultations were too short, or in hindsight, the intellectual disabilities of patients were too severe. Thirty-six individual patients and 19 individual professionals participated in the video-recorded consultations. During two video-recorded consultations, two professionals participated simultaneously in the consultations. Therefore, 38 consultations were discussed with 19 professionals.

SDM in Practice

The mean SDM score (0–100 score) was 40 (see Table 2). Of the OPTION scale items (see Table 1), the highest average score was observed for Item 1 (2.2; professional drawing attention to or confirming options and the need for a decision), the lowest average score was observed for Item 2 (1.2; professional reassures or reaffirms support to the patient for becoming informed or deliberate options).

This indicates that the extent to which clinicians involve patients in SDM in practice lies between a minimal effort (effort to communicate could be implied or interpreted) and a moderate effort (basic phrases or sentences used).

Potential Determinants Associated With SDM. Table 3 shows the results of the multilevel analysis and the determinants associated with SDM for each OPTION⁵ item. Potential determinants were the professionals themselves (on total SDM rates and individual items), composite consultations and consultation duration. Composite consultations are consultations in which multiple and sometimes unexpected or unplanned issues or complications were discussed. These consultations have a significantly higher degree of observed SDM for the total SDM rate and for Items 1 and 2. Consultation duration is significantly related to Items 1 and 3, indicating that longer consultations have a higher degree of observed SDM for these items.

Assessing Health Care Professionals' Perspectives on Their Own SDM

To illustrate categories and patterns that emerged during analyses, multiple quotes were used. Themes and quotes are presented in Table 4.

Table 2 Characteristics of Patients and Health Care Professionals in the Video-Recorded Consultations, in the OPTION⁵ Observations and the Stimulated Recall Interviews

<i>Video-recorded consultations (40 recorded^a; 36 selected for observing SDM)</i>			
Duration (in minutes) (<i>n</i> = 36)	Mean	SD	Range
	22.50	13.03	5.35–69.35
Type of consultations (<i>n</i> = 36)	Number	Percentage	
New	3	8	
Control (i.e., follow-up consultations)	25	70	
Composite ^a	8	22	
Type of decision (index problem) (<i>n</i> = 36)			
On treatment options or examinations	8	22	
On progress of treatment (e.g., time intervals between chemotherapy)	6	17	
On alleviating disease symptoms	14	39	
On alleviating side effects of treatment/medication	4	11	
On rehabilitation after treatment	4	11	
<i>Characteristics of patients in video-recorded consultations (36 individual patients included)</i>			
	Mean	SD	Range
Age (in years) (<i>n</i> = 35 ^b)	68.7	10.2	45–88
Condition (<i>n</i> = 36)	Number	Percentage	
Cancer	23	64	
COPD	13	36	
Sex (<i>n</i> = 36)			
Male	19	53	
Female	17	47	
<i>Characteristics of professionals in video-recorded consultations (19 individual professionals included)</i>			
Sex (<i>n</i> = 19)	Number	Percentage	
Male	9	47	
Female	10	53	
Profession (<i>n</i> = 19)			
Pulmonologists	7	37	
Physician's assistant in pulmonology	1	5	
Oncologists/internal medicine physicians	3	16	
Radiotherapists	6	32	
Specialist oncology nurse	1	5	
Specialist palliative care nurse	1	5	
	Mean	SD	Range
Average number of consultations per professional (<i>n</i> = 38 ^c)	2.0	1.1	1–4
Type of professional per consultation (<i>n</i> = 38 ^c)	Number	Percentage	
Nurse/physician assistant	6	16	
Physician in training ^c	6	16	
Physician	26	68	
<i>OPTION⁵ observation results per item (36 selected for observing SDM)</i>			
	Mean	SD	Range
Item 1	2.2	1.3	
Item 2	1.2	1.1	
Item 3	2.0	0.9	
Item 4	1.3	1.1	
Item 5	1.3	1.0	
Total 0–100 converted observation results (to a 0–100 scale)	40	21.3	0–85

(continued)

Table 2 (continued)

<i>Stimulated recall interviews</i> (19 individual professionals interviewed; 38 consultations discussed ^d)			
	<i>Mean</i>	<i>SD</i>	<i>Range</i>
Duration (in minutes, per consultation)	24.05	12.29	12.15–01.09.19
Number of consultations discussed per professional during interviews ($n = 38^d$)	2.0	1.1	1–4

COPD, chronic obstructive pulmonary disease; OPTION⁵, observing patient involvement in decision-making instrument; SD, standard deviation; SDM, shared decision making.

^aFour videos were excluded, because consultations were too short, or in hindsight, the intellectual disabilities of patients were too severe. Composite consultations are consultations in which multiple and sometimes unexpected or unplanned issues or complications were discussed in addition to the index problem.

^bOne patient was included solely based on expert opinion; the age of the patient was therefore not recorded.

^cDuring two video-recorded consultations, two professionals participated simultaneously. Therefore, 38 profession types were present in 36 video-recorded consultations.

Physicians in training were: one pulmonologists/oncologists (three video-recordings), one internal medicine physician (one video-recording), and two radiotherapists (both one video-recording).

^dWe met two professionals twice to allow the interview to be completed.

Multiple consultations were discussed during most individual interviews with professionals.

Gender and profession descriptors of the interviews are identical to “Characteristics of professionals in video-recorded consultations.”

During two video-recorded consultations, two professionals participated simultaneously. We met these professionals separately to discuss the interviews. Therefore, the total number of consultations discussed is 38.

Varying Degrees of Involving Patients in SDM. In the process of involving patients in SDM, all professionals in the interviews described themselves as advisors; varying degrees of involving patients could be identified from that outlook. The most limited involvement of patients occurred when professionals only proposed one option to the patient and asked them to approve it. This is indicated in Quote 1 (see Table 4), in which a female pulmonologist reflects on a preselected video fragment from the consultation and is asked whether the decision was made together with the patient. In another variation of limited patient involvement, the professional’s proposal was framed as their preferred decision. In Quote 2, a female radiotherapist/oncologist reflects on a fragment and was asked the same question as indicated in Quote 1; whether the decision was made together with the patient. Nevertheless, some professionals who presented patients with only one option tried to involve their patients by using another question for requesting approval. In Quote 3, a female pulmonologist reflects on a fragment and was asked the same question as indicated in Quotes 1 and 2. At the other end of the gradient, one professional reported a lot of patient involvement. In this example, the patient in the video fragment asked a male pulmonologist for a medical examination that, according to the professional, was irrelevant for treatment policy, as is indicated in Quote 4.

Perceived Barriers to Involving Patients in SDM. Multiple barriers to involving patients in SDM were identified

by the professionals in the interviews. The first is marked by the requirements and necessities of treatment protocols that professionals are bound to adhere to. In Quote 5, after reflecting on a fragment, a male pulmonologist is asked whether the decision was made together with the patient. Furthermore, a male pulmonologist who emphasizes his role as an expert in SDM and does not seem to support the concept of SDM also mentioned time constraints in outpatient clinical practice as barriers. These represent the second and third barriers, respectively, as indicated in Quote 6. A fourth barrier to involving patients in SDM reported by professionals is that they are unable to make patients understand the severity of their condition and, as a consequence, are unable to focus on SDM, unable to elicit the real preferences of patients, or focus on solving the wrong problems. According to the professionals, the reasons for patients’ lack of understanding were the imbalance between hope and reality and/or the patient’s conscious or subconscious denial of their condition or prognosis. In Quote 7, a male pulmonologist reports not being able to really discuss urgent matters with the patient, and therefore continues to discuss and make decisions about less important issues. In another example presented in Quote 8, and after asking a female pulmonology resident what she thought of the way the patient talked to her in the fragment, she indicated to be unable to get the patient to talk about herself and therefore found it difficult to elicit preferences for treatment. As a consequence, she had to decide while knowing too little about the patient.

Table 3 Factors Associated With Shared Decision Making Observations per OPTION⁵ Item and Total OPTION^{5a}

Variable	Category	Item 1			Item 2			Item 3			Item 4			Item 5			Total OPTION ⁵ Observations		
		Coeff.	SE	95% CI	Coeff.	SE	95% CI	Coeff.	SE	95% CI	Coeff.	SE	95% CI	Coeff.	SE	95% CI	Coeff.	SE	95% CI
Identification of professional Condition	Cancer	2.29	0.28	(1.74 to 2.85)	1.22	0.18	(0.86 to 1.58)	2.04	0.16	(1.73 to 2.36)	1.26	0.20	(0.87 to 1.65)	1.33	0.17	(1.00 to 1.67)	8.26	0.82	(6.66 to 9.86)
	COPD (cons.)	-0.31	0.47	(-1.24 to 0.61)	-0.37	0.38	(-1.12 to 0.37)	0.12	0.33	(-0.52 to 0.76)	-0.53	0.38	(-1.27 to 0.20)	0.16	0.36	(-0.54 to 0.86)	-1.45	1.59	(-4.57 to 1.66)
Patient age	Female	0.00	0.02	(-0.03 to 0.04)	0.01	0.02	(-0.03 to 0.05)	-0.00	0.01	(-0.03 to 0.03)	0.02	0.02	(-0.02 to 0.05)	-0.01	0.02	(-0.05 to 0.02)	0.05	0.08	(-0.10 to 0.19)
	Male (cons.)	0.40	0.34	(-0.26 to 1.06)	-0.20	0.37	(-0.92 to 0.52)	-0.48	0.28	(-1.07 to 0.10)	0.06	0.34	(-0.61 to 0.73)	0.15	0.34	(-0.52 to 0.82)	1.40	1.44	(-1.41 to 4.22)
Gender of professional	Female	2.12	0.32	(1.50 to 2.73)	1.32	0.25	(0.82 to 1.81)	1.83	0.21	(1.42 to 2.24)	1.23	0.25	(0.73 to 1.73)	1.26	0.24	(0.80 to 1.72)	7.63	1.06	(5.56 to 9.71)
	Male (cons.)	-0.04	0.57	(-1.15 to 1.07)	-0.38	0.37	(-1.10 to 0.34)	-0.21	0.32	(-0.84 to 0.43)	0.09	0.40	(-0.70 to 0.88)	0.23	0.35	(-0.45 to 0.91)	0.24	1.64	(-2.98 to 3.45)
Type of consultation	New	2.31	0.38	(1.56 to 3.06)	1.38	0.24	(0.91 to 1.85)	2.13	0.21	(1.72 to 2.55)	1.22	0.26	(0.70 to 1.74)	1.24	0.22	(0.80 to 1.67)	8.16	1.07	(6.05 to 10.26)
	Composite ^b	-0.10	0.53	(-1.13 to 0.94)	0.00	0.63	(-1.23 to 1.23)	0.81	0.52	(-0.21 to 1.82)	-0.14	0.59	(-1.28 to 1.01)	-0.24	0.61	(-1.44 to 0.96)	-0.70	2.31	(-5.23 to 3.83)
Consultation duration	Review (cons.)	1.28	0.41	(0.48 to 2.09)	1.00	0.42	(0.18 to 1.82)	0.53	0.34	(-0.14 to 1.21)	0.54	0.42	(-0.28 to 1.36)	0.51	0.41	(-0.29 to 1.31)	4.48	1.66	(1.22 to 7.74)
	Composite ^b	1.96	0.28	(1.42 to 2.50)	1.00	0.21	(0.60 to 1.40)	1.84	0.17	(1.51 to 2.18)	1.13	0.24	(0.66 to 1.61)	1.24	0.20	(0.85 to 1.63)	7.23	0.97	(5.34 to 9.13)
		0.03	0.01	(0.01 to 0.06)	-0.01	0.01	(-0.03 to 0.02)	0.03	0.01	(0.01 to 0.05)	0.02	0.01	(-0.00 to 0.05)	0.01	0.01	(-0.02 to 0.03)	0.09	0.06	(-0.02 to 0.21)

CI, confidence interval; COPD, chronic obstructive pulmonary disease; OPTION⁵, observing patient involvement in decision-making instrument; SE, standard error.

^aSignificant differences are printed in bold where $P < .05$.

^bComposite consultations are consultations in which multiple and sometimes unexpected or unplanned issues or complications were discussed in addition to the index problem.

Recommendations to Involving Patients in SDM. The professionals' recommendations for involving patients in SDM were to discuss all options, to allow time for patients to talk during consultations and to think about when to involve patients in SDM. According to professionals, even when they proposed only one option to a patient and asked for their approval, treatment goals and reasons for this must be clear. Professionals reported that it is important to discuss the available options with patients thoroughly, and to make sure that decisions are made based on a mutual understanding. This is indicated in Quote 9, in which after reflection, a male pulmonologist was asked whether the decision was made together with the patient. Furthermore, during the interviews, professionals recommended mentioning and explaining all available options to patients, even when some of them were not yet applicable or necessary in the disease progression. Professionals mentioned that the reason for this is to create awareness for patients of what might come in their disease progression and to not ignore prior knowledge of patients about some of the options. According to the professionals, this could possibly encourage patient involvement in SDM at that particular moment and when options become necessary later on. In Quote 10, after reflection, a female radiotherapist/oncologist was asked whether the decision was made together with the patient, in which she demonstrates the importance of explaining to patients why options were not yet applicable. Furthermore, in order to improve patient involvement in SDM, the professionals recommended leaving enough space and time for patients to talk during the consultations (e.g., when discussing sensitive subjects such as "do not resuscitate" decisions). Last, because patients do not remain consistent in their preferences, even after the decision is made to stop offering curative treatment, the professionals interviewed recommended involving patients in SDM during all the consultations in their disease pathway. One female radiotherapist/oncologist reported that patients sometimes change their preferences when problems occur, as indicated in Quote 11.

Discussion

This study provides insights into SDM in practice with LHL patients in the palliative phase of their disease and from the perspectives of professionals. Overall, the results of this study show that SDM is applied by professionals on average to a moderate extent. Compared to SDM scores in oncological settings in the Netherlands, with an average SDM rating of 35,³⁴ the average SDM score of 40 in this study was comparable, showing that

Table 4 Themes and Illustrative Quotes by Health Care Professionals From the Stimulated Recall Interviews*Theme: Varying degrees of involving patients in SDM*

Quote 1

Well, right. Actually, I proposed it and they agreed. I didn't present more than one option; I just made a proposal and they agreed. The woman agreed and I think he [her partner] did too.
Pulmonologist, female.

Quote 2

I asked it, and then at some point I actually suggested not doing it to the patient, right? [The professional's proposal to the patient was not do additional medical examinations]. So, I decided but I did ask if he agreed. Of course, it would have been more appropriate if I'd said something like, "When looking back, have you thought about it and changed your mind?" That would have been even more open; now I've summarized it for him. Someone who's more of a follower might say, "When you put it like that, I can no longer say no." I think he knows he can always say no to me.
Radiotherapist/oncologist, female.

Quote 3

I think that I presented the option to the patient and more or less included the pros and cons, and that I asked the patient, "Do you want to try this?" And that the patient said, "Yes, I want to try this." So yes, I think the decision was made together, or that I let the patient choose.
Pulmonologist, female.

Quote 4

I think this is funny because I let the patient decide. In principle, this [examination] will have no consequences for her treatment. [. . .] This is a patient I've known for a long time, and she wants to know more about those spots [on the hip and liver], and I go along with that wish, although it's actually medically nonsensical for the policy: it won't change it.
Pulmonologist, male.

Theme: Perceived barriers to involving patients in SDM

Quote 5

A little bit, yes. We have a protocol for working up those valves [meaning bronchoscopic lung volume reduction], so this is about whether the patient qualifies for that treatment. This treatment was requested by that lady, and I have thought about it with her and indicated what should be done, and we're now working on that together. So, it's shared decision-making within the boundaries of the protocol. [. . .] However, we're not going to decide what that protocol looks like; no, that has already been established. So shared decision-making to a certain extent, to a domain, protocol or treatment, where you cannot use too much democracy, otherwise it won't work.
Pulmonologist, male.

Quote 6

(. . .) but people come to me for advice, or for treatment. So, we won't discuss endlessly what that might be [the type of advice or treatment]. I am the expert who says, "I think you should do this or that." So, for me, shared decision-making is a relative concept. Obviously, you give people space to make their own choices or let them think about certain things, but there's a limit. And in the limited time you have, because that remains a common denominator in much of what I do, you obviously can't continue to negotiate for half an hour about what to do.
Pulmonologist, male.

Quote 7

So, I can't get this lady to understand that her condition is deteriorating further. I suggest that, I even say it once [in the video-fragment]: "That means that you're slowly deteriorating further." And the patient responds, "Yes, I don't want that." Then I should say, well, that's not possible. That could be my answer. However, if I did that, we would need another fifteen minutes in the consultation. So, what do I actually do? I take refuge in a technicality. "We're going to see if those valves succeed." [for bronchoscopic lung volume reduction] But what I actually should say is, "What should we do if those valves don't work?" I should actually say, "Stop talking about those valves: you have severe COPD, you are probably deteriorating further, and we should start thinking about how we're going to take care of you when you can no longer take care of yourself."
Pulmonologist, male.

Quote 8

Well, I found it unclear, difficult to grasp. And the thing is with this patient—and that remained the same all the times I saw her—is that she participated very little. So, some patients say things like, "I feel like this, I feel that, I want this, I want that, I want quality of life, and so forth." However, this patient gave me very little, which made me feel like I had to guide her treatment. And of course, as a doctor, you always have to steer a bit in treatment, or at least provide direction. But I never had the feeling that I knew what she wanted.
Pulmonology resident, female.

(continued)

Table 4 (continued)

Theme: Recommendations to involving patients in SDM

Quote 9

Yes, that's what this conversation is for. Look, deciding together here [referring to the video-fragment] is a choice: treatment or not. The final decision, of course, lies with the patient. [. . .] Essentially, I'm trying to explain what the treatment actually means for the patient. A decision must be made on that basis. With this patient, it is an option, because the patient is in good shape, so he's eligible for the treatment and I try to put that on the table. It is the choice that the patient makes, but I still have to substantiate what the actual options are. And I try to do that in the conversation.
Pulmonologist, male.

Quote 10

Well, not for the stent, that's too early, because I said we weren't offering that to him. So not that, no. But I said it using arguments. So, I told him that the option is not applicable yet but that it's still a shared decision. "That option isn't on the table." But sometimes people have already heard of such an option, so you have to mention why it is not on the list. Because before this consultation, we have obviously also talked about a stent, so they knew that.
Radiotherapist/oncologist, female.

Quote 11

So, I'm looking at that now [referring to the questioning look of the professional in the video fragment]. You try every time; people aren't always consistent in their opinions. They will tell you that they do not want this anymore [treatment] and then change their mind if there's a problem and actually do want it [treatment]. So, you have to discuss the preferences every time.
Radiotherapist/oncologist, female.

SDM, shared decision making.

improvement is needed.⁶⁰ The multilevel analyses and the interviews in this study showed that SDM is implemented heterogeneously across professionals and care domains in palliative care. This demonstrates that SDM is not yet fully implemented in everyday clinical practice.

This study also found that Item 2 in the OPTION⁵ instrument is the least observed item (see Table 1 for the items). Future interventions or research in this setting should focus on improving this particular element of SDM, as SDM for LHL patients is already challenging.^{11,13,15,16} In addition, as LHL patients are known to be more passive during SDM than health-literate patients, are less inclined to take control during the conversation and are prone to follow the advice suggested by their physician, additional support from their professional is required for effective SDM.^{61,62}

In addition to indicating a heterogeneous implementation of SDM, the multilevel analyses showed that composite consultations and consultation duration are potential determinants for SDM as well. A higher degree of SDM was observed when additional problems or complications were discussed during the consultation. Perhaps the assessment of the additional problem or complication increases the overall involvement of the professional with the patient and, in turn, increases SDM. Also, we observed a higher degree of discussing the problem and providing information for associated options by professionals when consultations were longer. This could indicate that more time facilitates SDM. Although the interviews with professionals indicated

time constraints as a barrier for involving patients in SDM, more research is needed investigating the exact role of time in SDM and additional contextual factors associated with it.³⁶

The interviews showed that professionals perceived SDM as proposing one option and asking the patient for their approval, which is in fact not SDM.⁴⁻⁶ That professionals did perceive this to be SDM underlines their limited understanding of the concept and the varied implementation of SDM in practice. This will negatively affect the application of SDM by professionals for all patients in palliative care. On the other hand, and underlining the varied implementation, some professionals offered recommendations to involving patients in SDM, such as substantiating and mentioning options, timing of information and allowing space and time. These additional recommendations could be used as best practices in future interventions or research, and could help improve the implementation of SDM for all patients.

The requirements of complying with a treatment protocol, limited support for the concept of SDM, time constraints, and the inability of making patients understand the severity of their condition were perceived barriers for involving patients in SDM. Future research should investigate the organizational and interventional opportunities hospitals have for additional training or schooling opportunities for their professionals.⁶³ These opportunities could increase support for SDM and enhance the ability of professionals involving patients in SDM. Also, they could enhance their ability of having deeper

conversations with patients about death and dying and nonmedical aspects of palliative care.

During the observations of cancer and COPD consultations using the OPTION⁵ protocol,⁴⁹ differences between the two types of diseases were found. On the one hand, COPD consultations generally involved the discussion of a more diversified range of options, focusing solely on alleviating symptoms (e.g., undergoing physical or rehabilitation therapy, prescribing antibiotics or morphine, or adopting a healthier lifestyle). On the other hand, cancer consultations generally involved the discussion of more treatment-oriented options available (e.g., deciding on immunotherapy, chemo or no treatment). From a methodological perspective, these differences made it difficult to determine an adequately uniform index-problem that is needed to assess SDM, and in turn, construct the overall assessment of SDM in palliative care consultations. Further research should elaborate on the possibility of using the OPTION⁵ instrument for merging different disease- and decision-types, and the influence of this on the overall assessment of SDM. Furthermore, another difference in context emerged through the conduct of professionals in SDM: during COPD consultations, some professionals tried to improve the decisions of patients by “beneficent persuasion.”⁶⁴ For instance, they urged the patient to stop smoking or to do rehabilitation therapy. This could have influenced SDM and patient involvement in these consultations and should be investigated in future research.

An important strength of this study was assessing SDM in practice, and discussing it with professionals. Both analyses pointed in the same direction, which enhances their validity. Furthermore, real-life video-recorded consultations were collected, increasing the ecological validity of the results found in this study. Also, we focused on a hard-to-reach population of LHL patients in the palliative phase of their disease, a subgroup not yet thoroughly investigated.

Despite these strengths, some methodological considerations should also be discussed. In addition to how it is applied by professionals, SDM also depends on patient characteristics and the context of the consultation.⁶⁵ Considering this, the relatively small number of hospitals and consultations included (4 hospitals and 36 video-recorded consultations) and the explorative research design could lead to reduced external validity in our study. In future research, when assessing SDM, more hospitals and video-recorded consultations should be included to increase the external validity. Furthermore, a majority (70%) of the consultations included in this study were follow-ups. This means that patients and professionals have had prior conversations that could


include elements of SDM. Although the OPTION⁵ protocol includes the rating of utterances related to prior conversations by professionals,⁴⁹ it is possible that professionals forget to relate to prior consultations during the consultations included in this study. This could indicate an overall underestimation of SDM using the OPTION⁵ instrument. Future research should experiment with observing SDM during multiple consultations between one patient and professional in order to more accurately assess SDM (i.e., assess SDM relevant to the different stages in the disease experience of patients⁶⁶). In addition, in some cases, there was discrepancy between patients’ and professionals’ assessments of the patient’s level of health literacy for including patients in this study. This could be related to the fact that LHL patients often hide that they do not understand health information because they are ashamed, or because LHL is also found in people with medium or high levels of education.^{16,31} When this occurred, expert opinion prevailed, yet future research is needed to investigate the validity of the opinion of the expert in assessing LHL. Also, the OPTION⁵ instrument only measures the assessment of SDM by professionals in practice; it is not a comprehensive measure for the overall quality of communication.⁴⁰ Although the aim of our study was to assess SDM, and the OPTION⁵ instrument is suited for this, other elements could have affected communication and should be measured as well to evaluate the overall quality. Assessing affective communication in consultations or the professionals’ responses to cues and concerns of patients, for instance, could create additional valuable understanding.^{10,67} Last, in future research, the time between the initial video-recording and interview should be reduced. This way, participants are better able to recall the consultation and associated perspectives on communication. We recommend to schedule interviews as soon as video recordings are confirmed.

The results of this study show that SDM is applied by professionals to a moderate extent and implementation is varied. This indicates that improvement is needed, as enhanced SDM more effectively addresses the needs of patients and improves patient autonomy and patient-centeredness for the most vulnerable in society.

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Supplemental Material

Supplementary material for this article is available on the *Medical Decision Making Policy & Practice* website at <https://journals.sagepub.com/home/mpp>.

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