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### Promoting interprofessional shared decision making

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# Promoting Interprofessional Shared Decision Making

Communication Skills Training in Palliative Cancer Care

**Danique Bos-van den Hoek**



# **Promoting Interprofessional Shared Decision Making**

Communication Skills Training in Palliative Cancer Care

**Danique Bos-van den Hoek**

**Promoting Interprofessional Shared Decision Making – Communication Skills  
Training in Palliative Cancer Care**

PhD dissertation, Amsterdam UMC, University of Amsterdam, Amsterdam,  
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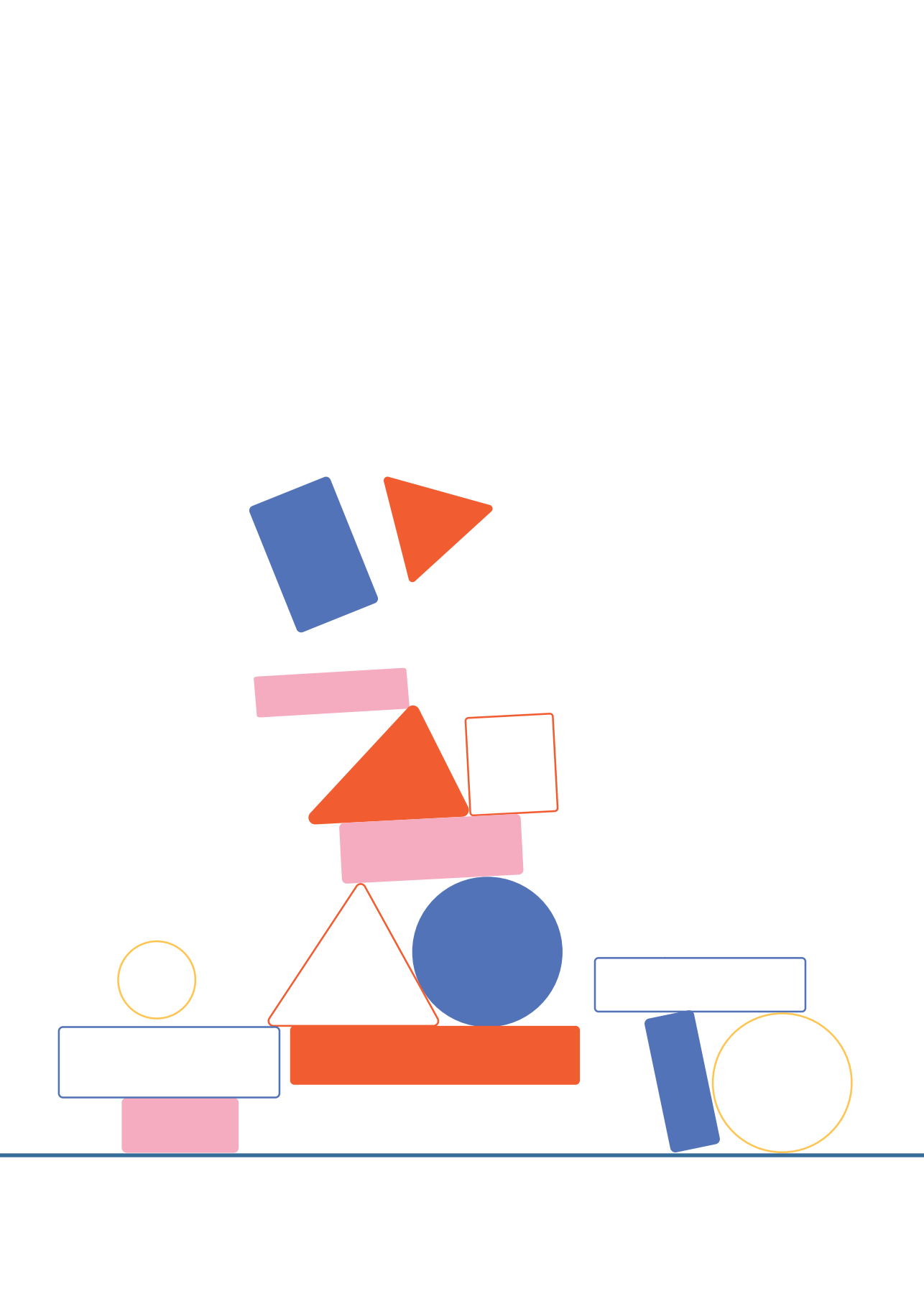
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# Chapter 1

## General introduction

Good medical communication between clinicians and patients should be at the heart of medicine to facilitate patient-centredness [1, 2]. Patient-centredness is described as a biopsychosocial approach to delivery of care that is respectful, individualised, and empowering and implies participation of the patient based on a relationship of mutual trust and knowledge [3]. Shared decision making (SDM), part of the functions of medical communication [1], is considered the pinnacle of patient-centred care [4, 5] and is endorsed by key national and international bodies [6, 7]. SDM enables the choosing of treatment best fitting a patient's personal values and preferences, which is essential when no single best treatment strategy exists. This applies eminently to treatment selection for patients with advanced cancer. SDM demands healthcare professionals (HCPs) to possess high order communication skills, which can be taught and improved by communication skills training (CST). This dissertation focuses on the effective promotion of SDM in palliative cancer care through CST for HCPs.

## **Patients with incurable cancer**

Recently, the Netherlands Comprehensive Cancer Organisation (IKNL) reported that the number of new cancer diagnoses will increase significantly in the coming ten years [8]. Besides, cancer is one of the leading causes of death worldwide [9]. Nearly ten million patients passed away due to cancer in 2020 globally [9, 10]. In The Netherlands, one in five patients has metastatic cancer at diagnosis and in a slightly smaller group metastases occur later in the disease trajectory [11]. It is widely valued that patients who cannot be cured receive appropriate healthcare and have a dignified end of life [12]. However, what is considered appropriate may vary from patient to patient [13]. In the early palliative phase, advanced cancer patients can choose disease-targeted treatment such as systemic therapy. Unfortunately, such treatment may have uncertain, possibly limited benefits and significant symptom burden [14]. Alternatively, patients can choose forgoing disease-targeted treatment, focussing on best supportive care [15]. Decisions about cancer treatment in the palliative phase are considered highly preference-sensitive – meaning that the best choice of treatment depends on patients' values and preferences [16, 17].

## **Shared decision making (SDM)**

To incorporate patients' values and preferences in the treatment decision, SDM is widely advocated [16, 18]. The goal of SDM is to reach high-quality treatment decisions, i.e. decisions that are conscious, informed, and person-centred [19, 20]. SDM has been defined and conceptualised in various ways over the years. Although a shared definition to describe SDM lacks [18, 21-23], most descriptions of SDM overlap [21]. Charles, Gafni, and Whelan [18] were the first to describe key characteristics of SDM [18]. Based on Elwyn *et*

*al.*'s three-talk model of SDM, i.e. team talk, option talk, and decision talk [24], Stiggelbout *et al.* [16, p.1173] distinguished the following stages, which will be used throughout this dissertation: "1) the professional informs the patient that a decision is to be made and that the patients' opinion is important, 2) the professional explains the options and the pros and cons of each relevant option, 3) the professional and patient discuss the patient's preferences; the professional supports the patient in deliberation, and 4) the professional and patient discuss patient's decisional role preference, make or defer the decision, and discuss possible follow-up."

SDM has been advocated for several reasons. First, SDM's value is attributed to ideological and bioethical principles [5], such as beneficence and non-maleficence [25], with patient autonomy being a central ethical imperative [16, 26]. Related, SDM is regarded a key element of patient-centred care [27]. Second, SDM may improve patient outcomes, even on the long term [28], although the evidence is still tentative [29-33]. A comprehensive review showed that SDM improves affective-cognitive outcomes, among which patient satisfaction, understanding, and trust [29]. Besides, multiple studies addressed the effect of SDM-related interventions on patient outcomes. Patient decision aids, i.e. evidence-based tools to help patients make deliberate healthcare choices [34], make patients feel more knowledgeable, better informed, and clearer about values [34]. In a similar fashion, early conversations about the end of life may lead to higher quality of life, less aggressive treatment, better matches of care with patients' preferences, and lower healthcare costs [15, 35-37]. As a last reason for advocating SDM, patients generally prefer to be involved in decision making about their treatment [38, 39], especially in later phases of the disease trajectory [40].

Although many physicians value SDM, there seems to be a disconnect between what is being advocated and clinical practice [41-43]. Observational studies showed that often neither sufficient awareness was created about the availability of multiple treatment options, including the option to forgo disease-targeted treatment, nor were these options presented equivalently during clinical consultations if discussed [44, 45]. The survival benefit of palliative chemotherapy was not discussed or only vaguely [46] and joint deliberation of treatment options and preference construction often did not take place [44, 47]. Last, physicians seemed to be reluctant to engage in explicit role clarification, i.e. who eventually makes the decision, and match the decision-making process accordingly [48].

## **Interprofessional SDM and decision support**

Delivery of care and decision making has become increasingly distributed and interdisciplinary, which has shifted the focus in SDM from the single patient-primary physician encounter to interprofessional SDM happening with multiple collaborating

HCPs both during and outside consultations [49-52]. In this context, decision support, i.e. “structured assistance in deliberating about the decision” has gained a more prominent role [53, p.382]. Decision support interventions include clinical counselling, patient decision aids, and decision coaching [53]. First, clinical counselling is provided by the HCP who has the competence, authority, and accountability to diagnose the health problem, identify options, and facilitate implementation of the final treatment decision, in this dissertation called the ‘primary physician’ [53]. They may counsel during consultations or refer to other decision support interventions. Second, patient decision aids are tools to prepare a patient to participate in SDM with one’s HCP, used alone or together with a decision coach [53]. Third, decision coaching is guidance by trained HCPs to develop patients’ skills for their final deliberation with the primary physician [20, 53]. Decision coaches may have a particularly important role in SDM for patients with advanced cancer.

In the Netherlands, patients with incurable cancer make treatment choices with their primary physician, the oncologist. Yet, in this healthcare system, both GPs and hospital oncology nurses, i.e. registered oncology nurses and nurse practitioners, provide care to patients with cancer and may take on the role of decision coach [54-57]. GPs have longstanding, continuous relationships with patients, thereby understanding their medical and psychosocial context, are accessible, and operate in a familiar setting [54, 58, 59]. In addition, GPs are accustomed to a holistic approach to health problems [54]. Similarly, hospital nurses have different relationships with patients than oncologists and unique expertise [60]. Among identified decision-making related tasks for nurses are educating patients about treatment as well as side effects and advocating on patients’ behalf [61-63]. In the palliative phase, both types of HCPs have an important role in broaching end-of-life matters [60, 64]. A recent survey among cancer patients and survivors showed that the majority appreciates involvement of GPs and/or hospital nurses after a cancer diagnosis [65, 66]. Moreover, albeit evidence is still uncertain, involvement of these HCPs in palliative care decisions may lead to positive patient outcomes, such as improved knowledge, satisfaction with the HCP, and reduced decisional conflict [67-69]. This all implies that GPs’ and nurses’ involvement in SDM about palliative cancer care could be of significant value. However, it seems that their role in this process is currently undervalued, understudied, and undefined, being a barrier to interprofessional SDM [55].

## **Communication skills training (CST) programmes**

Successful and wide implementation of (interprofessional) SDM is complex, requiring multifaceted strategies aimed at awareness, knowledge, and skills of all involved stakeholders [5, 16, 70]. One may differentiate between interventions focused on patients, HCPs, or both [71]. Examples of interventions focused on patients are decision aids, which

were mentioned before as a decision support intervention, and conversation aids [34, 72, 73]. Interventions focusing on HCPs include educational meetings or materials [74]. Lastly, interventions targeting multiple types of stakeholders simultaneously can include a combination of both previously mentioned interventions [71] or conversations between HCPs and patients [75].

As good medical communication is key for SDM, HCPs need to possess high order communication skills [1, 76-79]. Communication skills training (CST) aims to advance communication skills of HCPs. Multiple CST programmes on SDM have been developed [80] and shown to improve SDM [74]. In the palliative cancer care setting, a CST in SDM developed and evaluated in randomised controlled trials by Henselmans *et al.* [81, 82] was found to be highly effective in the simulated as well as in the clinical context and was the starting point of some research in this dissertation. CST can take on different formats. The CST by Henselmans *et al.* was intensive (10 hours) and entirely face-to-face. Increasingly, blended learning formats, i.e. online learning with some level of learner control (e.g. over time, place, or pace) combined with more traditional instructor-led synchronous learning [83, 84], are adopted for CST because of their flexibility, richness, cost-effectiveness [85, 86], and cautiously promising outcomes [87-92]. Nevertheless, little is known about which ingredients of CST, including training formats, are most effective.

## Evaluation methods

In literature, it has been argued that measuring the effectiveness of medical communication in general and SDM specifically is too focused on short-term outcomes and a broader conceptualisation of outcomes, e.g. on the long term and patients, is needed [1, 93]. Similarly, evaluating CST can be done at different levels and from different perspectives. Kirkpatrick's Model of Training Evaluation discerns four levels of training outcomes [94]: 1) *reaction* refers to HCPs' experiences with the CST itself, 2) *learning* concerns all that HCPs learned from CST, both through self-reported learning and observed learning in simulated settings, 3) *behaviour* involves behavioural changes of HCPs in clinical settings, reflecting the transfer of skills, and 4) *results* encompasses the impact of CST on patient and HCP outcomes. Regarding the perspectives with which outcomes of CST in (simulated) consultations are evaluated, four different quadrants can be distinguished: perspectives of stakeholders being either present in the consultation or not and carrying out either a subjective or an objective evaluation [95]. For example, real patients are present and subjective, while trained observers are not present and considered objective. It has been demonstrated that patients' and observers' experiences about SDM do not necessarily correspond [96-99]. This underscores the importance of incorporating not only observers' perspectives, but also those of patients when evaluating CST in SDM.

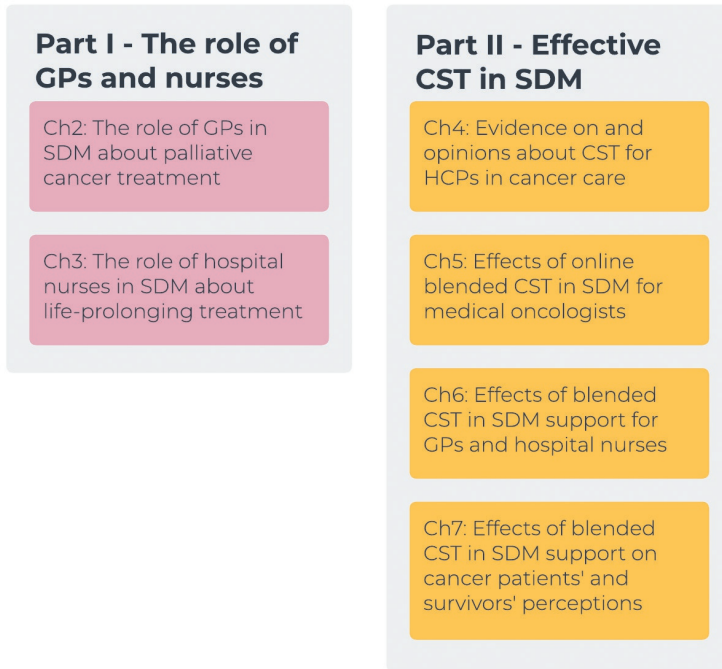
## Aim and outline of the thesis

Given that SDM is essential for appropriate care for incurable cancer patients, but that it is not always optimally applied and that the potentially valuable role of GPs and hospital nurses in this process is still underexposed, the overall aim of the research project was to effectively promote interprofessional SDM in palliative cancer care through CST for HCPs. The main objectives of this dissertation are 1) to gain insight into the role of GPs and hospital nurses in the SDM process and 2) to establish the effects of CST in (supporting) SDM about palliative cancer care.

We address the following overarching research questions:

1. How do GPs and hospital nurses perceive their role in SDM about palliative (cancer) care?
2. What are the effects of CST in SDM (support) about palliative cancer care?
  - What is the current evidence for the effectiveness of CST for HCPs in cancer care?
  - What are the effects of (online) blended CST in (supporting) SDM about palliative cancer care for medical oncologists, GPs, and nurses?

This dissertation consists of two parts (Figure 1.1). In part I, we explore how GPs and hospital nurses perceive their role in the SDM process about life-prolonging (cancer) treatment and thus their contribution to interprofessional SDM. *Chapter 2* describes GPs' perceptions of their role in SDM about palliative cancer treatment and *chapter 3* describes hospital nurses' perceptions of their contribution to SDM about life-prolonging treatment. For both HCP groups, the perceived preconditions for such a contribution will be explored and described as well. In part II, we establish the effects of CST in SDM about palliative cancer care. *Chapter 4* summarises the evidence for the effectiveness of CST as well as for effective CST features, i.e. intensity, format, and content, and synthesises the current opinion on CST in cancer care. *Chapter 5* establishes the effects of an online blended CST for oncologists in SDM about palliative cancer care and compares the effects of this blended format with those of a more extensive, face-to-face format. *Chapter 6* demonstrates the effects of a blended CST for GPs and hospital nurses in supporting SDM about palliative cancer care, which was largely based on findings from part I. *Chapter 7* examines the effects of this CST for GPs and nurses on cancer patients' and survivors' perceived SDM support. *Chapter 8* highlights and interprets the main findings of this dissertation, presents implications for practice and research, and gives final conclusions.



**Figure 1.1** Structure of this dissertation

*Abbreviations: Ch = chapter; CST = communication skills training; GP = general practitioner; HCP = healthcare professional; SDM = shared decision making*



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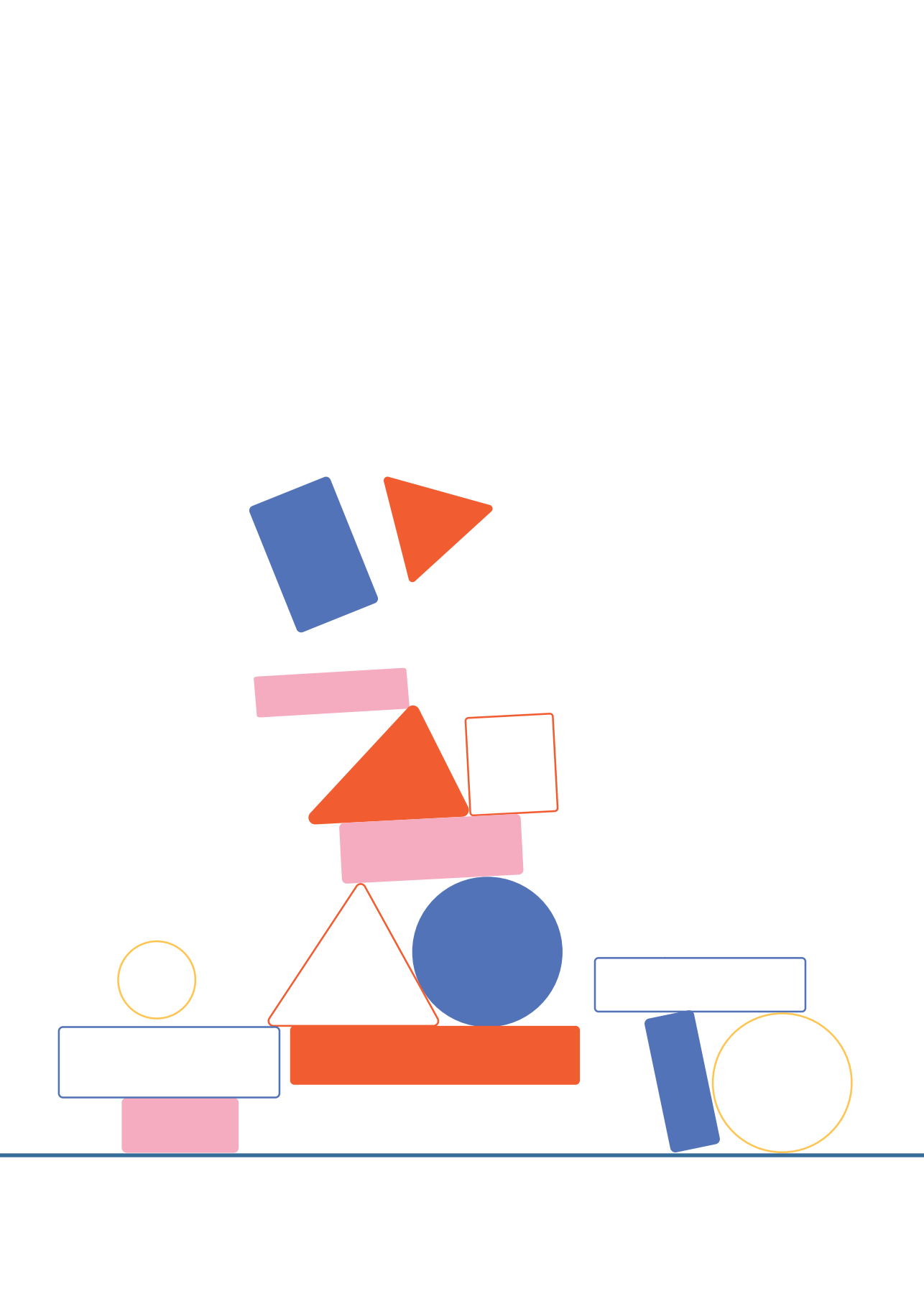




# **PART I**

**THE ROLE OF GENERAL PRACTITIONERS AND HOSPITAL  
NURSES IN SHARED DECISION MAKING**





# Chapter 2

## **The role of general practitioners in shared decision making with patients about palliative cancer treatment: A qualitative study in the Netherlands**

This chapter is published as:

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## ABSTRACT

**Background:** General practitioners (GPs) are well placed to enhance shared decision making (SDM) about treatment for patients with advanced cancer. However, to date, little is known about GPs' views about their contribution to SDM.

**Aim:** To explore GPs' perspectives on their role in SDM about palliative cancer treatment and the requirements they report to fulfil this role.

**Design and setting:** Qualitative interview study among Dutch GPs.

**Method:** GPs were sampled purposefully and conveniently. In-depth, semi-structured interviews were conducted, recorded, and transcribed verbatim. Transcripts were analysed by thematic analysis.

**Results:** Fifteen GPs took part in this study. Most of them reported practices that potentially support SDM: checking the quality of a decision, complementing SDM, and enabling SDM. Even though most of the GPs believed that decision making about systemic cancer treatment is primarily the oncologist's responsibility, they did recognise their added value in the SDM process because of their gatekeeper position, the additional opportunity they offer patients to discuss treatment decisions, and their knowledge and experience as primary healthcare providers at the end of life. Requirements for supporting the SDM process were described as: good collaboration with oncologists, sufficient information about the disease and its treatment, time to engage in conversations about treatment, a trusting relationship with patients, and patient-centred communication.

**Conclusion:** GPs may support SDM by checking the quality of a decision and by complementing and enabling the SDM process to reach high-quality decisions. This conceptualisation of the GP's supporting role in SDM may help understand how SDM is carried out through interprofessional collaboration and provide tools for how to adopt a role in the interprofessional SDM process.

## INTRODUCTION

Patients with advanced cancer often deal with complex treatment decisions that depend on their values and preferences and, hence, require shared decision making (SDM) [1-3]. SDM is the process of decision making in which the healthcare professional and patient jointly discuss pros and cons of different treatment options, as well as the patient's values and preferences to come to an agreed treatment decision [3-5]. The relevance of SDM is underscored by ethical considerations of patient-centred care and patient autonomy [6], as well as by its positive impact on patient outcomes [7-13]. In the context of palliative cancer care, most patients wish to be involved in making decisions about treatment [14-16]. However, SDM is not always visible in observational studies. These studies suggest insufficient discussion of patients' values and the option to refrain from disease-targeted treatment [17-20].

It is increasingly recognised that SDM often takes place across multiple encounters with and between different clinicians [21, 22]. Although oncologists have expert knowledge about cancer treatment and often make the final choices about treatment with patients, GPs are well placed to enhance SDM and contribute to high-quality decisions [23]. GPs have continuous relationships with patients, which can help them understand the medical and psychosocial context [24-26]. They are accustomed to using a holistic approach to health problems and, generally, receive training in effective communication [24]. A recent survey among patients with cancer found that the majority appreciate the GP's involvement in cancer care after diagnosis [27]. GPs' involvement might also increase patient satisfaction with the decision [28] and patient satisfaction with GPs' involvement [29], and may reduce decisional conflict for patients with advanced cancer [30].

While GPs are involved in cancer screening, diagnosis, follow-up, and terminal palliative care, they seem to hardly be involved in decision making about cancer treatment [25, 29, 31-34]. Despite suggestions that GPs should collaborate with oncologists to discuss treatment decisions with patients throughout the palliative phase [35-37], little is known about how GPs could contribute to SDM about advanced cancer treatment. By examining GPs' existing practices in SDM about advanced cancer treatment from their own perspective and conceptualising them, the study wished to identify ways of strengthening GPs' contribution and ultimately guarantee patient-centred care for people with advanced cancer. Thus, the aim was to explore GPs' perspectives on their role in SDM about palliative cancer treatment and the requirements to fulfil this role.

## **METHODS**

### **Design**

Semi-structured, in-depth interviews were conducted with GPs. Data were analysed thematically. This report meets the standards for reporting qualitative research items [38].

### **Recruitment**

GPs were eligible to participate in the study if they reported experience with patients with advanced cancer. GPs were recruited using purposeful and convenience sampling. The authors aimed to recruit a diverse sample of GPs with respect to sex, work experience, patient population, location (urban/suburban/rural), and type of practice (solo/duo/group practice). Interested GPs were sent information and an informed consent form.

### **Data collection**

Interviews were conducted face-to-face by two researchers in GPs' consultation rooms. The researchers' different backgrounds combined a conceptual approach to healthcare with practical experience in medicine, which helped them refine the interview guide and understand the experiences of GPs.

An interview guide was created and piloted with two GPs, resulting in small modifications (Table 2.1). The interview started with the participant reading the example case in Table 2.1 to set the scene to discuss the interview topics. The example case described a patient diagnosed with advanced stomach cancer who was considering palliative chemotherapy with a median survival gain of five months. While discussing the GPs' role in the example case, the interviewer probed for general reflections and opinions on the following topics: the current and desired role of GPs in (conversations about) treatment decision making, as well as the requirements to be able to fulfil this role. The interviews lasted 30-45 minutes each and were conducted between October 2018 and January 2019. All participants signed informed consent forms and reimbursement was offered to all GPs for their time.

Table 2.1. Topic guide

<b>A. Short introduction to the interview</b>
Introducing interviewer and research
Explaining confidentiality and anonymity
Signing informed consent
Asking permission for audio recording
<b>B. Substantive part of the interview</b>
Presentation of a case of a patient with incurable cancer who had to decide on treatment with a life-prolonging intent: <i>“Pieter de Vries, aged 74, is single, has two daughters and one grandson. He lives on a remote farm. His wife died a few years ago. He has been dizzy for some time and has little appetite. He also lost a lot of weight. After two visits to the GP, he was referred to the hospital and received bad news last week. He has stomach cancer, with metastases to the bones. The same week he had a conversation with the medical oncologist about treatment. He is eligible for palliative chemotherapy (CapOx). The median survival without chemotherapy is 6 months; with chemotherapy 11 months. Chemotherapy has side effects, including nausea or vomiting, fatigue, diarrhoea, tingling or numbness of the fingers and feet, hand-foot syndrome (redness, chapping).”</i>
Current role and ideal role for involvement in treatment decision making
Current and desired role
Position with respect to other health professionals
Goals in conversations with patients
Steps or actions to reach these goals
Involvement in four stages of shared decision making: 1) informing about decision, 2) explaining options with pros and cons, 3) discussing preferences and supporting deliberation, and 4) making decision [5]).
Added value of conversation with general practitioner
Moments for conversation
Stimulating and restraining factors for fulfilling the role
Needs required in order to fulfil the role
<b>C. Conclusion of the interview</b>
Issues that were not addressed

Data analysis

Interviews were audio recorded, transcribed verbatim, anonymised, and analysed by thematic analysis [39]. Coding was performed using MAXQDA software (versions 2018 and 2020). The approach was largely inductive; no coding sheet was prepared beforehand. The final categorisation of some themes and subthemes was informed, and likely influenced, by the simultaneous analysis of interviews with hospital nurses about their role in SDM about palliative treatment [40]. Three researchers were involved in the coding process. Four interviews were double-coded independently by two researchers and discussed until they reached consensus. Another combination of two researchers repeated this for another four interviews. As coding agreement was high, one of these two researchers coded the consecutive seven transcripts, and they both discussed uncertainties until they reached consensus.

During analysis, sections that referred to decision making in settings other than cancer care in the early palliative phase were not coded. Data saturation was monitored and considered achieved when no new substantial codes appeared in the final four interviews. A structure of categories and subcategories was developed throughout the analysis (Table 2.2). Two researchers refined potential overarching themes and the content of these themes was analysed to generate clear definitions and names for each theme. Participants received a short summary of the analysis to which they could respond. This is known as member checking, a technique for responder validation. Twelve GPs responded, and their comments led to small refinements.

**Table 2.2.** Themes and subthemes resulting from the thematic analysis

<b>Involvement of GPs in the SDM process</b>
Moments to engage in conversations about treatment
Initiative for the GP-patient conversation
<b>Supporting role of GPs in the SDM process</b>
Checking the quality of a decision (high-quality decision: conscious, informed and appropriate)
Checking choice awareness
Checking if decision is informed
Checking if decision is aligned with patient's values
Complementing SDM (adding to the decision-making process to reach a high-quality decision)
Increasing choice awareness
Clarifying and adding information
Exploring values and supporting preference construction
Enabling SDM (organising activities to ensure reaching a high-quality decision)
Acting as a patient advocate
Preparing upcoming conversations with the oncologist
<b>Interprofessional SDM: GPs' added value</b>
The unique position of GP in healthcare system
Additional and different conversations about treatment
Primary healthcare provider in the terminal stage
<b>Requirements for fulfilling a role in the SDM process</b>
Collaboration with the oncologist
Information about cancer and treatment options
Time to engage in conversations about treatment
Trusting relationship with patient
Patient-centred communication

*Abbreviations: GP = general practitioner; SDM = shared decision making*

## Ethics

Ethical clearance was obtained from the Human Ethics Committee at the Amsterdam UMC, location AMC (reference number W18\_268 # 18.312).

## RESULTS

Fifteen Dutch GPs participated; they were based at fourteen different practices representing eleven different health centres located in two provinces around Amsterdam. Eleven participants were recruited through the researchers' network, one through snowballing, and three GPs responded to an invitation sent by the academic network of GPs of the authors' institute. Table 2.3 gives the participants' characteristics. The themes and subthemes resulting from the thematic analysis are outlined in Table 2.2.

### Involvement of GPs in the SDM process

#### *Moments to engage in conversations about treatment*

Most GPs mentioned having conversations with patients about their physical and psychological wellbeing on several occasions throughout the cancer trajectory: before referral and after patients received their diagnosis or other bad news, such as disease progression. These latter conversations were mentioned as possible starting points for GPs' involvement in the SDM process:

*Often, when someone has received bad news, I'm definitely involved. So I get in touch with them and tell them I'd love to drop by and talk to you about this. (...) To hear what you've learned. And whether you've decided for yourself yet?*  
(GP10)

#### *Initiative for the GP-patient conversation*

GPs differed in their opinions about whether patients, oncologists, or GPs should initiate such conversations. A major consideration was the importance of tailoring contact to patients' needs, with some GPs waiting for patients to take the initiative while others contacted patients more proactively. Some GPs mentioned that, during cancer treatment, patients generally did not express needing GP involvement. Occasionally, oncologists actively referred patients to GPs to discuss treatment options:

*Only in rare cases, the oncologist goes: talk to your GP about this. Then it's usually in the letter, uhm, and that's of course fine by me. And that's generally to do with me knowing the circumstances just that bit better.*  
(GP01)



**Table 2.3.** Participants characteristics (N=15)

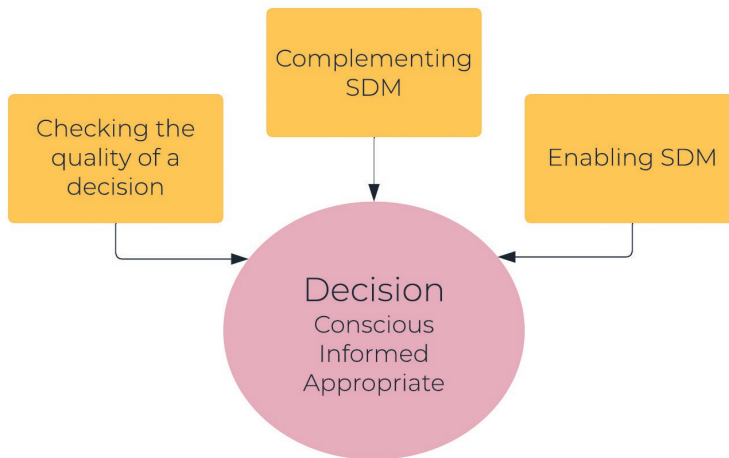
Characteristics	
Years of experience, mean (range)	17.43 (4-30)
<10 years, <i>n</i> (%)	4 (26.7)
10-20 years, <i>n</i> (%)	4 (26.7)
>20 years, <i>n</i> (%)	7 (46.7)
Sex, <i>n</i> (%)	
Male	6 (40.0)
Female	9 (60.0)
Patient population	
Origin, <i>n</i> (%)	
Mixed	11 (73.3)
Mostly native-born	2 (13.3)
Mostly foreign-born	2 (13.3)
Age group, <i>n</i> (%)	
Younger than average	5 (33.3)
Average	5 (33.3)
Older than average	5 (33.3)
Type of practice <sup>a</sup>	
Type, <i>n</i> (%)	
Solo	3 (20.0)
Duo	8 (53.3)
Group	4 (26.7)
Location, <i>n</i> (%)	
Rural	2 (13.3)
Suburban	8 (53.3)
Urban	5 (33.3)
Affinity with palliative care <sup>b</sup> , <i>n</i> (%)	
High	8 (53.3)
Average	6 (40.0)
Low	1 (6.7)

<sup>a</sup> General practitioners (GPs) worked in fourteen different practices; two GPs worked at the same practice

<sup>b</sup> Combined score of received training on palliative care (yes/no) and indicated affection with palliative care (yes/no); indicating having both was scored as high affinity, having either one was scored as average affinity, and having none was scored as low affinity with palliative care

## Supporting role

All GPs reported practices that potentially support SDM. These were categorised into three categories: checking the quality of the decision, complementing SDM, and enabling SDM. GPs appear to deploy these strategies to ensure that decision making about treatments is conscious, where the patient is aware of the choice; well informed so the patient knows about the various possibilities and their pros and cons; and appropriate, in that the decision aligns with patients' values and preferences [41, 42]. Figure 2.1 represents these strategies that GPs may use to reach high-quality decisions.



**Figure 2.1.** Three strategies GPs use to support shared decision making (SDM)

### ***Checking the quality of a decision***

GPs may check the quality of a decision by asking questions to check if there are any doubts or deficiencies for making high-quality decisions. GPs mentioned practices to check patients' choice awareness, information level, and/or values and treatment preferences. For example, GPs reported how they queried the patient-oncologist decision-making conversation, tried to gauge patients' understanding about treatment information, and probed for patients' thoughts about and expectations regarding the proposed treatment:

*First, I check, like, what have you been told? What stuck? I ask them, what have you heard from the specialist and what did you understand and can you tell me that in your own words. Sometimes there's a discrepancy already there.*

(GP05)

*And then with a patient as in this [example] case, of course for myself I want to know a little bit more about, well, how do you feel about this treatment, have you got any doubts, what would be important to you in the near future.*

(GP11)

### ***Complementing SDM***

This category comprised practices to add to the SDM process by, for example, introducing the choice, clarifying information, and supporting preference construction. With regard to increasing patients' choice awareness, GPs mentioned how they explained that a choice needed to be made between different treatment options:

*And then I also like to say, as a GP: ok, that may seem like the only option to you, but another option is actually to not do the chemo. Are you aware of that, that that is also an option? To say no?*

*(GP10)*

Additionally, GPs structured, clarified, and added information when they noticed that patients missed or misinterpreted information provided by the oncologist:

*When I notice any doubts, then I'll definitely try to present as honest as possible a picture [of the consequences of the treatment] and explain that no treatment is also an option. And that it doesn't mean they are on their own and that their life will end in suffering.*

*(GP10)*

GPs sometimes supported patients' preference construction by exploring their values, appraisals of treatment options, and, based on that, their preferences for treatment:

*One could look more at the bigger picture, like: gosh, what is the meaning of life for you? What is quality of life for you? What do you expect from palliative chemotherapy? What do you expect to happen if you don't get it?*

*(GP02)*

### **Enabling SDM**

GPs were found to enable SDM by organising additional activities to ensure that the SDM process will continue beyond GPs' direct involvement. GPs reported how they acted as an intermediary between the patient and oncologist, aided contact between the patient and oncologist, or helped prepare these conversations:

*I have called the oncologist once or twice with, listen, you propose this, but I'm worried. This really is a very vulnerable person, we really shouldn't do this. And to have the specialist say: that's great, thank you for that, that gives me another angle into this conversation.*

*(GP10)*

*And if I don't think I can do it [explain information], they just have to make another appointment with the specialist and I will call the specialist to say they have not understood a thing, you have to discuss it again.*

*(GP07)*

## Interprofessional SDM: GPs' added value

Although they mentioned many examples of practices that support SDM about advanced cancer treatment, most GPs suggested that – when talking about SDM in abstract terms independent of patient cases – they were hardly involved. Cancer treatment decisions were considered mainly the expertise and responsibility of oncologists. Also, GPs reported that patients were primarily hospital-oriented and GPs only acted on patient demand:

*Usually, I have no say in this [treatment decision making]. I don't see patients again until after they've made a decision with the oncologist. (...) They hardly ever come to me regarding a decision about whether to start chemotherapy. That's usually beyond my scope.*

(GP09)

Moreover, some GPs mentioned being cautious about interfering with hospital treatment decision making, reflecting their perception of the role boundaries between oncologists and GPs:

*If they've even already decided on something with the specialist and started that, then it's a bit like... Well. Meddling in a decision that's already been taken. So you don't go, uhm, causing trouble.*

(GP11)

Nevertheless, GPs recognised their potential added value in treatment decision making and mentioned several reasons for this:

### **The unique position of the GP in the healthcare system**

GPs pointed out their position as gatekeepers for specialised hospital care. The availability and accessibility of GPs may result in patients contacting them more easily:

*Well, I do think that visiting a GP is an easier step than making a new appointment with a medical specialist in hospital. Many questions patients have, take us one or two phone calls to answer or ease their minds, whereas to see a medical specialist they need to make another appointment, another trip to hospital, waiting rooms, and you name it.*

(GP05)

GPs believed that their longstanding relationships with patients enabled them to better tailor conversations about decisions than oncologists by accounting for patients' medical history and social context:

*But I also think that a GP is better qualified to check certain motives, more so than a specialist would. Think of certain aspects, like, what will family think of specific decisions?*

*(GP14)*

### **Additional and different conversations about treatment**

GPs indicated that their involvement offers patients an additional opportunity to deliberate on their treatment decision, which possibly reduces the sense of urgency and emotional load that may be present shortly after diagnosis. This way, patients have time to let the news settle and think about questions regarding treatment options:

*Of course, it's a very tense conversation, a bad news consultation like that. It often means decisions need to be made at short notice. I think the whole setting itself makes it difficult, where, once patients hear the word 'cancer', they miss out the rest of the conversation. So I think it's definitely a good idea to have a second conversation about it.*

*(GP07)*

### **Primary healthcare provider in the terminal stage**

In the Netherlands, GPs become the primary healthcare provider in later stages of palliative care. Some GPs pointed out that because of their specific expertise in this phase, they are able to help patients to anticipate the care offered if they choose to refrain from life-prolonging treatment or when no further life-prolonging treatment options exist:

*Then I'll also discuss my part in that [terminal phase], as in, what can I do for you. (...) I can make you as comfortable as possible, that's my part. So with regard to pain control, chest tightness, nausea, things like that, weight loss, to respond to that as well as possible. To me, that's my role as GP, to guide them in this, but definitely also to state very clearly what other options may be, or how I may help at home, outside of hospital.*

*(GP10)*

As medical generalists, GPs indicated that they may be less focused on treating the disease than oncologists, thereby providing more space to consider refraining from disease-targeted treatment:

*Well, I also explain a little, like... We ask a specialist to do what's possible, but not everything that's possible may be beneficial. (...) That is pretty much the specialist's tunnel vision: we provide treatment. Where we [GPs] come in from the angle of: what is good for you?*

(GP04)

Several GPs mentioned that being involved in early decision making about palliative treatment also helped build their relationship with the patient in preparation for the terminal phase:

*Really, from the moment of diagnosis I make sure I keep in touch by calling now and then. And over time you see that contact intensifies slightly. And at a certain point, someone's treatment is exhausted and they're handed over to me. And I try to not make that moment the first time I see them and have to work up a plan.*

(GP01)

## **Requirements for fulfilling a role in the SDM process**

In the interviews, GPs identified some requirements for their involvement in decision making about cancer treatment.

### ***Collaboration with the oncologist***

Good collaboration with oncologists was considered key for increased and valuable involvement of GPs. Many GPs also indicated that more insight into conversations between the patient and oncologist, and adequate reporting of such conversations, would be helpful:

*Yes, I think I'd like to know more about that [treatment decision-making] process and what is discussed, because you get the idea people get a more positive image than I have. (...) I get the idea people think: now I'm cured. While I think: well yes, you got a stay of execution.*

(GP09)

### ***Information about cancer and treatment options***

GPs believed that limited knowledge of and experience with cancer and cancer treatment restricted their contribution to decision making. Some GPs described the risk of providing patients with incorrect information. Information provided by oncologists about the diagnosis, treatment, and prognosis was considered helpful:

*But I notice, I'm not really trained to know: what chemotherapy, which side effects, life expectancy at which kind of metastatic cancer. But I'd certainly benefit from knowing that.*

(GP08)

### **Time to engage in conversations about treatment**

Several GPs stated the importance of having sufficient time to engage in conversations about treatment. Having enough time would reduce a sense of pressure and help build trust:

*It's a conscious choice to visit someone at 5 p.m. And that's what I tell them: I'd rather not come around lunch time, because I'll have to rush and only have 10 minutes or 20 maybe. And this is not an in-between conversation, so I'll come by around 5 and we can discuss this at length.*

(GP03)

### **Trusting relationship with patient**

A trusting relationship was described as essential. GPs indicated having high-quality contact and pre-existing relationships with patients was important to support patients emotionally, comfort them, and build trust. According to some, relationship building helped with discussing patient values and weighing these:

*So you can say: gosh, you've had some really bad news. I know you've always... You've always said I want to turn 100 and how do you feel about that now?*

(GP07)

### **Patient-centred communication**

Patient-centred communication was considered important. GPs explained they needed skills to adapt conversations to different patient characteristics such as patients' level of acceptance of their imminent death, health literacy, and spirituality. The ability to set aside personal preconceptions and to converse in a neutral and unprejudiced way were also regarded necessary, to avoid influencing the patients' decision-making process:

*But I think the most important thing is just no taboos. Being open to discuss everything and really listen. Don't give your own interpretation of what would I do, if... But really hear what the patient's fear or need is. I think that's the most important thing. And then see if you can somehow combine that in such a way that you actually let patients answer that question [what to do] themselves.*

(GP02)

## DISCUSSION

### Summary

GPs, in this study, who are involved with patients with incurable cancer report practices that potentially support SDM: checking the quality of the decision, complementing SDM, and enabling SDM. Even though most GPs believe that decision making about systemic cancer treatment is primarily the oncologist's responsibility, they do recognise their added value to interprofessional SDM. They referred to their accessibility and longstanding relationship with patients, the additional opportunity they offer patients to discuss treatment decisions, and their expertise as primary healthcare providers in the terminal phase. GPs report that requirements for an optimal supporting role in SDM are a good collaboration with oncologists, sufficient information about the disease and its treatment, sufficient time to engage in a conversation about treatment, a trusting relationship with patients, and patient-centred communication.

### Strengths and limitations

A qualitative design helped the authors to gain an in-depth understanding of GPs' experiences. By using an example case as a conversation starter for the interviews, the authors attempted to focus the discussion on the early palliative phase and decisions about disease-targeted treatment. However, using this case could have unduly directed participants' responses in parts of the interview. GPs did not know the reason for the patient's visit or the progress of the decision-making process, which may have caused them to be more hesitant initially when discussing their contribution to SDM. Additionally, even though data saturation was reached, the study might have benefited from the inclusion of a more diverse range of GPs. Most of the GPs were employed in urban areas and indicated having strong affinity with palliative care, which may have affected their views.

### Comparison with existing literature

In line with the findings of this study, other literature reports that GPs' involvement in caring for people with advanced cancer is common [31-34] and is perceived as valuable [23, 27, 37]. Descriptions of involvement include practices that may support SDM, for example, by clarifying diagnoses and adverse treatment effects, and acting as an intermediary between patients and medical specialists [25, 35, 43]. However, many such descriptions were not in the context of SDM nor explicitly identified as supporting SDM. This study adds an in-depth description of Dutch GPs' perspectives regarding their role in the treatment decision-making process of patients with advanced cancer. Moreover, the findings of the current study identified an additional type of GP involvement: checking the quality of treatment decisions. This seems to be an important intervention to discover patients' doubts and/or needs, and puts GPs in a monitoring role. The conceptualisation of



the GP's role in SDM helps us to understand how SDM is carried on through relationship-based care and interprofessional collaboration.

GPs described that longstanding relationships with patients enables them to support their patients in decision making after a cancer diagnosis. In terms of Haggerty *et al.*'s [26, p. 1220] categorisation of continuity, GPs outlined the importance of elements of so-called relational continuity [the "ongoing therapeutic relationship between a patient and one or more providers"], informational continuity [the "use of information on past events and personal circumstances to make current care appropriate for each individual"], and management continuity [the "consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs"]. All types of continuity of care present in family medicine seem to facilitate a supporting role in SDM about cancer treatment.

The results of the current study also show that GPs make an important contribution to interprofessional SDM. Although oncologists have decisional responsibility, GPs may help identify patients' decisional needs and ensure that these are responded to. Previously, the authors of the current study interviewed hospital nurses about their role in SDM about life-prolonging treatment and extracted similar categorisations of SDM support [40]. Although their roles are not identical, nurses and GPs might both be regarded as 'decision coaches' [42]: a "health professional who is trained to support the patient's involvement in healthcare decision making but who does not make the decision" [22, p.20]. The importance of healthcare professionals cooperating to reach high-quality decisions is stressed by Légaré and others [22, 44], who proposed an interprofessional model of SDM in which several healthcare professionals, including a decision coach, are involved in the SDM process. Both the findings of the authors' previous study involving hospital nurses [40], and the findings of the current study involving GPs show that healthcare professionals who are already involved in a patient's care may take on the role of decision coach without the need to involve additional healthcare professionals.

GPs did seem to struggle with interprofessional boundaries: who is responsible for and should be involved in which part of the collaborative SDM process. This may possibly explain some of the requirements they described, such as good collaboration with oncologists and having adequate information about the disease and its treatment. In addition, it may explain the experienced discomfort with 'meddling' in decision making, as GPs need to negotiate the tension between ensuring the quality of decisions, while at the same time preventing unnecessary doubts and confusion. The importance of collaboration between healthcare professionals was confirmed in a study that evaluated the effect of actively facilitating GP-patient conversations about the treatment decision [45]. These

conversations were often realised only after the decision had already been made in the hospital and, possibly as a consequence, decreased rather than increased patient-perceived SDM.

## Implications for research and/or practice

There is a growing body of evidence about the GPs' role in cancer patients' care and about interprofessional collaboration. In order to adopt an interprofessional model of SDM in advanced cancer care and to help its implementation, future research should explore the perspectives of oncologists, patients, and caregivers about the supporting role of GPs in SDM. To investigate the generalisability of the current study's findings, it would be valuable to whether GP support in SDM would also apply to decisions in non-oncological and non-palliative care settings, as well as in other geographical areas and other healthcare systems, with no universal coverage and/or gatekeeper system [46].

The proposed conceptualisation of how GPs can support SDM indicates how SDM could be administered through relationship-based care and interprofessional collaboration. To improve this collaboration and facilitate GPs' involvement, 'time out conversations' (TOCs), proactively organised conversations between patients and GPs about cancer treatment decisions, show promising results [30, 45, 47].

Additionally, training GPs effectively in SDM support might increase insight into and awareness of GPs' contribution to the decision-making process. This may make their involvement more conscious and hence more effective, allowing GPs to safeguard high-quality treatment decisions that are conscious, informed, and appropriate for patients with incurable cancer.

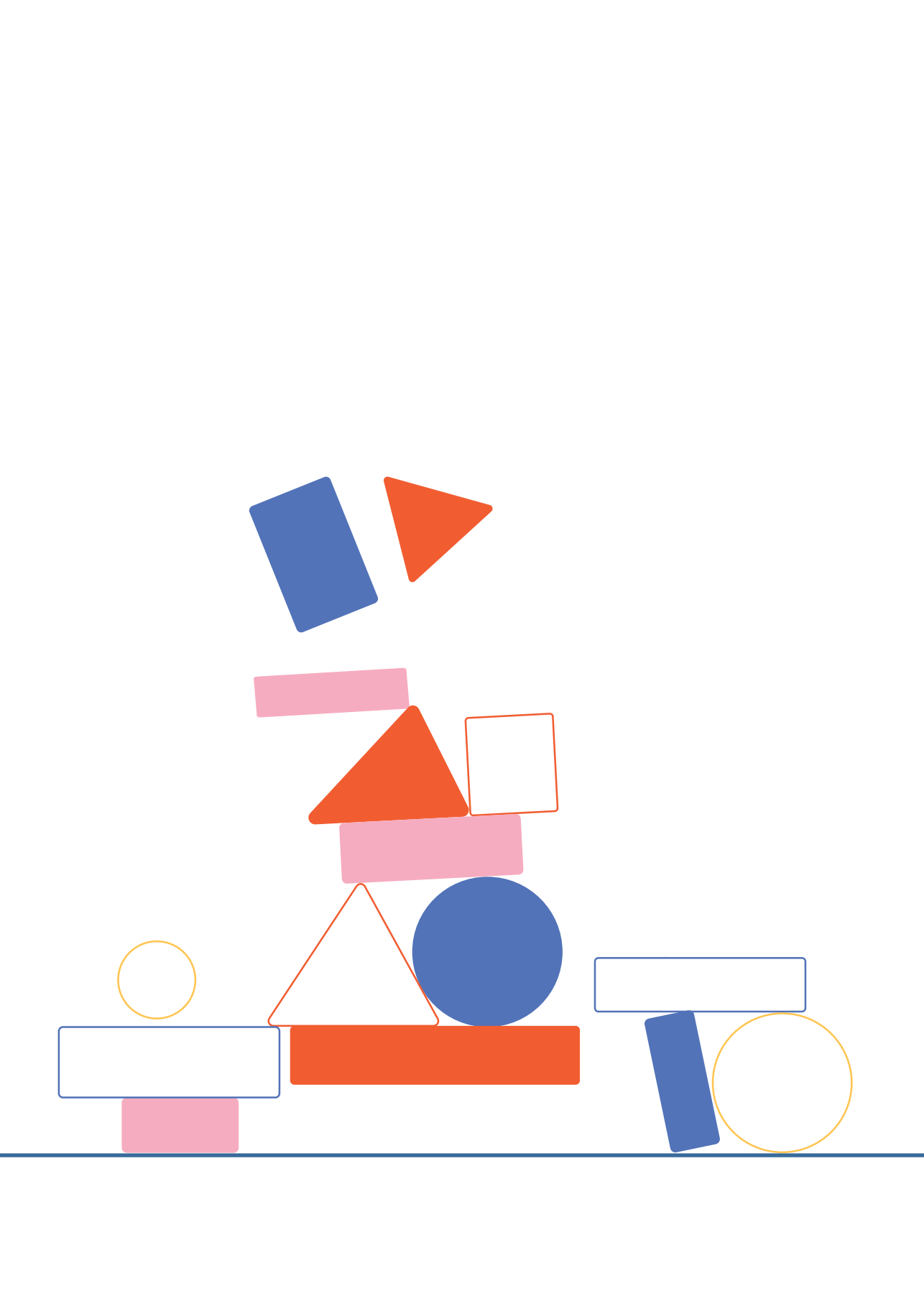
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# Chapter 3

## **The role of hospital nurses in shared decision making about life-prolonging treatment: A qualitative interview study**

This chapter is published as:

Bos-van den Hoek DW\*, Thode M\*, Jongerden IP, Van Laarhoven HWM, Smets EMA, Tange D, Henselmans I, Pasman HR. The role of hospital nurses in shared decision-making about life-prolonging treatment: A qualitative interview study. *Journal of Advanced Nursing*. 2021;77(1):296-307.

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## ABSTRACT

**Aims:** To examine hospital nurses' perception of their actual and potential contribution to shared decision making about life-prolonging treatment and their perception of the preconditions for such a contribution.

**Design:** A qualitative interview study.

**Methods:** Semi-structured face-to-face interviews were conducted with eighteen hospital nurses who were involved in care for patients with life-threatening illnesses. Data were collected from October 2018 to January 2019. The interviews were recorded, transcribed verbatim, and analysed using thematic analysis by two researchers.

**Results:** Nurses experienced varying degrees of influence on decision making about life-prolonging treatment. Besides, we identified different points of contact in the treatment trajectory at which nurses could be involved in treatment decision making. Nurses' descriptions of behaviours that potentially contribute to shared decision making were classified into three roles as follows: checking the quality of a decision, complementing shared decision making, and facilitating shared decision making. Preconditions for fulfilling the roles identified in this study were: 1) the transfer of information among nurses and between nurses and other healthcare professionals, 2) a culture where there is a positive attitude to nurses' involvement in decision making, 3) a good relationship with physicians, 4) knowledge and skills, 5) sufficient time, and 6) a good relationship with patients.

**Conclusion:** Nurses described behaviour that reflected a supporting role in shared decision making about patients' life-prolonging treatment, although not all nurses experienced this involvement as such. Nurses can enhance the shared decision-making process by checking the decision quality and by complementing and facilitating shared decision making.

**Impact:** Nurses are increasingly considered instrumental in the shared decision-making process. To facilitate their contribution, future research should focus on the possible impact of nurses' involvement in treatment decision making and on evidence-based training to raise awareness and provide guidance for nurses on how to adopt this role.

## INTRODUCTION

Patients and healthcare professionals in palliative care often deal with treatment decisions for which difficult trade-offs are at stake [1-3]. Given that for these decisions often no clear best strategy exists, the best treatment option depends on patients' values and preferences for treatment [4, 5]. Therefore, such decisions require shared decision making (SDM), an approach for involving healthcare professionals' evidence and expertise and patients' values and preferences in treatment decision making [6-8]. Given their strong relationship with patients and unique expertise, nurses are increasingly considered important for and complementary to physicians' role in treatment decision making [9-12]. Importantly, patients want nurses to be involved [13] and report that nurses are valuable and influential in treatment decision making [9, 10]. This all suggests that involving nurses in SDM about life-prolonging treatment would promote patient-centred care.

However, despite the potential for their involvement in SDM, the literature points to a gap between nurses' current and potential contribution to the decision-making process [10, 14, 15]. This gap may be attributed to several institutional and professional barriers nurses face, such as the lack of uniform practice standards or professional training and experience [10]. Yet, there is still much that is unknown about the role nurses have – or could have – in SDM about life-prolonging treatment in the palliative phase.

## Background

Shared decision making is most relevant for preference-sensitive decisions, decisions for which the best strategy is unclear because of a lack of evidence for the effect of different treatment options, similarity in outcomes, and/or likely individual differences in the weights assigned to the risk and benefits [5, 16]. Particularly for decisions about life-prolonging treatment, such as palliative chemotherapy and antibiotics, difficult trade-offs are at stake. These treatments may have uncertain and limited benefit and may impose a high burden on patients, such as side effects or prolongation of life without sufficient quality [2, 3, 17]. Consequently, the best strategy depends on patients' preferences [4, 5].

To incorporate those preferences, SDM entails the following four steps: 1) informing patients that a decision needs to be made, 2) explaining options with the associated benefits and disadvantages, 3) exploring patients' preferences, and 4) making or deferring the decision [6]. Alongside the ethical imperative to deliver patient-centred care and respect patient autonomy, SDM is also associated with positive patient outcomes such as higher satisfaction with the decision and trust in the physician [18]. In addition, the literature indicates that SDM in palliative care may result in patients receiving less aggressive treatment, possibly resulting in a higher quality of life for both patients and families [19, 20].

Yet, despite its benefits, SDM is not common practice in all palliative care settings [21-25]. This may be for several reasons. SDM in palliative care requires high-level communication skills known to be demanding for clinicians, such as dealing with patients' emotions and coaching patients in constructing a treatment preference. Also, both clinicians and patients have a tendency to focus on the short term and on active treatment [12, 26, 27]. Nurses might be well equipped to overcome these barriers in SDM.

Traditionally, decision making about life-prolonging treatment is considered to take place in a patient-physician interaction. Yet, attention for the role of nurses in treatment decision making has increased [10, 14, 28-31]. Among suggested roles for nurses related to decision making are educating patients about treatment and side effects, advocating on patients' behalf, and coaching patients in decision making [7, 10, 11, 14, 28, 32]. Additionally, nurses may have an important role in end-of-life discussions with patients [12]. This all suggests that nurses potentially contribute significantly to decision making about life-prolonging treatment.

## **THE STUDY**

### **Aims**

This study aims to examine hospital nurses' perception of their actual and potential contribution to shared decision making about life-prolonging treatment and their perception of the preconditions for such a contribution.

### **Design**

A qualitative study with face-to-face in-depth semi-structured interviews was conducted. This report adheres to the Consolidated criteria for Reporting Qualitative research (COREQ) [33].

### **Study participants and sampling strategy**

Nurses were considered eligible if they: 1) had a vocational or bachelor qualification in nursing, 2) practiced in inpatient or outpatient hospital settings, 3) were involved with the care of patients with life-threatening illnesses for whom life-prolonging treatment decisions were made, and 4) had at least one year's working experience.

We used a maximum variation sampling strategy for inviting participants [34]. We invited nurses working in different types of hospitals (university and general hospitals), hospital settings (inpatient, outpatient and day care), positions (Registered Nurses, Registered Nurses with additional relevant training and clinical nurse specialists) and with a range of years of working experience. Project group members and participating nursing teams in various hospitals in the Netherlands, with whom collaborations were established before the commencement of the study, were asked to forward an invitation by e-mail to eligible nurses. To reach maximum variation, nurses with particular characteristics were invited if needed. For example, when we observed that many nurses were employed at inpatient settings we invited nurses employed at the outpatient setting more actively. Twenty nurses showed interest, of whom eighteen eventually participated. Two nurses withdrew because of personal circumstances. The participants did not know the researchers. Prior to the interviews, the participants received an information letter.

## Data collection

Data were collected from October 2018 to January 2019. The interviews were conducted by DB (MSc, background in Health Sciences) and MT (MSc, background in Interdisciplinary Social Sciences and a Registered Nurse), both junior researchers with experience and training in conducting interviews. The interviews took place in a private meeting room at the participant's workplace during working hours. Interviews were audio recorded and lasted approximately between 45 and 60 minutes. Field notes were made after each interview.

The interview guide (Table 3.1) contained general questions about the current and desired roles of nurses in treatment decision making, stimulating and restraining factors, and the requirements for fulfilling this role. The interview started with asking participants to provide a case of a patient with a life-threatening illness who had to decide about treatment with a life-prolonging yet non-curative intent. This case allowed nurses to elaborate on their role, the preconditions, and the requirements for that particular case. Follow-up questions aimed to clarify the underlying reasons for experiencing or desiring roles, preconditions, or requirements. The interviewers continuously discussed the interview guide during data collection, resulting in minor changes. All interview recordings were transcribed verbatim. Interviews continued until perspectives were being repeated and data saturation was considered to have been reached. Two additional interviews were then conducted and used for checking data saturation; no new themes emerged.

**Table 3.1.** Topic guide

<b>A. Introduction to the research/interview by researcher</b>
Short explanation of the goal of the interview
Explanation of confidentiality and anonymity
Permission for audio taping
<b>B. Substantive part of the interview</b>
Case of an incurable patient who had to decide on treatment with a life-prolonging yet non-curative intent (provided by nurse)
Current role and ideal role for involvement in treatment decision making
Types of treatment decisions
Points during treatment trajectory at which nurse is involved
Position with respect to other healthcare professionals
Tools/interventions supporting involvement in life-prolonging decision making
Goals within conversations with patients
Stimulating and restraining factors for fulfilling his/her role
Examples: work culture, organisation, knowledge and expertise, type of patient, cooperation with other departments/healthcare professionals, workflows, communication
Requirements for fulfilling his/her role
Different levels: manager/organisation, colleagues, individual
<b>C. Conclusion of the interview</b>
Issues that were not addressed

**Ethical considerations**

The Medical Ethical Committee of Amsterdam UMC, location VUmc offered a written exemption for the study from the requirement to seek formal approval. We followed the Good Clinical Practice guidelines. Written informed consent for participation in the study and publication of the results was obtained from all respondents.

**Data analysis and rigour**

Data were analysed in ATLAS.ti version 7, following the principles of thematic analysis [35, 36]. After becoming familiar with the data by reading the transcripts, two researchers (DB and MT) carried out the initial coding, keeping very close to the original transcripts. The first five interviews were double-coded independently by the two researchers, after which each interview was discussed until consensus was reached. As coding agreement was high, the following eleven interviews were coded independently by one researcher and subsequently discussed by the two researchers. The different codes were sorted into groups to develop overarching themes. 2,547 codes were created initially, which were categorised into 36 code families. Themes and corresponding codes were continuously compared and

discussed by the two researchers. After this, potential themes were categorised, merged, and refined and the content of the themes was analysed to generate definitions and names for each theme in a codebook. Eventually, themes were arranged into four overarching themes (corresponding with the subheadings of the results section), sixteen subthemes and 21 explanatory themes related to the subthemes. In the meantime, ‘member checks’ were sent to the participants, encompassing a summary of the analysis. All participants agreed with the member check and no changes were made to the analyses. Finally, appropriate quotes were selected and translated by a professional translator. The analyses were discussed twice with the research group and on multiple occasions with one of the senior researchers (RP).

## FINDINGS

Eighteen nurses participated, mostly Registered Nurses (RN) with additional relevant training employed in oncology departments (Table 3.2). Nurses worked in different clinical settings – inpatient (where patients stay at least one night), outpatient (where patients visit the hospital for one or more appointments), and day care (where patients receive treatment during the day without an overnight stay).

### Influence on treatment decision making

Nurses experienced varying degrees of influence on decision making about life-prolonging treatment. Some nurses said that they had influenced the final decision taken by patients, whereas others mentioned not interfering with such decisions on life-prolonging treatment at all. Many nurses said that the responsibility for such decisions lies with the physician:

*Choosing and making the decision regarding the life-prolonging treatment is definitely a job for the physicians to discuss with the patients. I don't think nurses have a role in that.*

*(RN with additional relevant training, day care, university hospital)*

*It sometimes happens that there are different opinions between a physician and patient. Then my role is just to find out what the patient thinks. Sometimes I try to pass along information to physicians. I tell them I had a conversation with the patient and what they think.*

*(RN with additional relevant training, outpatient, general hospital)*

**Table 3.2.** Participants' characteristics (N=18)

Characteristics	
Age (years), <i>n</i> (%)	
20-34	5 (27.8)
35-49	5 (27.8)
50-65	8 (44.4)
Sex, <i>n</i> (%)	
Male	4 (22.2)
Female	14 (77.8)
Working experience (years), <i>n</i> (%)	
1-4	4 (22.2)
5-9	3 (16.7)
10-14	3 (16.7)
≥15	8 (44.4)
Nurses' job category, <i>n</i> (%)	
Registered Nurse (RN)	5 (27.8)
RN with additional relevant training (e.g. oncology or palliative care)	10 (55.6)
Clinical nurse specialist	3 (16.7)
Hospital setting, <i>n</i> (%)	
Inpatient	9 (50.0)
Outpatient	5 (27.8)
Day care	3 (16.7)
In- and outpatient	1 (5.6)
Department, <i>n</i> (%)	
Oncology (including neurology-oncology and haematology-oncology)	14 <sup>a</sup> (77.8)
Cardiology and pulmonary diseases	3 (16.7)
Urology and plastic surgery	1 <sup>a</sup> (5.6)
Surgery	1 (16.7)
Hospital type, <i>n</i> (%)	
University hospital	9 (50.0)
General hospital	9 (50.0)

<sup>a</sup> One nurse was employed in two departments

## Involvement in decision-making process

Nurses described interactions at different points in time with patients and physicians. We identified these interactions as potential opportunities for a conversation about – and thus involvement in – treatment decision making. Despite differences in the interactions depending on hospital settings, nurses' job category, and departments in the hospital, some general findings can be reported.

The different types of interactions (Table 3.3) that were identified are: 1) multidisciplinary team discussions, 2) patient-physician conversations, 3) nurse-patient conversations directly after the physician-patient conversation, 4) educational conversations, 5) formal conversations, 6) informal conversations, and 7) conversations between physicians and nurses.

**Table 3.3.** Occasions of contact with potential for conversation about treatment decision

Type	Who	Description	When
Multidisciplinary team discussions	Nurse(s), physician(s), other team members involved	Conversation with multiple team members in which patients' diagnoses and treatment proposals are discussed	Usually before start of (new) treatment
Conversation between physician and patient	Physician, patient, with or without nurse present	Conversation about starting or continuing treatment, in which decisions may be made	Multiple occasions in the period around the treatment decision
Nurse-patient conversation directly after the conversation between physician and patient	Nurse, patient	Emotional support and discussion about information from physician after conversation with physician	Multiple occasions in the period around the treatment decision
Educational conversation	Nurse, patient	Informational conversation about treatment and side effects	Before start of (new) treatment
Formal conversation	Nurse, patient	Official, organised conversations between patient and nurse about treatment	Multiple occasions in the period around the treatment decision
Informal conversation	Nurse, patient	Unofficial, unorganised conversations during care or the admission for treatment	Multiple occasions in the period around the treatment decision
Conversation between physician and nurse	Nurse, physician	Conversation about patient and his/her progress/wishes/etc.	Multiple occasions in the period around the treatment decision

Nurses said that many decisions about life-prolonging treatment were made in *outpatient settings*, with a leading role for the physician and that they usually did not have conversations with patients before the decision was made. Clinical nurse specialists were an exception as they did mention having conversations about treatment decisions with patients at this stage:

*I mainly outline what patients find important in their lives, what they expect from the treatment, what they know about the diagnosis. (...) And then the physicians often continue about what to expect from the treatment in this situation.  
(Clinical nurse specialist, outpatient, university hospital)*



In contrast, in *inpatient settings*, some nurses, especially clinical nurse specialists, said that they talked to physicians about the patient's treatment when attending multidisciplinary team discussions. Furthermore, nurses were sometimes present during physician-patient conversations about the treatment on admission. Nevertheless, their role during these conversations was perceived to be limited:

*The physician often then runs the whole conversation, right? They get it going, then there are a few questions from the patient and it goes back and forth a bit. Sometimes there are also a couple of action points for us at the end, or we can give them some tips, but we don't really have much to say during the conversation.*

*(RN with additional relevant training, inpatient, general hospital)*

Both nurses in the *inpatient* and *outpatient setting* explained having conversations with patients directly after a physician-patient conversation:

*Then I take the patient aside, after the conversation with the neurologist. Just to hear them repeat what they think they've heard – what they think about it. So I'm really helping them process that discussion, briefly summarising what the options are.*

*(RN with additional relevant training, outpatient, general hospital)*

Both *day care* nurses and nurses in the *outpatient setting* described systematically having educational conversations with patients about the treatment. These offered opportunities to discuss treatment decisions:

*But that kind of conversation usually takes place first [before the start of the treatment], as an informational conversation. So that the patients only decide for definite they're going to go ahead with it after the side effects really have been explained. Sure, they've often already made up their minds – I'm going to have this treatment and I'll get those side effects – but you do also often see people saying that's something they don't want and they're not going to do it. So yes, you do often see that in a discussion. That they only genuinely get the information then that makes an impression on them, that they then start to get a feeling that they might not have made the right decision about this therapy.*

*(RN with additional relevant training, day care, university hospital)*

After treatment started, nurses described having formal and informal conversations with patients. 'Formal' conversations include planned, organised conversations; 'informal' means having conversations with patients while in the course of providing care, during the

admission for treatment, or by deliberately taking a seat at the patient's bedside. During these conversations, nurses could receive important information related to the treatment decision, such as experiences with the treatment or patients' views on their end of life:

*Well, with this one woman it happened a lot while I was washing her. It just so happened (...) that we were talking a bit about [the end of life]. But I do also regularly go round to the patients and have a chat, sitting on the edge of the bed (...) If the patient hasn't been entirely clear [during the talk with the palliative team] about what they do or don't want, that can help you to get things clearer. I often notice that the patients are more open with us than during a formal discussion.*

*(RN with additional relevant training, in/outpatient, general hospital)*

Additionally, nurses described talking to physicians to share information they perceived as important for treatment decision making that emerged during previous conversations with patients. That way, physicians could consider this information during physician-patient conversations or during multidisciplinary team discussions:

*So yeah, you size up how the patient is doing, how they feel about it and depending on that you tell the physician and, well, the conversation or the timing of the decision will be changed to suit.*

*(Clinical nurse specialist, outpatient, university hospital)*

## **Roles of nurses in treatment decision making**

Although many nurses did not recognise their influence on treatment decision making, most of them nevertheless described behaviour that might have influenced the treatment decision-making process when discussing patient cases during the interviews. Nurses' descriptions of behaviours that potentially contribute to shared decision making were grouped into three different roles: checking the quality of the treatment decision, complementing SDM, and facilitating SDM.

### ***Checking the quality of the treatment decision***

Nurses looked at the quality of a treatment decision. They checked the extent to which the treatment choice had been made consciously, was based on complete information, and an understanding of this information, and fitted the needs, values, and preferences of the patient. This was mainly done by asking patients all sorts of questions and assessing patients' reactions:

*What I actually do, I guess, is get a clear picture of how someone feels about their life, what they expect from the treatment, whether they know what the diagnosis means and so whether they actually understand what we're talking about and what the life expectancy is and the purpose of the treatment, so that things can be weighed up properly.*

*(Clinical nurse specialist, outpatient, university hospital)*

Some nurses mentioned that checking the quality of the decision is of particular importance in palliative care:

*Look, treatments in the palliative phase are about extending your life. But it's the patient who determines the quality of life. We're not the ones who can say whether it's good or bad. (...) [Our job is] to pick up the signals correctly if it's troubling the patients.*

*(RN with additional relevant training, day care, university hospital)*

All nurses considered checking the decision quality to be present in all conversations with patients, before and after the start of treatment, although it was most clearly present in conversations directly after the physician-patient conversation. Besides, nurses mentioned that as the treatment progressed, they repeatedly asked about the patient's perception of the balance between the quality of life, satisfaction with the treatment choice, and end-of-life wishes. This way, they could monitor whether values or treatment preferences had changed:

*I see it as a nurse's responsibility to (...) flag up how that balance is working out. Whether people are still happy with the life that they are leading, as far as possible. In combination with the treatment.*

*(RN with additional relevant training, day care, university hospital)*

### **Complementing shared decision making**

In response to identified patient needs or deficiencies in the quality of the decision-making process, nurses mentioned behaviour that complemented the SDM process. This could partly involve the same behaviours as were described for checking the quality of the decision (e.g. asking questions about patient values), yet now with the intention to support patients in constructing a treatment preference.

Nurses reported that they may create choice awareness or inform patients about treatment options and the benefits or disadvantages of such treatments:

*I think it's important to discuss with patients that they can choose to start chemotherapy and that they can always reconsider their decision when they notice that the chemotherapy leads to many complaints and a terrible decline in their quality of life.*

*(RN with additional relevant training, outpatient, academic hospital)*

Examples nurses provided of their complementary role included answering questions, repeating or clarifying information given by the physician, adding information about their own experiences with the treatment and side effects as observed from other patients, or mentioning the option to refrain from life-prolonging treatment. The latter option was mentioned by only a few nurses; some nurses said that if the physician did not mention the option to refrain, they were not in the position to interfere:

*But it's not as if I ask very specifically whether they might not want anything done at all. I don't ask that specific question. (...) Because I think that can be pretty confusing if we mention that as one of the options, or it might scare them off.*

*(RN with additional relevant training, inpatient, general hospital)*

Additionally, nurses mentioned helping patients by exploring their values and treatment preferences. Several nurses said they supported patients in choosing or evaluating a treatment by encouraging them to weigh the treatment or treatment proposal against the patient's values or quality of life:

*So I sometimes then ask them what's actually important to them. What can you still get genuine moments of pleasure from?*

*(RN with additional relevant training, inpatient, general hospital)*

### **Facilitating shared decision making**

Nurses mentioned various behaviours that could be classified as facilitating SDM – organising contact between patients and physicians (sometimes in the presence of the nurse) and preparing patients for these conversations:

*I generally then say that it's useful for us to have a talk – what questions have they got. And I often give them a pen and paper so that they can write things down too and then don't get overwhelmed in the formal conversation because they've run out of time. Or because they just don't think of something. It means they won't forget things.*

*(RN with additional relevant training, inpatient, general hospital)*

Additionally, nurses described facilitating the SDM process by passing on important additional information or doubts in conversations with the physician so that the physician could adapt the treatment proposal or conversation with the patient accordingly. Some nurses referred to this intermediary position as patient advocacy. Mainly *inpatient* nurses and nurse specialists mentioned being able to contact the physician directly or by attending multidisciplinary team discussions; *day care* nurses described using electronic notes to communicate with the specialist. By having these conversations, nurses and physicians were able to align their understanding of patients' health and mental status and, consequently, the quality of the treatment decision:

*I did do it once, by the way and I was proud of it: simply emphasised the fact that I didn't think this was a good quality of life. And I thought that we [the care providers] all ought to think carefully about how we tackle this discussion; we have to be open, of course, but we also need to see not giving treatment as one of the options.*  
(RN, inpatient, university hospital)

### **Preconditions for nurses' role in SDM**

Six preconditions for nurses' participation in the decision-making process were deduced from nurses' responses.

A first precondition is the transfer of information among nurses and between nurses and other healthcare professionals so that they all stay informed about the patient's health and mental status:

*If you want to make the most of each other's capabilities and the knowledge you've built up during the process, then you – well, actually, you have to pass that knowledge on to each other. (...) We make very little use of each other's input and know-how. Sure, a physician can read the notes I've made, but that's as far as it goes.*  
(RN with additional relevant training, outpatient, university hospital)

Many nurses mentioned that working part time and changing shifts have a negative effect on their ability to stay informed about the patient's current situation and be involved in the treatment decision:

*I think that it [working full-time] is sometimes helpful and sometimes not, because I think that continuity... it's often nice for the patient if you keep seeing the same face – provided you can get on with that person, at any rate. And I reckon that you then automatically have more meaningful conversations.*  
(RN with additional relevant training, inpatient, general hospital)

As a way to improve the transfer of information, some nurses mentioned the need for more structural involvement in the decision-making process, for example by having more organised conversations with patients. Additionally, assigning case managers to patients would help improve the transfer of information, as nurses would then closely monitor the patient and have direct contact with him/her from the start of the treatment.

Secondly, a positive and supportive hospital or departmental culture towards nurses' involvement in SDM may facilitate this. For example, some nurses said that psychosocial care was considered important in their departments, providing space for investing time in conversations with patients and the opportunity to influence the treatment decision-making process.

A third precondition is nurses' relationship with the physician. Nurses often said that if physicians were open to nurses' contribution to the decision making, they dared to give their opinion sooner. Several nurses mentioned that clarity and recognition of their role in treatment decision making would help them to position themselves better with respect to contributions by other healthcare professionals:

*I sometimes find it awkward to see where the role of the nurse starts and the role of the physician ends. The extent to which I can stand my ground, as it were. I mean, it's fine to be forthright – but you have to think whether this is your role at that moment.*

*(RN, inpatient, university hospital)*

Knowledge and skills were considered a fourth precondition for being involved in the treatment decision-making process. Nurses mentioned that experience in and knowledge about SDM, possibilities in palliative care, and conversation techniques helped in starting conversations about treatment decision making and discussing end-of-life issues with patients.

Time was a fifth frequently mentioned precondition as time is needed for starting in-depth conversations, especially for informal conversations. However, some nurses mentioned making time for these conversations as they considered it an investment for ensuring a good treatment relationship.

Lastly, a good relationship and personal connection with the patient influenced the conversations as well. Nurses mentioned that if they supported patients socially and emotionally, that enabled open and valuable conversations about the treatment decision. It helped SDM as nurses gained a better understanding of patients' motives, thereby allowing

nurses to support value clarification and preference construction. Besides, it helped patients feel more at ease in asking questions:

*And really being there for them, because they often get emotional [in nurse-patient conversations] and then they start really thinking about it. And you often provide support for them. (...) You reassure them or get them thinking a bit... that's more our role.*  
(RN with additional relevant training, inpatient, general hospital)

Nurses reported taking into account differences between patients to have fruitful conversations, such as differences in the attitude towards death, mental capacity, ethnicity, and religion.

## **DISCUSSION**

This study aimed to examine hospital nurses' perceptions of their contribution to decision making about life-prolonging treatment as well as the preconditions for such a contribution. The results showed that nurses experienced varying degrees of influence on the treatment decision. We identified different points of contact in the period around the treatment decision that could lead to involvement in treatment decision making. Nurses described behaviour that reflected three roles in treatment decision making: checking the quality of the decision, complementing shared decision making (SDM), and facilitating SDM. We identified several preconditions for fulfilling the aforementioned roles: 1) the transfer of information, 2) a culture where there is a positive attitude to nurses' involvement in decision making, 3) a good relationship with physicians, 4) knowledge and skills, 5) sufficient time, and 6) a good relationship with patients.

### **Involvement and roles in treatment decision making**

Most nurses initially had difficulties in describing their role in decision making. The degree of perceived influence on treatment decision making seemed to depend at least partly on differences in setting and types of interactions. For example, nurses initially reported to have limited influence on decision making in the outpatient setting, where physicians have a prominent role. This corresponds with the suggestion that nurses mainly contribute to the decision-making process during day-to-day care and clinical activities [9]. However, when invited to discuss their own experience with a specific patient case, all nurses described different behaviours that could be classified as related to supporting SDM. This implies that nurses are not always aware of their actual and potential contribution to SDM about life-prolonging treatment.

Our results suggest that checking the quality of the decision, complementing SDM, and facilitating SDM may be considered important roles for nurses in decision making about life-prolonging treatment. When adopting these tasks in their work, nurses can support physicians in ensuring high-quality decisions – decisions that are made consciously, informed by the best available evidence, and based on values of patients [32].

In the palliative phase, some aspects of nurses' roles in decision making seem to be of particular importance. Firstly, nurses reported various attitudes towards mentioning the option to refrain from life-prolonging treatment if the physician did not communicate this to the patient first. In practice, physicians appear to focus on life-prolonging treatment options and often do not address the alternative [21]. A previous study concluded that nurses may be more inclined to express their doubts concerning further treatment [12]. The current study shows that some nurses indeed take on this role while others perceive barriers to do so. This hesitation may reflect a need for training on how to raise choice awareness without causing unnecessary confusion. Secondly, nurses described checking patients' attitude towards the impending death. Previous work also showed that nurses were more focused on making best use of the time that is left, in contrast with physicians' and patients' mutually reinforcing attitudes of 'not giving up' [12]. These findings stress the importance of nurses' role in SDM about life-prolonging treatment.

Stacey and colleagues [32] introduced the concept of the decision coach, which Légaré *et al.* [30, p.20] defined as "the health professional who is trained to support the patient's involvement in healthcare decision making but who does not make the decision for the patient". Among the tasks of the decision coach are: 1) assessing decisional conflict, 2) identifying and addressing decisional needs such as a need for information value clarity and support, and 3) accommodating these needs by providing information, verifying understanding, clarifying values, facilitating access to decision aids, and building skills in deliberation, communication, and accessing support [32]. These tasks largely correspond to the roles of nurses identified in this study, which support the assumption that nurses could take on the role of decision coach [32]. Currently, decision coaching is rarely embedded into clinical practice [32]. Factors such as unclear expectations, a lack of structured processes, and low patient awareness of nurses' possible decision coaching role may impede implementation of decision coaching [37]. One way to implement decision coaching for patients in hospitals would be to make use of the contacts nurses already have with patients, as identified and categorised in the current study. O'Connor and colleagues [38] recognise that the linkage of decision coaching to care has various benefits, among which better identification of cases of decisional conflict, tailoring of coaching to the patient's clinical needs, and involving the patient's own physician more closely.



## **Preconditions for contributing to SDM**

Several of the identified preconditions for contributing to SDM are recognised in the existing literature as well [14, 15, 28]. When applying an interprofessional approach to SDM where at least two healthcare professionals are involved, the transfer of knowledge and a good relationship and cooperation amongst these healthcare professionals are essential [28]. Healthcare professionals should cooperate and determine which health professional is best prepared with knowledge and skills to address the particular needs of patients at different time points [15]. Earlier research has also pointed out the importance of a facilitating hospital or department culture for implementation of SDM by, for example, allowing flexible use of decision aids and fostering an amicable and safe work environment [39, 40]. In this study, nurses' knowledge and skills were found to influence their perception of and confidence in participating in treatment decision making, which corresponds with findings described in literature [14, 28, 37, 39].

## **Strengths and limitations**

A strength of this research is the variation in the sample regarding clinical setting, job type, and type of hospitals. This allowed us to provide a broad picture of nurses' potential involvement in treatment decision making. Another strength is the qualitative design, which enabled us to elaborate with participants on what they and what we meant and understood by SDM; as they did not always realise they were contributing to the decision-making process.

A limitation is the restricted variation between hospital departments – nurses were employed predominantly in oncology departments. This could have influenced the results since decision-making processes and nurses' involvement in decision making may vary between departments. Given that many previous studies on this topic were conducted among oncology nurses too, future research should investigate whether these findings apply to other departments as well. However, the few nurses in the present study who were employed in non-oncology departments did not seem to perceive a different role compared to those in oncology departments.

## **Impact**

Our findings point to the potential for nurses' involvement in SDM about life-prolonging treatment if they were to be more aware of the roles they could adopt. Involving nurses sooner and more systematically in the SDM process, preferably before the treatment decision is made, could improve the quality of the decision. Presumably, more cases of decisional conflict could be detected, and more patients could be supported in making a high-quality decision. For example, nurses could help assess the appropriateness of life-prolonging treatment or support patients in articulating their aims and preferences before

decisions are made [41]. This corresponds with previous calls to apply an interprofessional approach and involve decision coaches [30, 32]. Formal involvement may not always be necessary, as nurses could also be made more aware of their potential role during standard care.

Training in the skills and knowledge required for conversations about the decision-making process is needed. Other studies have already confirmed the successfulness of such training in decision coaching for nurses [29], coaching patients in decision making for nurses [42], and applying SDM about palliative chemotherapy for medical oncologists [43]. Training may also increase awareness and clarity about nurses' supporting role in the decision-making process. Preferably, there is a common conceptual understanding of the roles, expertise, and responsibilities in SDM of all the healthcare professionals involved [30]. Articulation of nurses' behaviour and attributes would help clarify their expected tasks and purposes [15].

For a better understanding of nurses' roles in SDM, further research should focus on other healthcare professionals' perceptions of nurses' position when deciding about treatment. Furthermore, research should focus on how checking the quality of the decision and complementing and facilitating SDM by nurses has an impact on treatment decisions in clinical practice. Lastly, research should focus on effective training for nurses to improve their awareness and skills in supporting SDM about life-prolonging treatment. Bos-van den Hoek, Visser, Brown, Smets, and Henselmans [44] concluded that, although implementation of communication skills training for healthcare professionals is widely advocated, evidence for the effectiveness of such training is often lacking.

## CONCLUSION

Nurses described behaviour that potentially supports SDM about life-prolonging treatment, although not all nurses were aware that they were contributing to decision making. This study revealed three roles that nurses could adopt for supporting SDM, that is, checking the quality of a decision, complementing SDM, and facilitating SDM. Research on nurses' actual impact on treatment decision making and on evidence-based training is needed to raise awareness and provide guidance for nurses on how to adopt this role.

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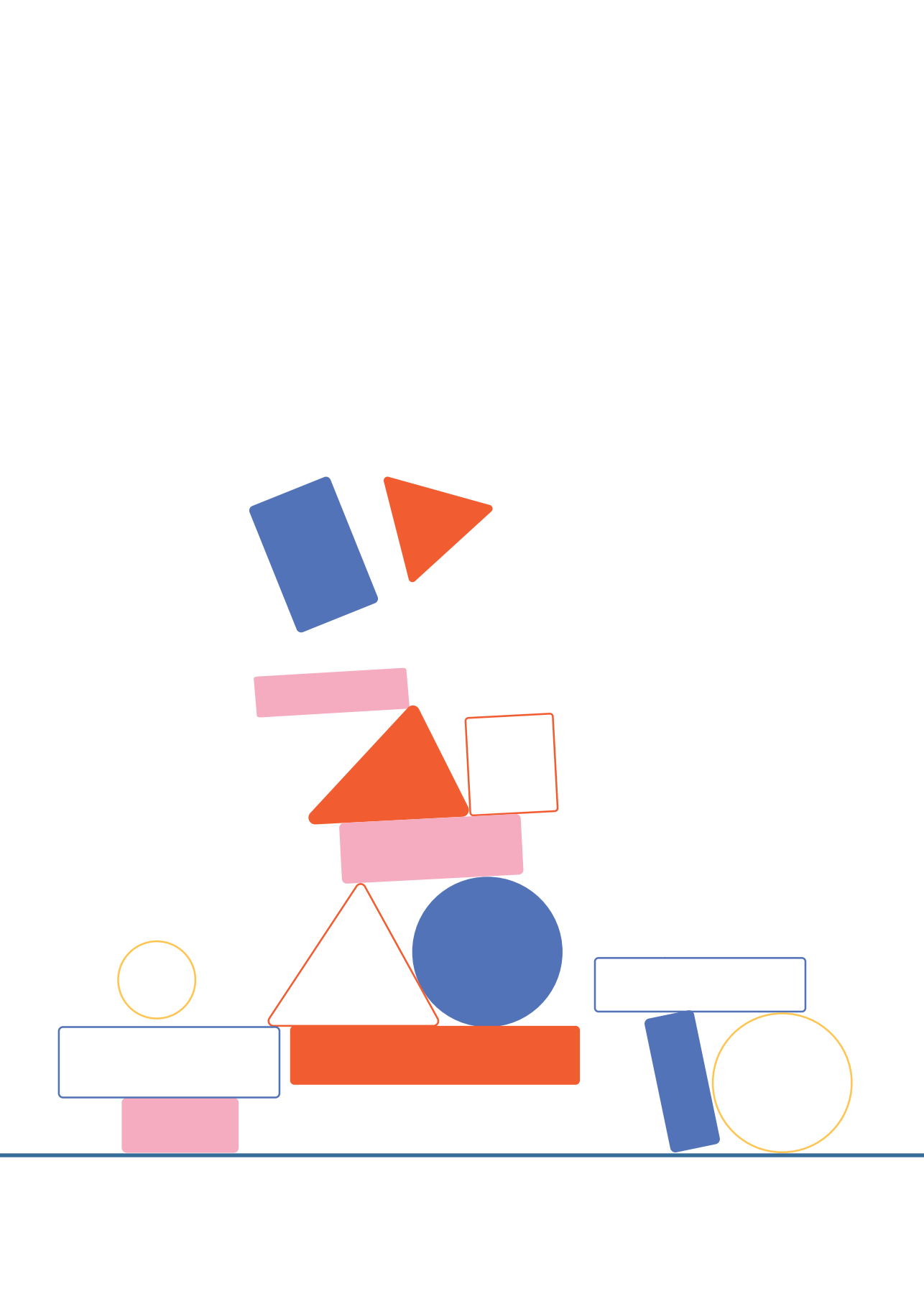




# **PART II**

## **EFFECTIVE COMMUNICATION SKILLS TRAINING IN SHARED DECISION MAKING**





# Chapter 4

## **Communication skills training for healthcare professionals in oncology over the past decade: A systematic review of reviews**

This chapter is published as:

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## ABSTRACT

**Purpose of review:** Effective communication in cancer care requires complex communication skills of healthcare professionals (HCPs), which can be advanced by communication skills training (CST). The number of empirical studies on CST has grown steadily over the last decade. However, controversies on CST abound. The aim of this review of reviews is to summarise evidence for the effectiveness of CST in oncology as well as for effective CST features (intensity, format, and content), and to synthesise the current opinion on CST.

**Recent findings:** The evidence synthesised from multiple reviews supported the effect of CST on HCPs' communication skills. Yet, the certainty of evidence was limited as studies were diverse and effects heterogeneous. Furthermore, limited evidence was found for effective CST intensity, format, and content. Authors of the reviews advocated further high-quality research with robust outcome measurement to establish the most essential features of CST and recommended implementation of CST in the standard training of HCPs with continuous supervision.

**Summary:** CST can probably improve some aspects of HCPs' communication skills. Despite the uncertain evidence, implementation of CST into clinical practice is widely advocated and specific recommendations regarding intensity and format are provided. Evidence to justify and substantiate implementation efforts is needed.

## INTRODUCTION

Effective communication is essential for high-quality healthcare and is associated with important patient outcomes, such as patient information recall, participation in decision making, and quality of life [1-5]. Particularly in cancer care, communication is highly complex because of the life-threatening nature of the disease, the increase in available treatment options, and the often highly uncertain outcomes of treatment [4, 6]. Modern medical encounters need to fulfil the requirements of a patient-centred approach to communication. That is, healthcare professionals (HCPs) are expected to meet patient preferences for information and shared decision making (SDM), while simultaneously be responsive to patients' vulnerability and emotional needs [7-11]. Hence, they need to possess communication skills of a high order to communicate effectively in this challenging context. Assuming that communication skills are amenable to change, the purpose of communication skills training (CST) programmes is to advance communication skills of HCPs [12\*, 13\*\*, 14, 15].

In the past decade, various studies have reported on the development and evaluation of CSTs in cancer care [16-19]. Although many of these have demonstrated improvement in communication skills, controversies in the CST literature abound. In 2008, Brown and Bylund [12\*] criticised the best practices in CST as lacking specificity and consistency regarding their aims and assessment, whereas more recently Salmon and Young [20] denounced the tendency of CST to reduce communication to a set of technical skills. In addition, the ever increasing empirical work on CST [13\*\*, 21, 22\*\*] shows little consensus on outcomes to be measured, methods for assessing effectiveness, and best practice components of CST. Thus, a comprehensive overview of research and opinions about CST in oncology is needed to provide insight into the current state-of-the-art CST and future directions. Since several reviews on the topic, albeit with different focus, have been published in the past decade, we decided to conduct a review of reviews. The aim of this review of reviews is to summarise evidence on the effectiveness of CST for HCPs in oncology as well as on the effective features of CST, and to synthesise the current opinions on CST based on the included reviews.

## METHODOLOGY

Our report follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [23]. No review protocol was registered.

### Search strategy and selection criteria

A PICO [23] search strategy was set up and PubMed, PsycINFO, and CINAHL (Table 4.1) were searched on July 26<sup>th</sup>, 2018, restricted to reviews published in the last decade (2008-2018). Two authors (DB, LV) independently screened a random ten percent of titles and abstracts on inclusion and exclusion criteria (Table 4.2). After three rounds of such screening, a hundred percent agreement was reached on articles judged to be eligible. The remaining publications were screened independently by the first author. All (possibly) eligible articles were independently examined full text by two authors (DB, LV). Differences were discussed until consensus was reached, consulting a third author (IH) when necessary.

### Data extraction and synthesis

Data were extracted from the reviews by one author (DB) and checked by another (LV or IH). Data included the first author, the publication date, the number of papers included in the review (overall and on CST), the covered time period of the papers, the type of review, and various inclusion criteria, such as participants, interventions, study designs, outcomes, and other notable criteria (Table 4.3). Findings on CST effectiveness were extracted from the result and conclusion sections. These data were ordered according to the four levels of Kirkpatrick's Model of Training Evaluation [24]: reaction, learning, behaviour, and results. In the context of this review, 'Reaction' outcomes refer to the HCPs' reaction to CST, such as satisfaction with the training. 'Learning' outcomes evaluate what HCPs learned from CST, either through self-reported changes in knowledge or attitudes ('self-reported learning') or through observation of behaviour in simulated settings ('observed learning'). 'Behaviour' outcomes assess change in behaviour of CST participants in clinical settings, reflecting the transfer of skills to the workplace. The last level, 'Results', assesses the impact of CST on patient outcomes, such as satisfaction and quality of life, and HCP outcomes, such as burnout. Outcomes were included irrespective of the time of assessment or length of follow-up. If mentioned, outcomes regarding the long-term maintenance of training effects over time were extracted.

**Table 4.1.** PICO<sup>a</sup> with search terms for PubMed

PICO	Participants	Intervention	Context	Outcome
Description	All HCPs involved in medical care for cancer patients	All HCP-targeted training/strategies/interventions to improve communication (skills)	Patient-provider communication	Effectiveness of CST according to Kirkpatrick's model of evaluation [24]; Reaction of participants to CST (e.g. satisfaction/attitude) Learning of participants after CST (e.g. knowledge/skills in simulated settings) Behaviour of participants in practice after CST (e.g. skills, behaviour, speech time) Results of CST (e.g. patient and healthcare outcomes) No search terms included
Search terms for PubMed	Neoplasms [MeSH] Cancer Oncolog*	Education [MeSH] Teaching [MeSH] Teaching materials [MeSH] Mentoring [MeSH] Counselling [MeSH] Curriculum [MeSH] Education, Distance [MeSH] Education, Medical [MeSH] Education, Medical, Continuing [MeSH] Train* Coach* Counsel* Prompt* Instruct* Teach* Workshop Education Program* Curriculum Serious game Blended learning E-learning/learning Webinar Seminar Continuing medical education Postgraduate education	Communication [MeSH] Health communication [MeSH] Social skills [MeSH] Physician-Patient Relations [MeSH] Nurse-Patient Relations [MeSH] Professional-Patient Relations [MeSH] Decision Making [MeSH] Truth Disclosure [MeSH] Empathy [MeSH] Motivational Interviewing [MeSH] <i>Synonyms of communication<sup>b</sup></i> Communication skill* Communicati* Conversati* Consultati* Dialog* Visit Interpersonal <i>Interaction patient provider<sup>b</sup></i> Patient centred communication Clinical communication Physician-patient relations Nurse patient relations Patient provider Patient doctor Patient physician Patient nurse Patient oncologist <i>Elements of communication<sup>b</sup></i> Decision making Shared decision making Breaking bad news Information exchange Information provision Empathy Motivational interviewing	

All search terms within one column were combined with OR and between columns with AND; searches were limited to publication type (systematic reviews, reviews and meta-analyses) and publication date (2008-01-01 to 2018-12-31)

<sup>a</sup> The C of Comparison/Control in PICO was replaced by C of Context to better match with the specific search for this review, as we did not look for reviews/studies with specific control conditions

<sup>b</sup> Italicised phrases were not part of the search strategy

Abbreviations: CST = communication skills training; HCP = healthcare professional; PICO = population, intervention, comparison, outcome

**Table 4.2.** Inclusion and exclusion criteria

<b>Inclusion criteria</b>
Publication date: 2008-2018
Publication type: systematic review, meta-analysis. Review was considered systematic if – at least – the key terms for the search and the number of included studies (on CST) were described
Describing training/strategies/interventions to improve communication (skills). The aim or search had to include key words reflecting the inclusion of or interest in CST
Training targeting healthcare professionals involved in medical care for cancer patients
Describing outcome(s) of training at any point in time
<b>Exclusion criteria</b>
Languages other than English
Targeting only patients or caregivers
Publication type: conference abstract, original empirical study, opinion articles, protocol
Focus on screening or prevention phase of cancer care
No studies on CST included in the review

*Abbreviations: CST = communication skills training*

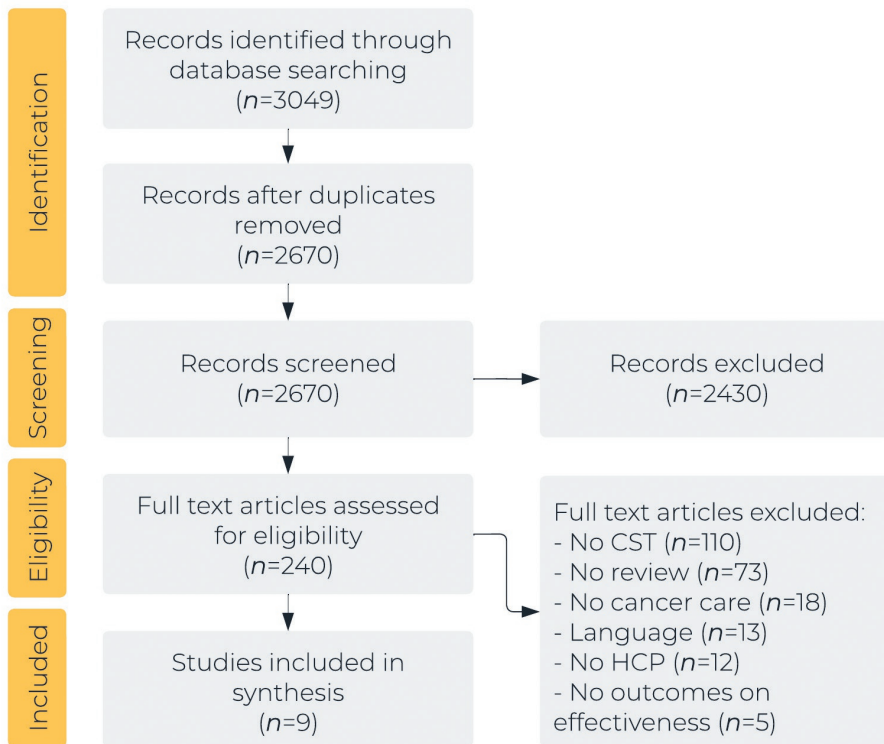
Results regarding effective CST features were identified and categorised into three categories: intensity, format, and content. Intensity represents the frequency (including follow-up training) and length of CST. Format encompasses the method of learning that is used, for example role-play, feedback, or lectures. Content comprises the specific set of skills targeted by the CST, for example skills related to breaking bad news, information provision, and responding to emotions.

Stated implications, that is statements on practice recommendations, future directions, or solutions to identified gaps, were extracted from the discussion sections of the reviews. After deductive categorisation of these implications into research or practice, thematic content analysis was applied to inductively identify common themes. These were plotted against the reviews, to present the number of reviews that stated the different implications. Data extraction and initial thematic analysis was performed by one author (LV) and checked by a second author (DB).

The final conclusions about CST effectiveness, effective features of CST, and current opinion were based on a narrative synthesis of the findings reported in the included reviews.

## RESULTS

Searching yielded 3,049 papers, of which nine met the inclusion criteria. Figure 4.1 depicts the selection process [25]. Three reviews were key, reviewing effectiveness of CST in oncology in general. The aims and searches of the remaining six reviews did relate to CST, yet were either more broad or more specific: they did not solely focus on CST, dealt with CST in a specific discipline, patient population, or type of consultation in oncology, and/or focused on a specific communication skill set only. Table 4.3 presents the characteristics of the reviews; Appendix 4A shows the overlap between the articles included in the three key reviews and in the six remaining reviews. These six reviews added a total of fourteen articles that were not included in the three key reviews.



**Figure 4.1.** Selection process

*Abbreviations: CST = communication skills training; HCP = healthcare professional*



**Table 4.3.** Details of included reviews

Review's first author	Publication date	# studies/articles in review (period covered)	# articles on CST in oncology	Inclusion criteria					
				Type of review	Type of participants	Type of intervention	Type of studies	Type of outcomes	Other notable criteria
Moore <i>et al.</i> <sup>a</sup> [26**]	2018	17 studies/56 articles (until May 2018)	All	Systematic/meta-analysis	All qualified HCPs within all hospital, hospice, or ambulatory settings working in cancer care	CST, all types and approaches to teaching, any length, any focus of communication	RCTs, including cluster-randomised studies	HCP behaviour or skills, other HCP outcomes, and patient-related outcomes	Excluded CST on informed consent for research; excluded studies with reported (instead of observed) outcomes
Barth and Lan-nen <sup>a</sup> [27**]	2011	13 studies/22 articles (until Jun/Jul 2008)	All	Systematic/meta-analysis	HCPs working with cancer patients	CST in oncology, active parts such as role play, and >6 hours	Controlled studies	Communication behaviour, attitudes, and patient outcomes	Excluded CST on SDM, recruitment, or genetic counselling
Uitterhoeve <i>et al.</i> <sup>a</sup> [28**]	2010	7 studies/10 articles (1990 – 2007)	All	Systematic	HCPs in cancer care	All CST programmes	Controlled studies and studies with single pre-post-test design	HCP communicative behaviour in real patient encounters and patient outcomes	Only outcomes that included both HCPs' communicative behaviour in real patient encounters and patient outcomes
Gorman <i>et al.</i> [29*]	2018	8 articles (Jan – May 2016)	1 article	Scoping	AYA cancer survivors (age 15-39) and/or HCPs who care for them	Any practice or programme to improve patient/survivor communication with HCPs	Qualitative and quantitative	Explicit or implicit outcomes in one of Epstein and Street's [4] six functions of patient-centred communication in cancer care	Only studies that included outcomes related to the patient-centred communication in cancer care framework
Christie and Glew [30*]	2017	5 articles (search date not specified)	4 articles in cancer care	Non-systematic	Professionals working in haematology or haematology oncologists	CST for haematologists or haematologists	Not specified	Not specified	

Gilligan <i>et al.</i> [31*]	2017	47 articles (Jan 2006 – Oct 2016)	8 articles	Systematic (development of ASCO consensus guidelines)	Clinicians and adults with cancer	CST for clinicians (one of nine questions on effective communication focused on CST)	Guidelines, position papers, systematic reviews, meta-analyses, and RCTs	Not specified	Excluded studies on prevention, risk assessment, or screening; systematic reviews and RCTs were included only if published after the 2013 Cochrane review [21]
Kao <i>et al.</i> [32*]	2017	9 articles (2000 – May 2013)	2 articles	Systematic	Adults with cancer, participating in drug-related clinical trials	Various interventions (audio-visual, written), including oral (face-to-face) information	Pre-posttest, quasi-experimental, case-control, or RCTs	Patient knowledge, comprehension, or understanding of a clinical trial; patient satisfaction with information provided and decision-making process; anxiety about informed consent process	Studies needed to measure patient knowledge, comprehension, or understanding of a clinical trial
De Vries <i>et al.</i> [33*]	2014	27 articles (Until Nov 2012)	6 articles	Systematic	Patients with cancer, clinicians	Not specified	Not only interventions, yet all clinician characteristics, including training, in relation to communication and patient outcomes	Association between clinician characteristics, including training, and quality of communication or patient outcomes	Excluded studies with (only) reported (instead of observed) outcomes
Paul <i>et al.</i> [34]	2009	4 studies/7 articles (Jan 1995 – Mar 2009)	All	Not specified	HCPs	Provider-patient interactions about bad news related to cancer	For review of intervention studies: RCT, CCT, CBA, ITS	Communication skills, provider psychosocial outcomes (e.g. anxiety, stress, burnout, satisfaction), patient psychosocial outcomes (e.g. anxiety, satisfaction, quality of life)	Intervention studies needed to include a patient psychosocial outcome

<sup>a</sup> The author names of the three key reviews included in this Table are in bold font

Abbreviations: ASCO = American Society of Clinical Oncology; AVA = adolescents and young adults; CBA = controlled before and after study; CCT = controlled clinical trial; CST = communication skills training; HCP = healthcare professional; ITS = interrupted time series; RCT = randomised controlled trial; SDM = shared decision making

## Effectiveness of CST

Among the three key reviews were the recently updated Cochrane meta-analysis of Moore *et al.* [26\*\*] on the effect of CST on HCP behaviour and patient outcomes, the meta-analysis of Barth and Lannen [27\*\*] on the effect of basic CST and booster sessions on HCPs' communication behaviour, attitudes, and patient outcomes, and the review of Uitterhoeve *et al.* [28\*\*] on the effect of CST on patient outcomes. These will be discussed first (Table 4.4). None of these reviews described outcomes at the 'Reaction' level. At the level of 'Self-reported learning', one review concluded that HCPs' attitudes towards death and dying improved as a result of CST [27\*\*]. Two reviews presented findings on the 'Observed learning' and 'Behaviour' levels together [26\*\*, 27\*\*]. In both reviews, about one third of the included studies evaluated the effectiveness of CST in a simulated setting only, one third in a clinical setting only, and one third in both settings. Moore *et al.* [26\*\*] concluded that there are significant differences between both settings, although it is unclear on what results this conclusion is based. Barth and Lannen [27\*\*] reported no clear differences. Uitterhoeve *et al.* [28\*\*] focused on clinical settings only and found that CST had an effect on HCP communication behaviour as well. Overall, irrespective of the setting, CST was found to have an effect on observed communication skills [26\*\*-28\*\*]. On a specific skill level, CST improved the use of open questions, showing empathy, and less fact giving [26\*\*]. Yet, in general, the certainty of evidence for these effects was reported to be limited as studies were diverse and effects heterogeneous [26\*\*-28\*\*]. At the level of 'Results', evidence on the effectiveness of CST was scarce [26\*\*] and not consistent across studies [28\*\*]. There was some evidence indicating that patients' mental or physical health and satisfaction benefitted from CST [26\*\*, 27\*\*, 28\*\*], yet effect sizes were small [27\*\*]. Moore *et al.*'s review reported that CST had no effect on HCP burnout [26\*\*]. Few reviews were able to draw conclusions about the long-term effects of CST as a result of inconclusive evidence [26\*\*, 27\*\*].

Some supplementary findings were reported in the six additional reviews (Table 4.4). Gorman *et al.* [29\*] reviewed practices or programmes that aim to improve patient-centred communication with adolescents and young adults (AYAs), including CST for HCPs. They identified only one study on CST, which indicated that CST improves HCPs' perceived confidence in patient care in this setting. The review of Christie and Glew [30\*] reviewed CST for haematologists and haemato-oncologists, in which four out of five included studies were conducted in oncology. They concluded that CST improved HCPs' communication skills in simulated and clinical settings as well as patient satisfaction and anxiety. CST also improved HCPs' reported confidence in their skills. Gilligan *et al.* [31\*] reported on new evidence-based guidelines for patient-clinician communication in oncology. They reviewed the CST literature to summarise the most effective ways for physicians to acquire communication skills and identified benefits of CST on several HCP communication skills,

based on the 2013 Cochrane review [21] of CST and randomised controlled trials (RCTs) published afterwards. Kao *et al.* [32\*] searched the literature for interventions aimed at improving patient understanding of clinical trial participation in oncology; two studies on CST were identified. Inconclusive evidence was found on the effect of CST on patient satisfaction, comprehension, understanding, and knowledge. De Vries *et al.* [33\*] reviewed the literature to identify clinician characteristics that influence communication, including receiving CST. They report six studies on the effect of CST and conclude that CST has a positive effect on HCP skills as well as patient satisfaction. Paul *et al.* [34\*] reviewed the evidence to support guidelines on breaking bad news, focussing on the effect of training on patient psychosocial outcomes. Their findings reported effects of CST on patient distress, conflicting results on patient satisfaction, and no effect of CST on patient anxiety.

**Table 4.4.** Review authors' conclusions on effectiveness of CST

Review	Self-reported learning	Observed learning <sup>a</sup>	Behaviour <sup>a</sup>	Results
<b>Moore et al.<sup>b</sup> [26**]</b>		<ul style="list-style-type: none"><li>CST had a beneficial effect on several skills: more likely to show empathy (six studies, moderate certainty), less likely to give facts only (five studies, low certainty), and more likely to use open questions (five studies, very low certainty). CST had no effect on eliciting patient concerns (three studies, moderate certainty), providing appropriate information (four studies, moderate certainty) and other HCP communication skills such as clarifying and/or summarising information (three studies) and negotiation (three studies)</li><li>Six studies examined skills in a simulated setting only; five studies in a clinical setting only; six studies in both. Tests for differences between both settings were significant, although it remains unclear how this conclusion is reached and what this means</li><li>Two studies reported the effect of CST over time (up to one year after training); it seemed that significant improvements at 3 or 6 months post-intervention were maintained after 12 or 15 months in the group that received CST. However, inconclusive evidence on whether these improvements were significant</li><li>When specifying effects to HCP subgroups, results for physicians were consistent with main findings (four studies); nurses showed no significant differences between intervention and control group (two studies)</li></ul>	<ul style="list-style-type: none"><li>CST had no effect on patient anxiety (three studies, very low certainty), patient perception of (two studies) and satisfaction with communication (two studies, very low certainty); psychiatric morbidity was significantly lower in intervention group (one study); CST had no effect on HCP burnout (three studies); emotional exhaustion (three studies), personal accomplishment (three studies), and depersonalisation (two studies, low certainty)</li><li>When specifying to HCP subgroups, no significant differences were reported</li></ul>	
<b>Barth and Lannen<sup>b</sup> [27**]</b>	CST had an effect on HCPs' attitude towards death and dying (5 studies, small effect size)	<ul style="list-style-type: none"><li>Overall, CST improved communication skills (eight studies, moderate effect size with large variability between studies)</li><li>Five studies examined skills in a simulated setting only; three in a clinical setting only; two studies in both. No clear differences in effectiveness between both settings</li><li>Midterm follow-up results supported short-term effect (five studies), long-term effect studies (two studies) found no support for efficacy of CST</li><li>When specifying effects to HCP subgroups, it was found that the effect of CST is larger for nurses than for physicians</li></ul>	CST had an effect on patient outcomes such as mental distress or satisfaction with the physician (five studies, small effect; non-significant trend)	
<b>Uitterhoeve et al.<sup>b</sup> [28**]</b>		CST had an effect on HCP communication behaviour in clinical settings (six studies). Yet, most studies included multiple behavioural outcomes and CST did not consistently show an effect on all. The clinical significance of the demonstrated CST effects remains inconclusive	CST had an effect on patient satisfaction with information and support as well as assessment of concerns (three of seven studies). However, the clinical significance of the demonstrated CST effects remains inconclusive. There was no evidence for an effect of CST on patient distress or quality of life	

Gorman <i>et al.</i> [29 <sup>a</sup> ]	Indication that CST would improve HCPs' perceived confidence in patient care (one study; no statistics reported)		
Christie and Glew [30 <sup>a</sup> ]	CST improved HCPs' reported confidence in their skills (one study; no statistics reported) and patient-centred communication (one study; no statistics reported)	CST improved communication skills in simulated and clinical settings (4 studies, no statistics reported)	CST improved patient satisfaction and anxiety (one study, no statistics reported)
Gilligan <i>et al.</i> [31 <sup>a</sup> ]		One review reported effect of CST on some skills: empathy and using open questions [21]. Six RCTs reported some benefits of CST as well. Unclear whether in simulated or clinical setting. There is little evidence for the maintenance of effects over time	CST had no effect on patient outcomes, but few studies assessed these outcomes
Kao <i>et al.</i> [32 <sup>a</sup> ]			Inconclusive evidence on the effect of CST on patient satisfaction with information and their comprehension, understanding, or knowledge about clinical trials was reported (two studies, no statistics reported); one study reported significant improvement of these patient outcomes; another study did not report differences after CST
De Vries <i>et al.</i> [33 <sup>a</sup> ]		CST had a positive effect on HCP skills (five studies, no statistics reported); one observational study reported a lack of correlation between CST and empathetic responses; one study reported increase of nonverbal expression of empathy (nods, facial expression, gestures and touching). Unclear whether observed in simulated or clinical setting	CST had a positive effect on patient satisfaction with HCP performance (one study, no statistics reported)
Paul <i>et al.</i> [34 <sup>a</sup> ]			CST had no effect on patient anxiety (three studies, no statistics reported); one study found reduced patient distress and conflicting results were found for patient satisfaction (two studies, no statistics reported)

<sup>a</sup> Several reviews reported an overall effect of CST on behaviour in either simulated ('Learning') or real consultations ('Behaviour'); few also stated the difference between the two. When no clear difference was reported, we merged both columns to explain the effect of CST on behaviour in both outcome categories of Kirkpatrick's model in this Table

<sup>b</sup> The author names of the three key reviews included in this Table are in bold font  
Abbreviations: CST = communication skills training; HCP = healthcare professional

## Effective CST features

Limited evidence was found for effective features of CST (Table 4.5). Several reviews reported that no clear conclusions can be drawn on CST intensity [26\*\*, 27\*\*, 31\*]. Nevertheless, Barth and Lannen [27\*\*] concluded that a minimum of three days seems to be necessary for a promising change in communication skills, based on a non-significant trend for longer courses ( $\geq 24$  hours) to be more effective and the small effects of CST with a shorter duration. On the basis of a comparison of two trials, Paul *et al.* [34\*] reported that an intensive (105 hours) CST resulted in higher patient satisfaction with care, whereas a less intensive CST (2x4 hours) did not. In contrast, Moore *et al.* [26\*\*] described one study that reported no overall differences between 6 and 2 hours training. The evidence for the effect of follow-up training was also inconclusive. Barth and Lannen reported an additional benefit of consolidation workshops or supervision on HCP behaviour [27\*\*] and Moore *et al.* [26\*\*] similarly reported some, but inconclusive evidence for a benefit of follow-up training. Even fewer conclusions can be drawn regarding the most effective format of CST. Moore *et al.* [26\*\*] report one study that found no difference on HCP communication skills between groups that did or did not receive feedback. The guidelines published by Gilligan *et al.* [31\*] recommend some effective formats for skill-practice exercises such as role-play, directly observed or videotaped interviews with real or simulated patients, or structured feedback. In addition, they mention the added value of trained, experienced, and competent facilitators. However, the empirical evidence base for these recommendations was unclear. None of the reviews mentioned the effect of CST content, that is whether the effect of CST depends on the behaviour it targets.

## Implications

The authors of all nine reviews provided implications for research and practice (Table 4.6). Most reviews agreed that more research is needed for demonstrating the effects of CST on patient outcomes [26\*\*-28\*\*, 29\*, 30\*, 32\*-34\*] and for determining the essential or most effective features or types of CST [26\*\*, 27\*\*, 29\*-31\*]. Research on the effect of CST should be of high quality and be conducted beyond simulated contexts [26\*\*-28\*\*, 33\*, 34\*]. Outcome measurement should be improved and consensus should be reached among researchers on the measures used [26\*\*-28\*\*, 30\*-32\*, 34\*]. Preferably, researchers should use a limited number of measures and define one primary outcome. Further, one third of the reviews recommended the implementation of CST in the (mandatory) training of HCPs [27\*\*, 30\*, 33\*] and continuous supervision in clinical practice for those who attended CST to sustain training effects [27\*\*, 28\*\*, 33\*]. Another practice implication mentioned was the necessity of tailoring of CST to the role of different HCPs [29\*, 30\*], HCP characteristics (e.g. a priori skill level) [33\*], and patient populations (e.g. younger patients) [29\*]. Finally, several authors recommended developing CST that is effective in improving specific communication skills, such as addressing emotions [26\*\*, 29\*, 34\*].

**Table 4.5.** Evidence for effective features

Review	Training intensity	Training format
<b>Moore et al.<sup>a</sup></b> <b>[26**]</b>	<ul style="list-style-type: none"> <li>Length of training and time spread were diverse, no conclusions could be drawn</li> <li>Follow-up training showed some positive effects on the maintenance of behaviour change; yet little and inconclusive evidence</li> <li>No overall differences found for longer CST (6 vs. 2 hours), only significant differences of some skills in HCP subgroups</li> </ul>	<ul style="list-style-type: none"> <li>Types of CST were diverse, no conclusions could be drawn</li> <li>One study reported comparing between feedback and no feedback, but found no difference between HCP communication skills</li> </ul>
<b>Barth and Lannen<sup>a</sup></b> <b>[27**]</b>	<ul style="list-style-type: none"> <li>For effective CST, no clear cut-off could be determined. Short courses (&lt;24 hours) seemed less effective than longer courses (&gt;24 hours). Interventions lasting &lt;3 days showed consistently small effects, so a minimum of 3 days seem to be the least duration for a promising change in communication skills</li> <li>Additional training (consolidation workshop or supervision) after basic CST showed additional benefit on HCP behaviour (three studies, small to moderate effect size), yet not on patient outcomes</li> </ul>	
Gilligan et al. [31*]	The optimal duration of training remains unclear; CST may need at least 3 days for the transfer of skills into practice (based on position paper [13**])	<ul style="list-style-type: none"> <li>Effective formats for changing HCP behaviour (quality of evidence: intermediate; strength of recommendations: strong): skill-practice exercises such as role-play, directly observed or videotaped interviews with real or standardised patients, structured feedback, role-reversal, exercises to increase practitioner self- and situational awareness such as reflection and mindfulness</li> <li>Facilitators should be trained, experienced and competent</li> </ul>
Paul et al. [34*]	Comparing two studies on the effect of CST indicated that an intensive CST resulted in higher patient satisfaction (105 hours), whereas the less intensive CST (2x4 hours) did not	

*Note: No review reported evidence for training content and therefore this ingredient was not included in this Table. Uitterhoeve et al., Gorman et al., Christie and Glew, Kao et al. and De Vries et al. did not report effective ingredients and were not included in this Table.*

<sup>a</sup> The author names of two of the three key reviews included in this Table are in bold font

Abbreviations: CST = communication skills training; HCP = healthcare professional



**Table 4.6.** Categorisation of research and practice implications as mentioned by the review authors

RESEARCH IMPLICATIONS, regarding	Moore <i>et al.</i> <sup>a</sup>	Barth and Lannen <sup>a</sup>	Uitterhoeve <i>et al.</i> <sup>a</sup>	Gorman <i>et al.</i>	Christie and Glew	Gilligan <i>et al.</i>	Kao <i>et al.</i>	De Vries <i>et al.</i>	Paul <i>et al.</i>	<i>n</i>
<b>The effectivity of CST</b>										
• Demonstrate the effect of CST on patient outcomes, such as psychological wellbeing, quality of life, and satisfaction	x	x	x	x	x		x	x	x	8
• Investigate the impact of CST on HCP outcomes, such as burnout	x				x					2
• Investigate the long-term effect of CST	x					x				2
<b>Moderating factors influencing the effectivity of CST</b>										
• Investigate the role of HCP characteristics, such as a priori skill level, self-efficacy, and attitude towards CST		x		x				x		3
• Investigate the role of a voluntary vs. mandatory nature of CST	x				x					2
• Investigate the role of broader system-level and contextual factors, such as support from management and colleagues			x	x						2
<b>The intensity, format and content of CST</b>										
• Investigate which CST components/types/features are most effective	x	x		x		x	x			5
• Establish the optimal length and/or intensity of CST	x	x								2
• Investigate the role of e-learning	x					x				2
• Investigate the impact of consolidation courses	x									1
• Investigate the role of training both HCPs and patients in communication skills	x									1
• Refine our understanding of how best to train healthcare communication trainers						x				1
<b>Methodological factors investigating CST</b>										
• Improve outcome measurement: agree on/use standardised/robust outcomes measures, preferably a limited number or a single primary outcome measure	x	x	x		x	x	x		x	7
• Conduct further high-quality clinical studies (with real patients)	x	x	x					x	x	5
• (Develop and) evaluate CST within the context of a theoretical/conceptual framework			x				x			2
• Report clearly and comprehensively on CST trial methods, outcomes and data, including a priori skill level	x	x								2
<b>PRACTICE IMPLICATIONS, regarding</b>										
<b>The format and content of CST</b>										
• Develop CST tailored to the role of different HCPs, HCP characteristics (e.g. locus of control or experience), and patient populations (e.g. younger patients)				x	x			x		3
• Develop effective CST aimed at improving (more/other) specific communication skills in HCPs, e.g. appropriate eliciting and addressing of concerns/cues/emotions, information-giving skills, breaking bad news, and discussing sensitive issues such as sexuality	x			x				x		3

• Create awareness among HCPs regarding their own communication preferences and (possible) consequences for the patient	x		x	2
• Develop CST based on sound educational principles, including role-play scenarios, direct observation of patient encounters, and other validated techniques	x			1
• Use CST facilitators who have sufficient training and experience to teach and model communication skills	x			1
Implementation of CST into clinical practice				
• Implement CST in the (mandatory) training or curriculum of HCPs/oncologists	x		x	3
• Incorporate adequate transfer strategies of acquired skills in the CST design	x			1
• Provide CST during work hours	x			1
Sustaining the effects of CST				
• Incorporate (continuous/individual) supervision for those who attended the CST	x	x		3
• Create positive attitudes and beliefs in HCP in order to sustain the effects of CST over time			x	1
• Add consolidation courses to refresh/deepen/sustain learned skills in practice	x			1

<sup>a</sup> The author names of the three key reviews included in this Table are in bold font  
Abbreviations: CST = communication skills training; HCP = healthcare professional

## DISCUSSION

In summary, evidence supporting the effect of CST on HCPs' communication skills continues to emerge through multiple reviews [26\*\*–28\*\*, 30\*, 31\*, 33\*]. Yet, as our findings show, the certainty of evidence is limited. An effect of CST on patient outcomes was not demonstrated, as evidence was scarce and inconsistent [26\*\*–28\*\*, 30\*–34\*]. Furthermore, limited and inconclusive evidence was found for effective features of CST. The authors of the included reviews recommended implementation of CST in the standard training of HCPs with continuous supervision [27\*\*, 28\*\*, 29\*, 30\*, 33\*] and advocated further high-quality research to establish the most essential features of CST with robust outcome measurement [26\*\*–28\*\*, 29\*–34\*]. Indeed, despite some evidence for the effectiveness of CST on HCP behaviour, many questions remain unanswered.

### Effectiveness

The conclusions drawn on the overall effectiveness of CST should be put into perspective. Several reviews note the high heterogeneity between studies [26\*\*–28\*\*], not only in terms of effects, but also in terms of types of CST, types of patients (simulated or real), the outcomes assessed, and the measurement tools used [26\*\*]. For example, in Moore *et al.* [26\*\*], the length of included CST programmes differed between 1 and 105 hours and Uitterhoeve *et al.* [28\*\*] reported five different instruments used to assess patient

satisfaction. These differences could explain heterogeneity in effects and prevents strong conclusions. Uitterhoeve *et al.* [28\*\*] warn that the multitude of behavioural outcomes assessed in most studies has the risk of concluding that CST had an effect when no true effect exists. Moreover, only two reviews mention the sustenance of the effect of CST over longer periods. As Barth and Lannen notice, the short-term perspective in most studies complicates making assumptions about the long-term impact of CST [27\*\*].

## Effective features of CST

It remains unknown which features contribute to CST effectiveness, because of the diversity in CST intensity, format, and content across studies and the few studies that attempted to make comparisons. Moore *et al.* [26\*\*] made such an effort by examining the effect of follow-up training, different types of CST, and a feedback component, but found no conclusive evidence. Despite the lack of evidence, several authors tentatively concluded that longer CST [27\*\*, 31\*, 34\*], follow-up training [26\*\*, 27\*\*], and formats such as role-play, feedback, and conversing with simulated or real patients [31\*] seemed more effective. In their recent review contrasting existing CSTs with consensual recommendations formulated in a 2010 position paper [13\*\*], Stiefel *et al.* [22\*\*] observed that most CST programmes did indeed describe role-play or feedback as their formats, yet often lasted shorter than the recommended three days and did not include follow-up components. Of note, Stiefel *et al.*'s position papers [13\*\*, 22] and Gilligan *et al.*'s [31\*] guidelines adopted the three day criterion suggested by Barth and Lannen [27\*\*], despite a lack of strong evidence to substantiate this cut-off. Other consensus recommendations, for example small group size, a learner-centred focus, or experienced trainers [13\*\*] were not supported by evidence deducted in our review and seem entirely based on expert opinion.

## Implications

Authors of reviews advocate further high-quality research on CST, preferably in clinical settings with RCTs and using a predefined primary outcome. This should increase the amount and certainty of evidence on CST. We noticed that the reviews often merged different types of CST outcomes, such as skills in simulated or clinical settings, general or specific HCP communication skills, or different types of patient wellbeing. The high diversity across the limited number of studies obviously left them no choice, yet it does limit the meaning of the conclusions drawn. Thus, more work is warranted to standardise best practice outcomes and instruments. Authors of reviews recommended using conceptual frameworks for creating consensus among CST experts about how to comprehensively assess communication competencies across programmes. Brown and Bylund [12\*], for example, propose the Comskil Model to help organise and explicate communication skills and ensure accurate assessment through clear matching of training goals and outcome measurement.

Another frequent recommendation was the investigation of the most effective CST components or types of CST. Strikingly, half of the practice implications in the reviews concerned effective features of CST, whereas no evidence for effective features was demonstrated. Although these recommendations are to a great extent in line with consensual recommendations [13\*\*], evidence to support these assumptions is still warranted [22\*\*]. One way to do so is to break down the effect of training with different presumably effective features. For example, regarding the length of CST, our group has recently demonstrated the effect of a face-to-face SDM training (10 hours) based on experiential learning for medical oncologists [18]. A next step is to attempt to achieve the same results with a blended (face-to-face training combined with e-learning) version. These kind of efforts might help establishing the right balance between efficacy and feasibility of CST.

In addition, further research should untangle the relationship between CST, HCP communication behaviour, and patient outcomes. For example, it is not yet clear which communication behaviour is sensitive to what types of or approach to training. The findings in our recent RCT on face-to-face SDM training (10 hours) for medical oncologists suggest that agenda setting and information provision skills were more amenable to change than skills related to exploring the patient perspective [18]. Possibly, these skill sets require different forms of training. Opinions differ as to how to improve HCP communication, ranging from a preference for teaching knowledge about relationships and curiosity [35], to a preference for broad CST to be used in a variety of contexts [22\*\*], to a preference for a more technical approach, focusing on specific skills and strategies in different contexts [12\*]. By investigating which approach fits what communication behaviour, CST can be embedded more efficiently. Besides, for tailoring CST to HCP subgroups (e.g. nurses or medical specialists), HCP characteristics (e.g. a priori skills level), or patient populations (e.g. AYAs or palliative care patients), research may be warranted to understand how to target training to best meet learners' varying needs. In addition, Paul *et al.* [34\*] note that the very limited inclusion of patient outcomes suggests that it is generally assumed that improved HCP skills are beneficial for patients. He, and many authors with him, recommended investigating the effect of CST on patient outcomes [26\*\*-28\*\*, 29\*, 30\*, 32\*-34\*]. It would be valuable to unravel what HCP skills are most impactful for patients, at various moments in their disease trajectory. Of note, none of the reviews mentioned the cost-effectiveness of CST, whereas CST might affect the costs of, for example, unnecessary patient distress, unnecessary treatment, and indirect system distress, such as physician burnout [36].

## **Strengths and limitations**

One strength of this review is the combination of synthesising both the evidence for the effectiveness of CST and the implications of these findings. This puts the evidence found in perspective. In addition, by conducting a review of reviews, a comprehensive overview of the literature was compiled. A challenge encountered in this review of reviews is how to define a systematic review. We chose to include all articles that described a search and the number of papers (on CST) included. However, one review did not distinct itself as a systematic review [34\*] and a guideline was included as well [31\*]. We could have adopted more stringent criteria for the quality of the reviews [37], yet we preferred to maintain a broad scope.

## **CONCLUSION**

Adopting the phrasing used in the plain language summary of the recent Cochrane review, CST can probably improve some aspects of HCPs' communication skills. Despite the scarce and low certainty evidence for the effectiveness of CST and for effective CST features, authors of reviews advocate the widespread implementation of CST into clinical practice and provide specific recommendations on intensity and format. It seems that several of these recommendations are made based on expert consensus and opinions, not on strong empirical evidence. More and higher quality evidence to justify and substantiate the development and implementation of CST into clinical practice is needed, as is generally agreed on by authors of reviews in their implication sections.

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## APPENDIX 4A. OVERLAP BETWEEN STUDIES/ARTICLES IN REVIEWS

Study	Articles	Moore <i>et al.</i> <sup>a</sup>	Barth and Lannen <sup>a</sup>	Uitterhoeve <i>et al.</i> <sup>a</sup>	Gorman <i>et al.</i>	Christie and Glew	Gilligan <i>et al.</i>	Kao <i>et al.</i>	De Vries <i>et al.</i>	Paul <i>et al.</i>	<i>n</i>
1	Butow 2008 [1]	x	x								2
	Girgis 2009 [2]	x									1
2	Epstein 2017 [3]	x									1
	Fenton 2016 [4]	x									1
	Hoerger 2013 [5]	x									1
	Rodenbach 2017 [6]	x									1
											1
3	Fallowfield 2002 [7]	x	x						x		3
	Fallowfield 2003 [8]	x							x		2
	Jenkins 2002 [9]	x	x	x							3
	Shilling 2003 [10]	x	x	x							3
4	Fujimori 2014a [11]	x									1
	Fujimori 2014b [12]	x					x				2
	Fujimori 2011 [13]	x									1
5	Goelz 2011 [14]	x									1
	Goelz 2009 [15]	x									1
6	Gorniewicz 2017 [16]	x									1
	Bishop 2016 [17]	x									1
7	Heaven 2006 [18]	x	x								2
8	Kruijver 2001a [19]	x		x							2
	Kruijver 2001b [20]	x									1
9	Lienard 2010a [21]	x									1
	Bragard 2009 [22]	x									1
	Bragard 2010 [23]	x									1
	Darnas 2009 [24]	x									1
	Gibon 2009 [25]	x									1
	Hasoppe 2009 [26]	x									1
	Lienard 2010b [27]	x									1
	Lienard 2009a [28]	x									1
	Lienard 2009b [29]	x									1
	Merckaert 2013 [30]	x					x				2
	Meunier 2013 [31]	x									1
10	Merckaert 2015 [32]	x					x				2
	Gibon 2011 [33]	x									1
	Gibon 2013 [34]	x									1
	Lienard 2016 [35]	x									1

11	Razavi 1993 [36]	x	x							2
	Delvaux 1993 [37]	x								1
12	Razavi 2002 [38]	x	x					x		3
	Canivet 2011 [39]	x								1
	Canivet 2014 [40]	x								1
	Delvaux 2004 [41]	x	x	x				x		4
	Gibon 2010 [42]	x								1
13	Razavi 2003 [43]	x	x	x				x		4
	Bragard 2010 [44]	x								1
	Delvaux 2005 [45]	x	x	x			x			4
	Lienard 2008 [46]	x	x	x						3
	Lienard 2006 [47]	x	x	x				x		4
	Merckaert 2008 [48]	x	x							2
	Merckaert 2005 [49]	x	x				x	x		4
	Libert 2007 [50]		x							1
14	Stewart 2007 [51]	x	x							2
15	Tulsky 2011 [52]	x								1
	Koropchak 2006 [53]	x								1
	Rodriguez 2010 [54]	x								1
	Skinner 2009 [55]	x								1
16	van Weert 2011 [56]	x								1
17	Wilkinson 2008 [57]	x	x							2
18	Alexander 2006 [58]		x							1
19	Hainsworth 1996 [59]		x							1
20	Kruse 2003 [60]		x							1
21	Razavi 1988 [61]		x							1
	Razavi 1991 [62]		x							1
22	Brown 2007 [63]			x	x		x			3
23	Hulsman 2002 [64]			x						1
<b>Total</b>		<b>56</b>	<b>22</b>	<b>10</b>	<b>1</b>	<b>0</b>	<b>3</b>	<b>1</b>	<b>4</b>	<b>5</b>
Residual articles		na	na	na	0	4	5	1	2	2

Note: all articles included in the three key reviews are represented in the rows; of the remaining six reviews, it was only indicated if there was overlap with articles included in the three key reviews; the bottom row displays how many residual papers on CST were included in those reviews

<sup>a</sup> The author names of the three key reviews included in this Table are in bold font

Abbreviations: na = not applicable

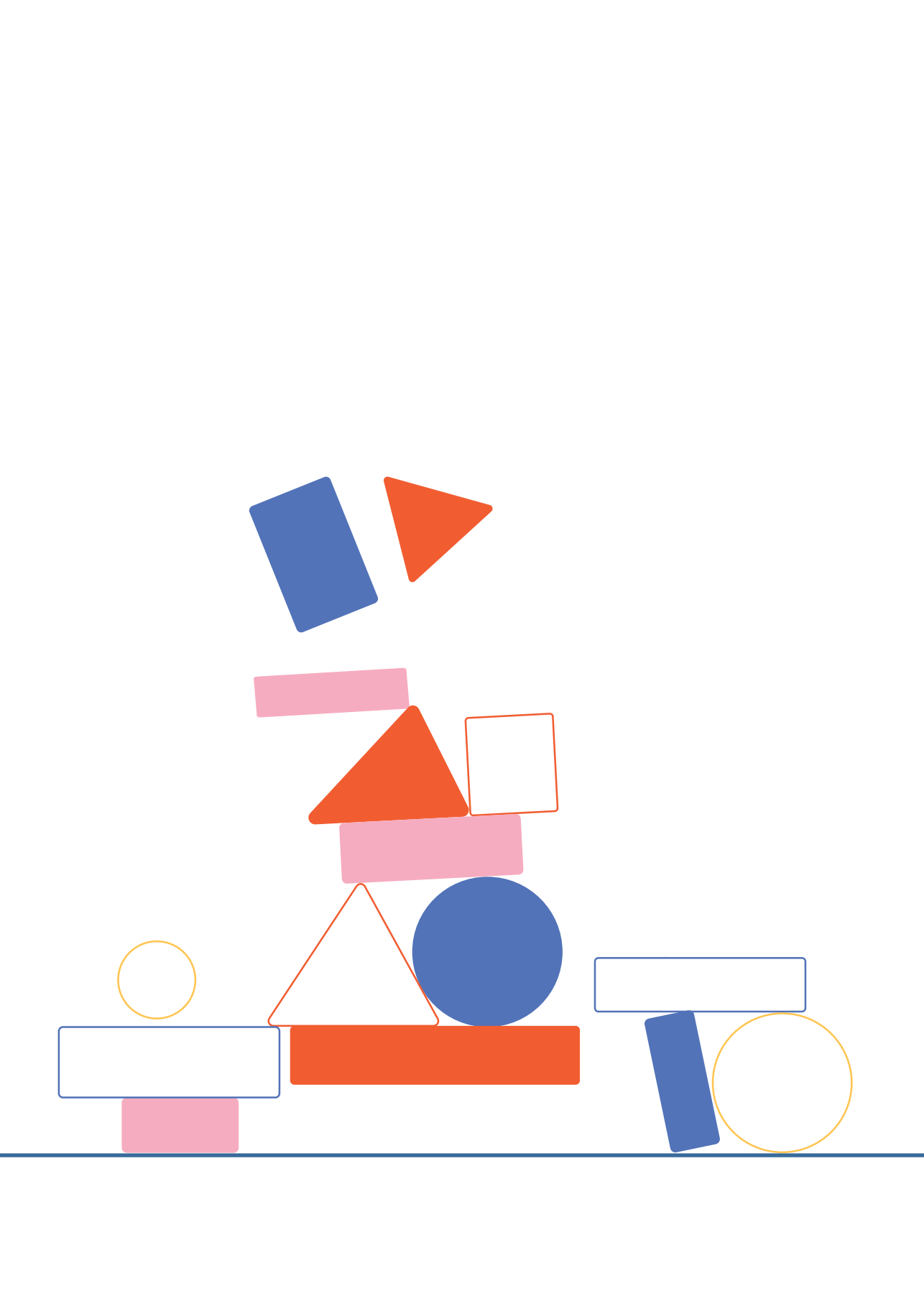
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# Chapter 5

## **Online blended communication skills training for oncologists to improve skills in shared decision making about palliative chemotherapy: A pre-posttest evaluation**

This chapter is submitted for publication as:

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## ABSTRACT

**Purpose:** To improve shared decision making (SDM) with advanced cancer patients, communication skills training (CST) for oncologists is needed. The purpose was to examine the effects of an online blended CST (i.e. e-learning and online training session) for oncologists about SDM in palliative oncological care and to compare this blended format with a more extensive, face-to-face format.

**Methods:** A one-group pre-posttest design was adopted. Before (T0) and after (T2) CST, participants conducted simulated consultations (SPAs) and surveys; after the e-learning (T1) an additional survey was filled out. The primary outcome was observed SDM (OPTION12 and 4SDM). Secondary outcomes included observed SDM per stage, SPA duration, and the decision made, as well as oncologists' self-reported knowledge, clinical behavioural intentions, satisfaction with the communication, and evaluation of the CST. Additionally, outcomes of the blended CST were compared with those of the face-to-face CST cohort. Analyses were conducted in SPSS by Linear Mixed Models.

**Results:** Oncologists ( $n=17$ ) showed significantly higher SDM scores after the online blended CST. The individual stages of SDM and the number of times the decision was postponed as well as oncologists' beliefs about capabilities, knowledge, and satisfaction increased after the blended CST. Consultation duration was unchanged. The CST was evaluated satisfactory. When compared with the face-to-face CST, the blended CST effects were smaller.

**Conclusion:** Online blended CST in SDM for oncologists was effective, although the effects were smaller compared to face-to-face CST. The availability of different CST formats provides opportunities for tailoring CST to the wishes and needs of learners.

## INTRODUCTION

For most patients with metastatic cancer, the primary goals of anti-cancer treatment are maintaining quality of life and prolonging survival. However, treatment options have uncertain, possibly limited benefits with high burden. Alternatively, patients may choose foregoing anti-cancer treatment. Often, no single best treatment strategy exists. In this setting, shared decision making (SDM) is required to provide care that matches patients' values and preferences best. SDM involves four steps: 1) introducing the choice, 2) explaining options with related pros and cons, 3) elucidating patients' values and constructing preferences, and 4) jointly making or postponing the decision [1]. SDM is advocated because of respect for patient autonomy [1, 2], reports of positive patient outcomes, including improved satisfaction and less decisional conflict [3], and patients' wish to be involved in SDM [4].

Although physicians value SDM [5], observational studies show that SDM is not always visible in palliative cancer care [6-10]. Often, limited awareness is created about available treatment options and the option to refrain from chemotherapy [6, 7]. Patients do not always receive clear information about the survival benefit of palliative chemotherapy [8], nor are their values and appraisals of treatment option characteristics explicitly addressed [6, 9]. Lastly, patients' preferred decision-making role is infrequently elicited and the decision-making process is not matched accordingly [10].

Physician training is proposed to facilitate the implementation of SDM. Several communication skills training (CST) programmes on SDM have been developed [11] and have shown to improve SDM [12-14]. Blended learning formats, i.e. online learning with some level of learner control (e.g. over time, place, or pace) combined with more traditional instructor-led synchronous learning [15], are increasingly adopted for CST because of their flexibility, richness, and cost-effectiveness [16]. Online and blended CST, both with and without participant interaction, benefits cancer and palliative healthcare professionals [17] and its completion rate can be up to six times higher compared to traditional training [18]. Although a review comparing e-learning or blended learning with conventional learning suggests that e-learning may be at least as effective as conventional training, no definite conclusions can be drawn given the large heterogeneity across studies [19].

In response to the call for more research into the effects of different formats of CST about SDM [14, 20], an online blended learning format (4 hours) of a previously evaluated highly effective intensive, face-to-face CST (10 hours) in SDM about palliative oncological care [12, 13] was developed and evaluated. The aim of this study is to examine the effects of this online blended CST. We hypothesise that the online blended CST will improve observed

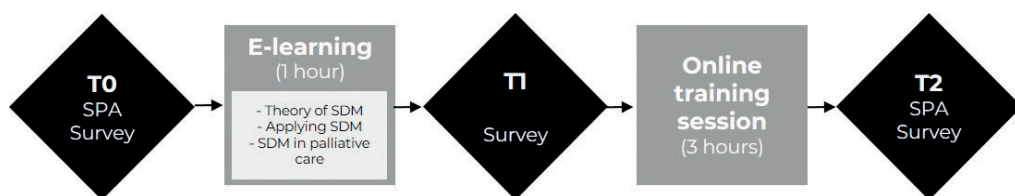
SDM about palliative systemic treatment in simulated consultations. Secondary outcomes include observed SDM per stage, knowledge, clinical behavioural intentions, satisfaction with communication, consultation duration, the decision made, and evaluation of the blended CST. Additionally, we aimed to compare the effect of the online blended format with a more extensive, face-to-face CST format, which was evaluated in a similar design.

## MATERIALS AND METHODS

The Human Ethics Committee at the Amsterdam UMC, location AMC provided ethical clearance for the study and local permission was obtained at all participating hospitals. The STROBE guidelines [21] were followed in this report.

### Design

The study adopted a one-group pre-posttest design (Figure 5.1). Participants engaged in standardised patient assessments (SPAs), i.e. simulated consultations with actors, at baseline (T0) and after the CST (T2). In addition, participants filled out surveys at baseline (T0), after completing the e-learning (T1), and after the second SPA (T2).



**Figure 5.1.** Study design

*Abbreviations: SDM = shared decision making; SPA = standardised patient assessment*

### Setting and participants

Participants were medical oncologists (in training), who regularly have decision-making conversations with advanced cancer patients regarding starting, continuing, or changing palliative systemic treatment.

### Sample size

Based on previously reported effect sizes [12, 13], the study was powered to detect a large effect (Cohen's  $d=0.80$ ). This required a sample size of fifteen oncologists (G\*Power 3.1.9.2,  $\alpha=0.05$ ,  $\beta=0.80$ ; paired t-test).

## Recruitment

Potential participants were contacted via medical oncology departments within hospitals, until at least fifteen oncologists were recruited. Interested oncologists were informed about the study by e-mail, and received an information and informed consent letter, which was signed by all participants before the baseline SPA was performed. After attending the blended CST, oncologists received accreditation by the Netherlands Association of Internal Medicine.

## Communication skills training (CST)

The online blended CST consisted of two parts: an asynchronous e-learning and a synchronous online training session with an instructor. We originally planned an in-person training session, but constrainedly switched to an online modality due to the COVID-19 restrictions. Both training parts addressed SDM knowledge, attitude (i.e. motivation and personal barriers), and skills (i.e. ability to apply the four stages of SDM). The e-learning consisted of three obligatory modules: 1) theory of SDM, 2) applying SDM, and 3) SDM in palliative care, e.g. communication about prognosis and incorporating advance care planning, which were estimated to take 1 hour in total. The training session content was based on the previously evaluated face-to-face CST [12, 13]. It adopted behaviour change techniques [22] among which providing instruction and prompting practice by role-play with professional actors according to the fishbowl working format, in which one learner practiced with one of the stages of SDM with an actor and the other participants observed and provided feedback [23]. The online training sessions were provided in small groups ( $n=2-5$ ) by an experienced trainer in a session of 3 hours. Afterwards, participants received a pocket-size card with the four SDM steps and example phrases as a follow-up prompt [22]. On average, the total CST was estimated to take 4 hours. The blended CST was piloted in an in-person setting with six oncologists (in training) from three hospitals, after which small modifications were made.

## Standardised patient assessments (SPAs)

Two different standardised patient assessment (SPA) cases, adopted from the previous trial [12], reflected a patient with either metastatic gastric or oesophageal cancer who met the oncologist to discuss the start of first-line palliative chemotherapy. For each participant, the cases were randomly assigned to either T0 or T2. Participants received a simulated medical file. Three professional male actors played both roles. The SPAs took place online due to COVID-19 restrictions and were video recorded (Augustus 2020 to May 2021).

## Measurements

The outcomes were assessed at level one (reaction, i.e. evaluation of training) and two (learning, i.e. self-reported changes or observed changes in simulated settings) of Kirkpatrick's Model of Training Evaluation [24].

### **Sample characteristics**

**Participants.** Oncologists reported their age, sex, whether or not they were in training, years of experience in medical oncology (including residency), number of palliative cancer patients in their care for the period of one month, and receipt of CST during medical school, residency, and post education (yes/no). Besides these background characteristics, both oncologists' perception of their patients' and their own attitude towards SDM were assessed with the Control Preferences Scale (CPS, a 1-item measure with five different treatment decision making roles [25]). The items were rearranged to reflect an active, shared, or passive role of patients [26] or an informative, SDM, or paternalistic role of oncologists [5].

**SPAs.** After each SPA, oncologists were asked how realistic and comparable to their clinical practice the simulated consultation was using four study-specific items with Likert scale responses (1-10).

### **Primary outcome**

The primary outcome was the level of SDM as assessed from video-recorded SPAs using two instruments. First, the observing patient involvement scale (OPTION12), a widely used 12-item scoring instrument of physician communicative behaviour associated with SDM [27, 28]. Items are rated on a 5-point Likert scale (0: not observed – 4: very high standard) and the sum score is transformed to reflect a total out of 100. Next to the general OPTION12 manual, a study-specific manual from the previous evaluation study was used [12]. Second, the 4SDM was used, an instrument developed by Henselmans *et al.* [12] based on the four-stage SDM model [1]. The 4SDM has eight items, which are coded on a 4-point Likert scale (0: not observed – 3: observed and of high quality). Two blinded assessors rated the video-recorded consultations. The coding process consisted of training, calibration to achieve sufficient interrater reliability, and independent coding. Since intraclass correlations (ICCs) and kappa's were not considered sufficient for independent coding, all SPAs were double coded and scores averaged or discussed until consensus was reached (Appendix 5A).

### **Secondary outcomes**

See Table 5.1 for a description of the secondary outcomes and how they were assessed.

**Table 5.1.** Secondary outcomes

Outcome	Time	Measures
Observed SDM per stage	T0, T2	<p>Subscales of the 4SDM:</p> <ul style="list-style-type: none"> <li>• Setting the SDM agenda (2 items, range 0-6)</li> <li>• In forming about options (2 items, range 0-6)</li> <li>• Exploring values (2 items, range 0-6)</li> <li>• Making a decision (2 items, range 0-6)</li> </ul>
Clinical behavioural intentions	T0, T1, T2	<p>Subscales of the Continuing Professional Development (CPD; 12 items) scale [29]:</p> <ul style="list-style-type: none"> <li>• Intention to adopt a behaviour (2 items; range 1-7)</li> <li>• Social influence: perception of approval by persons significant to the individual (3 items; range 1-7)</li> <li>• Beliefs about capabilities: oncologists' perceptions of facilitators and barriers (3 items; range 1-7)</li> <li>• Moral norm: feeling of personal obligation (2 items; range 1-7)</li> <li>• Beliefs about consequences: subjective probability that certain consequences will follow (2 items; range 1-7)</li> </ul>
Knowledge about SDM	T0, T1	Self-developed knowledge test covering the content of the e-learning modules (12 items, range 0-12 right answers)
Satisfaction with SPA communication	T0, T2	Adjusted Patient Satisfaction Questionnaire (PSQ; 5 items; Visual Analogue Scale (VAS) range 0-100 [30] in a modified version for oncologists [31] and an additional sixth item on satisfaction with patient involvement in decision making
SPA duration	T0, T2	Registered based on the video-recorded SPAs
Decision to start chemo	T0, T2	Registered based on observation of the SPAs and categorised into 1) start chemotherapy and 2) decision postponed
Evaluation of blended CST	T1, T2	<p>Self-developed survey (19 items) on one or more of the separate elements of the blended CST:</p> <ul style="list-style-type: none"> <li>• Content (1: very bad – 10: very good)</li> <li>• Usefulness (1: not useful at all – 10: very useful)</li> <li>• Helpfulness to apply (even) more SDM (1: totally disagree – 10: totally agree)</li> <li>• Perceived change in knowledge through e-modules (1: totally disagree – 7: totally agree)</li> <li>• Time spent (0-15, 15-30, 30-45, 45-60 and over 60 minutes)</li> <li>• Recommending the training elements to colleagues (yes/no/maybe)</li> <li>• Expectation of colleagues to accept the training elements (yes/no/maybe)</li> <li>• Perceived fit between/evaluation of combination of elements (2 items; 1: very bad – 10: very good)</li> <li>• Experiences with online instead of the in-person modality of the training session (4 items; range 1-10), transformed into: online modality is worse (1-4), equal (5-6) or better (7-10) than in-person modality</li> <li>• Preference of in-person over online modality (1: totally disagree – 10: totally agree)</li> </ul>

Abbreviations: CST = communication skills training; SDM = shared decision making; SPA = standardised patient assessment

## Comparison of CST formats

For comparing different CST formats, data ( $n=31$  oncologists) from a previously evaluated face-to-face CST conducted in 2016 was used [12]. This CST took 10 hours, including preparatory reading (1.5 hours), two small group training sessions with mainly role-play (3.5 hours each), and a booster session (1-1.5 hours, six weeks after the last training session). The face-to-face CST was evaluated in a randomised controlled trial, in which both the intervention and the control group participated in SPAs and surveys. The eligibility criteria, SPAs, actors, coding instruments, and survey items (except from the items regarding clinical behavioural intentions and knowledge) were similar to those of the current study. Apart from the CST format, there were additional differences between both trials: the previous trial 1) involved a different trainer, 2) involved different observers, 3) had SPA cases not randomly assigned to either T0 or T2, 4) had SPAs taking place in-person instead of online, 5) had a shorter average time between CST and T2 (on average 11 days as opposed to 41 days), and 6) took place five years earlier. These differences warrant cautious interpretation of the comparison.

## Statistical analyses

Linear Mixed Models (LMMs) were conducted in IBM SPSS Statistics 26 (IBM Corporation, Armonk, NY) with time as independent fixed effect. Separate analyses were conducted for the outcomes observed SDM (OPTION12 and 4SDM), the stages of SDM (4SDM), satisfaction with the conversation (PSQ), clinical behavioural intentions (CPD), and knowledge. For the dichotomous outcome decision made, a Generalized Estimating Equation (GEE) model was used with time as independent fixed effect. For each model, different repeated covariance types were compared and the model with the lowest AIC was used. Cohen's  $d$  was presented as a measure of effect size ( $d=0.20$  small,  $d=0.50$  medium,  $d=0.80$  large effects) [32]. The comparison between the two training formats was assessed in LMMs with time, condition and time\*condition, as fixed factors and, except from clinical behavioural intentions (CPD) and knowledge, the same outcomes as described above. First, the control group of the face-to-face CST trial was used as reference category and, second, the blended CST group was used as reference category to compare the face-to-face CST with the blended CST group.

## RESULTS

After contacting 25 hospitals, seventeen oncologists from two academic and five non-academic hospitals participated in the evaluation. Of two respondents, the T0 SPA recording missed due to technical issues and one oncologist missed T1 after the e-learning. See Table 5.2 for participant and SPA characteristics.

**Table 5.2.** Participant (N=17) and SPA characteristics (N=34)

Participant characteristics		
Age in years, mean (SD)	42.82 (9.68)	
Sex, <i>n</i> (%) female	11 (64.7)	
Staff or resident, <i>n</i> (%) staff	12 (70.6)	
Type of hospital, <i>n</i> (%) academic	9 (52.9)	
Years of experience, mean (SD)	10.18 (9.53)	
CST during, <i>n</i> (%)		
Medical school	16 (94.1)	
Residency	12 (70.6)	
Post education <sup>a</sup>	5 (29.4)	
Role of patients in SDM, <i>n</i> (%)		
Active role	2 (11.8)	
Shared role	9 (52.9)	
Passive role	6 (35.3)	
Role of oncologist in SDM, <i>n</i> (%)		
Informative role	7 (41.2)	
Shared decision making role	10 (58.8)	
Days between CST and T2, mean (SD)	41.41 (23.43)	
SPA characteristics	T0 ( <i>n</i> =17)	T2 ( <i>n</i> =17)
Actor in SPA, <i>n</i> (%)		
Actor A	5 (29.4)	9 (52.9)
Actor B	9 (52.9)	6 (35.3)
Actor C	3 (17.6)	2 (11.8)
Case used in SPA, <i>n</i> (%) case 1	8 (47.1)	9 (52.9)
Perceived realism (1-10), mean (SD)		
Perceived realism	7.29 (1.72)	7.12 (2.29)
Perceived comparability	6.77 (1.68)	6.77 (1.68)
Influence of actor	4.06 (1.85)	4.76 (2.44)
Influence of online	5.88 (2.69)	5.47 (2.58)

<sup>a</sup> The five residents and one staff member indicated 'not applicable'

Abbreviations: CST = communication skills training; SD = standard deviation; SDM = shared decision making; SPA = standardised patient assessment

## Effect of the online blended CST

The oncologists demonstrated significantly more SDM after the online blended CST as measured with both the OPTION12 ( $F(1,26.44)=17.18$ ,  $p<.001$ ) and the 4SDM ( $F(1,28.82)=20.54$ ,  $p<.001$ ) (Table 5.3). The effect size was large for both primary outcomes. In addition, SDM in all four stages (stage 1:  $F(1,24.96)=18.32$ ,  $p<.001$ ; stage 2:  $F(1,15.00)=24.38$ ,  $p<.001$ ; stage 3:  $F(1,15.81)=18.32$ ,  $p=.001$ ; stage 4:  $F(1,16.13)=5.28$ ,  $p=.035$ ), oncologists' knowledge about SDM ( $F(1,28.42)=7.18$ ,  $p=.012$ ), and the satisfaction of oncologists with the conversation ( $F(1,17.00)=24.36$ ,  $p<.001$ ) improved after the online blended CST. Of the measures relating to clinical behavioural intentions, only oncologists' *beliefs about*



capabilities significantly improved after the blended CST ( $F(2,37.67)=5.59$ ,  $p=.007$ ); intention ( $F(2,33.08)=1.53$ ,  $p=.233$ ), social influence ( $F(2,20.27)=1.20$ ,  $p=.322$ ), moral norm ( $F(2,33.49)=1.52$ ,  $p=.234$ ), and beliefs about consequences ( $F(2,31.15)=0.40$ ,  $p=.675$ ) did not. The SPA duration did not change ( $F(1,16.18)=0.35$ ,  $p=.561$ ) and the decision was almost eight times more likely to be postponed after the blended CST ( $OR=7.76$ ,  $p=.039$ ).

**Table 5.3.** Effect of blended CST; raw means and standard deviations at T0, T1 and T2 and parameter estimates and 95% CIs of the fixed effects in the mixed linear models on all outcomes

Outcome (range)	T0 <sup>a</sup> (n=15)	T1 (n=17)	T2 (n=17)	b (95% CI)	Sig.	d <sup>b</sup>
SDM OPTION12 <sup>c</sup> (0-100)	43.13 (12.29)	-	58.33 (8.57)	15.21 (7.67, 22.74)	<.001	1.01
SDM 4SDM <sup>c</sup> (0-24)	13.27 (4.31)	-	19.38 (3.47)	6.12 (3.36, 8.88)	<.001	1.10
Stage 1 Setting SDM agenda (0-6)	3.77 (1.18)	-	5.24 (0.75)	1.47 (0.76, 2.18)	<.001	1.04
Stage 2 Informing about options (0-6)	3.57 (1.74)	-	5.44 (0.83)	1.93 (1.10, 2.77)	<.001	1.20
Stage 3 Exploring values (0-6)	3.23 (1.19)	-	4.88 (1.17)	1.66 (0.84, 2.48)	.001	1.04
Stage 4 Making a decision (0-6)	2.70 (2.02)	-	3.82 (1.81)	1.18 (0.09, 2.27)	.035	0.56
Oncologist clinical behavioural intentions (1-7)						
Intention	6.24 (0.50)	6.28 (0.71)	-	0.03 (-0.32, 0.37)	.827	0.04
		-	6.50 (0.59)	0.27 (-0.07, 0.60)	.120	0.39
Social influence	5.12 (1.08)	5.26 (0.67)	-	0.13 (-0.37, 0.63)	.602	0.13
		-	5.46 (0.53)	0.34 (-0.21, 0.88)	.213	0.31
Beliefs about capabilities	5.63 (0.51)	5.73 (0.82)	-	0.00 (-0.35, 0.36)	.982	0.01
		-	6.04 (0.53)	0.41 (0.14, 0.69)	.004	0.74
Moral norm	6.09 (0.51)	6.25 (0.68)	-	0.17 (-0.18, 0.52)	.332	0.24
		-	6.38 (0.67)	0.29 (-0.05, 0.64)	.092	0.42
Beliefs about consequences	6.21 (0.55)	6.19 (0.63)	-	0.02 (-0.31, 0.35)	.428	0.03
		-	6.27 (0.59)	0.15 (-0.22, 0.52)	.894	0.19
Oncologist knowledge (0-11)	8.41 (1.46)	9.50 (0.89)	-	1.09 (0.26, 1.92)	.012	0.65
Oncologist satisfaction (0-100)	63.27 (8.98)	-	71.90 (7.34)	8.63 (4.94, 12.32)	<.001	1.20
SPA duration, mm:ss	30:43 (06:41)	-	29:59 (04:59)	-0:55 (-4:13, 2:22)	.561	-0.14
Decision postponed <sup>d</sup> , n (%)	10 (66.7)	-	16 (94.1)	2.05 (0.10, 3.99)	.039	0.50

<sup>a</sup> Two recordings of SPAs were missing due to technical issues

<sup>b</sup> Cohen's d was calculated by  $b/(\sqrt{n} * SE)$

<sup>c</sup> The correlation between the OPTION12 and the 4SDM was strong (T0:  $r=.92$ ,  $p<.001$ ; T2:  $r=.90$ ,  $p<.001$ )

<sup>d</sup> Decision postponed was analysed by Generalized Estimating Equations, b was  $\ln(OR)$  and the p-value was based on the  $X^2$ -statistic

Abbreviations: 4SDM = four-step SDM instrument; CI = confidence interval; OPTION12 = 12-item observing patient involvement scale; SDM = shared decision making; SPA = standardised patient assessment

## Evaluation of blended CST

Except for three oncologists, all participants completed the three required e-learning modules. Oncologists assessed the e-learning with a 7.3 and the online training session with an 8.5 averagely (Table 5.4). About sixty percent would recommend the e-learning to colleagues and about ninety percent would recommend the training session. Most

participants indicated it took 15-30 minutes to complete an e-learning module, adding up to a total of 45-90 minutes for all three modules. When asked about the online modality of the training session, most respondents implied that its quality, usefulness, and enjoyment was equal to an in-person modality and that it was more practical.

**Table 5.4.** Evaluation outcomes of blended CST

Outcome (range)	E-learning <sup>a</sup>			Overall (n=16)	Online training session (n=17)
	Theory of SDM (n=16)	Applying SDM (n=15)	SDM in palliative care (n=16)		
Rating (1-10), mean (SD)					
Content	7.38 (0.81)	7.53 (0.83)	7.13 (0.89)	7.31 (0.79)	8.47 (0.80)
Usefulness	7.50 (0.89)	7.40 (0.99)	7.25 (0.93)	7.38 (0.81)	8.35 (0.86)
Helped applying SDM <sup>b</sup> (1-10), mean (SD)	7.95 (2.08)	8.29 (1.23)	7.95 (1.47)	-	8.24 (0.97)
Knowledge gain (1-7), mean (SD)	5.56 (0.72)	5.80 (0.68)	5.25 (0.93)	-	-
Time spent (in minutes), n (%)					
0-15	7 (43.8)	4 (26.7)	5 (31.3)	-	-
15-30	8 (50.0)	7 (46.7)	10 (62.5)	-	-
30-45	1 (6.3)	3 (20.0)	-	-	-
45-60	-	1 (6.7)	1 (6.3)	-	-
Recommendation to colleagues, n (%)					
Yes	-	-	-	10 (62.5)	15 (88.2)
Maybe	-	-	-	5 (31.3)	2 (11.8)
No	-	-	-	1 (31.3)	-
Would colleagues use CST to improve knowledge (e-learning)/skills (training session), n (%)					
Yes	-	-	-	8 (50.0)	15 (88.2)
Maybe	-	-	-	6 (37.5)	2 (11.8)
No	-	-	-	2 (12.5)	-
Assessment of combination e-learning and online training session (1-10), mean (SD)					
Fit	7.41 (1.12)				
Quality combination	7.59 (1.18)				
Assessment of online instead of in-person modality of training session					
	median (IQR)	worse, n (%)	equal, n (%)	better, n (%)	
Quality (1-10)	6.0 (5.0-8.0)	2 (11.8)	9 (52.9)	6 (35.3)	
Usefulness (1-10)	6.0 (5.0-7.0)	-	11 (64.7)	6 (35.3)	
Enjoyment (1-10)	6.0 (4.5-7.0)	4 (23.5)	8 (47.1)	5 (29.4)	
Practicality (1-10)	8.0 (7.0-9.0)	-	3 (17.6)	14 (82.4)	
Preferring in-person modality (1-10)	5.0 (4.5-7.0)	-	-	-	

<sup>a</sup> One respondent was missing in the e-learning assessment

<sup>b</sup> In the e-learning evaluation, this item was assessed on a scale of 1-7 and transformed to reflect a range of 1-10  
Abbreviations: IQR = interquartile range; SDM = shared decision making; SD = standard deviation

**Table 5.5.** Comparison of CST formats; raw means and standard deviations pre and post intervention on all outcomes

Outcome (range)	Blended CST 2020/2021 (n=17)		Reference group 2015/2016 (n=16)		Face-to-face CST 2015/2016 (n=15)	
	Pre	Post	Pre	Post	Pre	Post
SDM OPTION12 (0-100)	43.13 (12.28)	58.33 (8.57)	34.63 (11.56)	44.14 (11.46)	35.63 (12.36)	63.96 (8.77)
SDM 4SDM (0-24)	13.27 (4.31)	19.38 (3.47)	11.75 (5.13)	14.56 (3.94)	11.70 (3.86)	22.07 (2.03)
Stage 1 Setting SDM agenda (0-6)	3.76 (1.18)	5.24 (0.75)	2.94 (1.44)	3.44 (1.47)	2.90 (1.00)	5.30 (0.68)
Stage 2 Informing about options (0-6)	3.57 (1.74)	5.44 (0.83)	2.81 (1.33)	3.78 (1.05)	2.83 (1.19)	5.83 (0.52)
Stage 3 Exploring values (0-6)	3.23 (1.19)	4.88 (1.17)	2.81 (1.80)	3.81 (1.22)	2.93 (1.75)	5.40 (1.17)
Stage 4 Making a decision (0-6)	2.70 (2.02)	3.82 (1.81)	3.19 (1.76)	3.53 (1.23)	3.03 (1.39)	5.53 (0.86)
Oncologist satisfaction (0-100)	63.27 (8.98)	71.90 (7.34)	58.68 (14.71)	64.95 (9.93)	55.02 (12.96)	68.56 (8.65)

Abbreviations: 4SDM = four-step SDM instrument; CST = communication skills training; SDM = shared decision making; OPTION12 = 12-item observing patient involvement scale

**Table 5.6.** Post hoc comparisons of CST formats; parameter estimates and 95% CIs of the fixed effects in the mixed linear models on all outcomes

Outcome (range)	Face-to-face CST vs. control		Blended CST vs. control		Face-to-face vs. blended format	
	b (95% CI)	Sig.	d <sup>a</sup>	b (95% CI)	Sig.	d <sup>a</sup>
SDM OPTION12 (0-100)	18.83 (8.14, 29.52)	.001	1.18	5.70 (-4.86, 16.27)	.286	0.41
SDM 4SDM (0-24)	7.55 (3.72, 11.39)	<.001	1.33	3.30 (-0.49, 7.10)	.087	0.65
Stage 1 Setting SDM agenda (0-6)	1.90 (0.79, 3.01)	.001	1.25	0.97 (-0.12, 2.06)	.081	0.65
Stage 2 Informing about options (0-6)	2.03 (0.88, 3.18)	<.001	1.26	0.91 (-0.24, 2.05)	.118	0.57
Stage 3 Exploring values (0-6)	1.47 (0.09, 2.85)	.038	0.81	0.65 (-0.72, 2.02)	.348	0.42
Stage 4 Making a decision (0-6)	2.16 (0.81, 3.50)	.002	1.30	0.83 (-0.51, 2.16)	.218	0.48
Oncologist satisfaction (0-100)	7.26 (0.52, 14.01)	.035	0.57	2.36 (-4.18, 8.89)	.472	0.21

<sup>a</sup> Cohen's d was calculated by b/SD<sub>pooled</sub>  
Abbreviations: 4SDM = four-step SDM instrument; CI = confidence interval; CST = communication skills training; SDM = shared decision making; OPTION12 = 12-item observing patient involvement scale

## Comparison between different CST formats

Table 5.5 presents the raw means of the current online blended CST group ( $n=17$ ) as well as of the face-to-face CST group ( $n=15$ ) and the control group ( $n=16$ ) of the previous trial [12]. Except for stage 3 of SDM ( $F(2,84.54)=2.23$ ,  $p=.114$ ) and satisfaction ( $F(2,48.00)=2.43$ ,  $p=.099$ ), the interaction between time and condition (previous control group, previous face-to-face CST group, and current blended CST group) was significant for all outcomes, among which the primary outcomes (OPTION12:  $F(2,88.21)=6.40$ ,  $p=.003$ ; 4SDM:  $F(2,84.13)=7.68$ ,  $p=.001$ ) and the three other stages of SDM (stage 1:  $F(2,90.01)=5.83$ ,  $p=.004$ ; stage 2:  $F(2,73.28)=6.20$ ,  $p=.003$ ; stage 4:  $F(2,46.31)=5.30$ ,  $p=.008$ ). Post-hoc comparisons showed that the group which received the blended CST did not differ significantly from the control group of the previous study on any of the outcomes (Table 5.6). The differences between the blended CST group and the previous control group on the primary outcomes were of small to medium size, while the differences between the face-to-face CST and the control group were large. When comparing the two formats with each other, the blended CST format showed a significantly smaller effect compared to the face-to-face format on the primary outcomes. Except for stage 4, the two formats did not differ significantly on the other individual SDM stages nor on oncologist satisfaction with the conversation.

## DISCUSSION

By means of a one-group pre-posttest design, we showed a large and significant effect of the blended CST on observed SDM in standardised patient assessments. To the best of our knowledge, this is the first positively evaluated online blended CST for oncologists about SDM. In addition, the blended CST improved oncologists' skills in all four SDM stages, their knowledge about SDM, beliefs about capabilities, satisfaction with the consultation, and increased the frequency of postponing the decision. The blended CST did not increase the consultation duration. Oncologists evaluated the online blended CST satisfactory and did not clearly express a preference for either an online or an in-person modality. Secondly, we compared CST formats by contrasting the 4-hour online blended CST to a previously evaluated 10-hour face-to-face CST. Taking limitations into account when comparing the two CST formats, the effect of the blended CST on SDM appears to be smaller compared to the face-to-face CST.

As stated in the Introduction, several CST programmes in SDM for oncologists (in training) and internal medicine residents have large training effects. This study shows that SDM skills can also improve with CST in an online blended learning format, partly without an instructor. Although the low response rate might suggest little enthusiasm for the blended CST, participating oncologists graded the online blended CST with an average of 7.9 (range

1-10). Probably, the low response rate was due to the emergency situation during the first months of the COVID-19 pandemic during which the study was performed. The online modality was well appreciated, especially from a practical perspective. All this is promising from an efficiency and implementation point of view, especially taking into account the physical restrictions during the COVID-19 pandemic era [33].

The results tentatively suggest that the more intensive, 10-hour face-to-face CST format is more effective than the 4-hour online blended CST format. Previous research regarding CST duration yielded mixed results: while some research shows that longer CST, for example at least one [34] or three [35] days, is most successful, other research demonstrates that CST less than ten hours is as successful as longer CST [36]. Besides, a review concluded that blended learning formats may be more effective than traditional learning [19]. Strong evidence for effective features of CST regarding format, intensity, and content is not yet available [20]. Nevertheless, as both the face-to-face and the blended learning format evaluations showed large effects on SDM skills, albeit in different study designs, the results call for a personalised CST approach, using the right ingredients in different situations and for different learners.

A first issue in the comparison of CST formats may be the changing SDM zeitgeist. The OPTION12-scores were significantly higher at baseline in the blended CST evaluation (2020/2021) as compared to the face-to-face CST evaluation (2015/2016). This might imply that, over time, SDM has become better incorporated in clinical practice due to physicians better applying SDM or patients being more aware of SDM principles. Secondly, the duration between the last training moment and the follow-up SPA was significantly longer in the blended CST. When adjusting for this duration, the differences between the two formats decreased. This may indicate that CST effects decrease over time, probably hindering the transfer of skills in clinical practice. Furthermore, it has yet to be established what the effects are of online SPAs, as were conducted in the current study, rather than in-person SPAs, as were conducted in the previous study, on observed SDM skills. Possibly, participants can demonstrate the learnt skills better in in-person than online SPAs. In line, a study on Objective Structural Clinical Examination found that those participating in online examinations performed worse than those participating onsite [37].

Despite all inherent limitations, the comparison of CST formats may be regarded a strength of the current study. Such comparisons are rare in literature and contribute to the better use of research data. Another strength is the evaluation of CST outcomes on different levels of Kirkpatrick's model, i.e. the level of reaction and learning. On the level of learning, we both evaluated if the participant 'knows how' (e.g. the knowledge test) and 'shows' (the SPA) in terms of Miller's model of clinical competence [38]. The design of the current study has limitations as well. Different training intensities (10 vs. 4 hours) and formats (face-to-face

vs. e-learning and online training session) were simultaneously compared, which hinders understanding about which effective ingredient has which effect. Secondly, the online blended CST was not evaluated in a randomised controlled trial and, given the lack of randomisation and absence of a true parallel control group, confounding explanations for its effect cannot be excluded. Also, participants may have learned unintentionally from the baseline SPA. Indeed, in the previous face-to-face CST evaluation, the control group also significantly improved their SDM skills. Thirdly, the study population may not be completely representative, as possibly only highly motivated oncologists participated in this COVID-19 era. Lastly, the trial was powered to establish large training effects, which were demonstrated in this study design. However, when comparing the blended CST with the control group of the previous trial, small to medium effect sizes were found, for which the trial was not powered. Nevertheless, these effects may imply clinically relevant change in SDM behaviour.

Next research steps should be to conduct non-inferiority trials in robust study designs, comparing different intensities and formats of CST in SDM to find the ideal dose-response balance. Ideally, research also establishes effects of CST on behaviour of oncologists in the clinical setting and on patient outcomes [14, 20], including both observer and patient reported outcomes. Since patients may experience more involvement than observers recognise [39], different methods, e.g. conversation analysis [40], or different instruments, e.g. MAPPIN'SDM that includes observers' as well as physicians' and patients' perspective [41], could be deployed to perceive insight in patient experiences. Future research should also demonstrate if the acquired skills are retained over time and whether differences between CST formats continue to exist. Additionally, SDM increasingly takes place in multiple conversations with multiple healthcare professionals, also referred to as interprofessional SDM [42]. This is supported by this study's finding that, after CST, significantly more decisions were postponed, suggesting that patients would need another conversation about the treatment decision, either with the oncologist or another healthcare professional. It was previously stated that for optimal implementation of SDM in practice, the interprofessional nature of SDM should be acknowledged [43]. Given that current as well as previous research has shown that SDM skills of oncologists can be improved through CST, other healthcare professionals in the SDM process may benefit from such CST.

In conclusion, the online blended CST in SDM for oncologists was found to be effective. This is promising given the flexible, rich, and cost-effective nature of blended CST formats, especially in pandemic times. These findings are not entirely conclusive, since a pre-posttest evaluation design was adopted and the comparison with data from a previous study involving a face-to-face CST showed smaller effect sizes for the blended online CST. Nevertheless, opportunities arise for tailoring CST formats to the wishes and needs of learners.

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## APPENDIX 5A. CODING PROCESS

### Assessor training

Two psychologists with experience in using the OPTION12 and 4SDM [13] and providing communication skills training in a medical setting restudied the manuals and discussed them with two researchers (IH, DB). They independently rated three video-recorded SPAs from the previous evaluation study with SPAs [12]. After rating these video recordings, the assessors compared their scores and discussed inconsistencies to reach a common understanding of the items and response categories. One of the researchers (DB) facilitated these discussions.

### Assessor calibration

The assessors repeatedly double coded sets of five SPAs with both the OPTION12 and 4SDM. Interrater reliability (IRR) was calculated after each set. The IRR of the OPTION12 and 4SDM was considered sufficient if the intraclass correlation (ICC) and the average weighted kappa ( $\kappa$ ) across items were higher than .60 for each item (reflecting substantial agreement) [44]. Kappas were prevalence-adjusted by balancing the matrix [45] if needed when row and column totals contained zeroes due to the low number of coded consultations and skewed distributions of ratings within items. When IRR was insufficient, scores of items with low  $\kappa$  were discussed and the study-specific manuals extended if needed. After the first set of SPAs ( $n=5$ ), the IRR was considered moderate for the OPTION12 (ICC=.76,  $\kappa=.58$ ) and substantial for the 4SDM (ICC=.94,  $\kappa=.63$ ). After coding the second set of SPAs ( $n=5$ ), the IRR was considered moderate to sufficient (OPTION12: ICC=.65,  $\kappa=.49$ ; 4SDM: ICC=.86,  $\kappa=.50$ ). The third set showed no improvement: the IRR was still moderate to sufficient (OPTION12: ICC=.87,  $\kappa=.55$ ; 4SDM: ICC=.71,  $\kappa=.50$ ). See Appendix 5A. Table 1 for more details.

### Double coding SPAs

As the ICCs and kappas were not considered sufficient for independent coding after three calibration rounds, the remaining ( $n=17$ ) SPAs were coded double. After each sixth consultation, the items with scores  $>1$  point difference were discussed until consensus was reached and study-specific manuals extended if required. The scores with 1 point difference between the assessors were averaged.

### Overall IRR

The overall ICC between the assessors of the 32 SPAs was 0.87 (OPTION12) and 0.92 (4SDM). The overall average kappas of the OPTION12 and the 4SDM were both .62, reflecting substantial agreement. Of the OPTION12, five items had  $\kappa < .60$  and of the 4SDM, two items. The observed percentage agreement was 64.6 percent for the OPTION12 and

66.0 percent for the 4SDM. One assessor seemed more strict than the other on scoring the OPTION12 (e.g. T0:  $M_1=41.39$ ,  $SD_1=13.20$ ;  $M_2=44.44$ ,  $SD_2=12.62$ ). However, paired sample t-tests between both assessors showed no significant differences (two-sided p-values) between the total scores of the OPTION12 (T0:  $p=.153$ ; T2:  $p=.089$ ) and 4SDM (T0:  $p=.935$ ; T2:  $p=.079$ ), indicating no assessor bias.

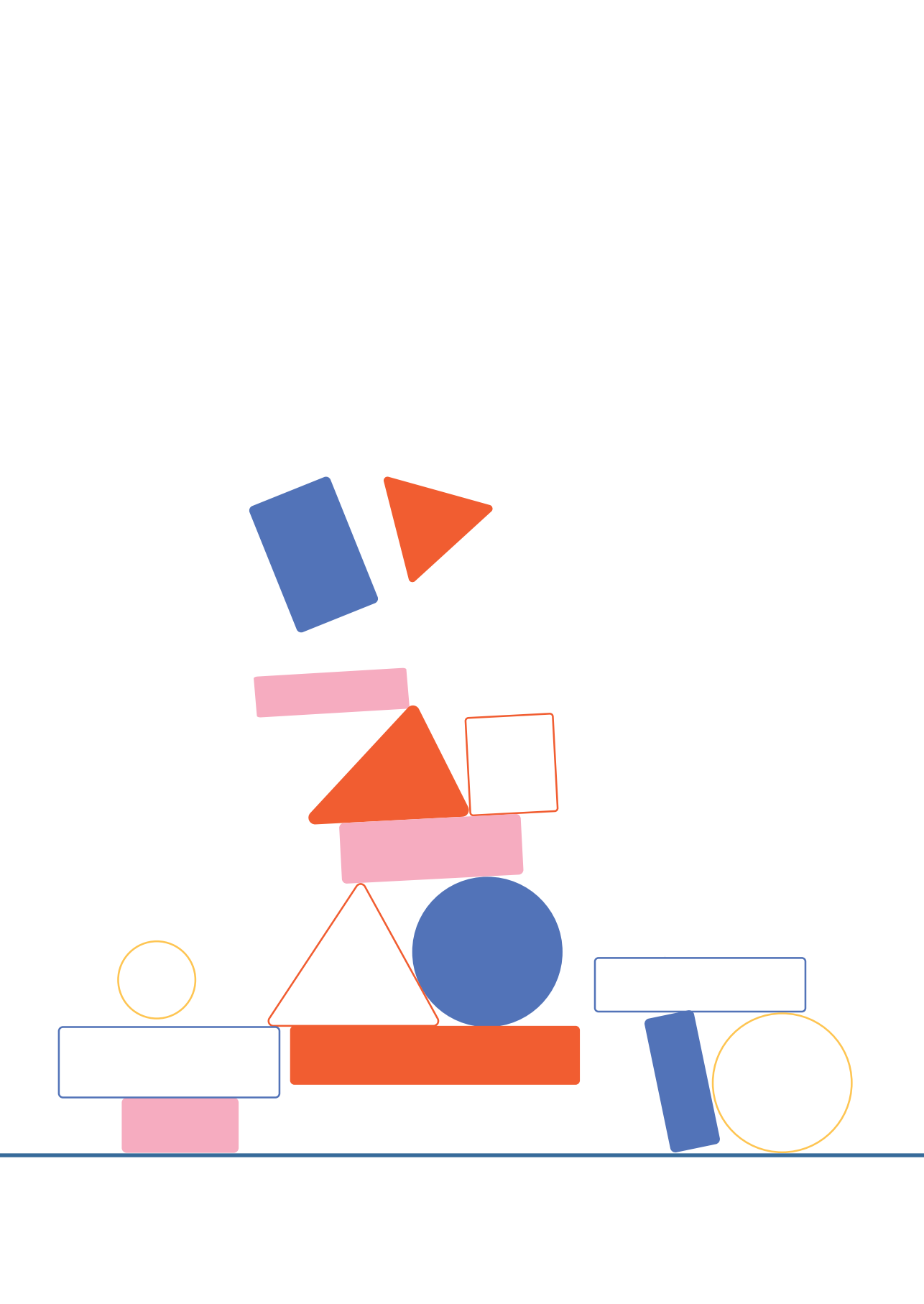
**Appendix 5A. Table 1.** Interrater reliability (IRR) in the calibration phase

	Set 1 (n=5)			Set 2 (n=5)			Set 3 (n=5)			Overall (n=15)		
	% agree	$\kappa$	ICC	% agree	$\kappa$	ICC	% agree	$\kappa$	ICC	% agree	$\kappa$	ICC
<b>OPTION12</b>	<b>56.7</b>	<b>.58</b>	<b>.76</b>	<b>56.7</b>	<b>.49</b>	<b>.65</b>	<b>60.0</b>	<b>.55</b>	<b>.87</b>	<b>57.8</b>	<b>.54</b>	<b>.71</b>
Item 1	40.0	.44		60.0	.48		40.0	.33		46.7	.46	
Item 2	60.0	.69		80.0	.62		40.0	.55		60.0	.64	
Item 3	80.0	.84 <sup>a</sup>		60.0	.33 <sup>a</sup>		100.0	1.00 <sup>a</sup>		80.0	.79 <sup>a</sup>	
Item 4	80.0	.74		60.0	.67		60.0	.64		66.7	.70	
Item 5	60.0	.74		40.0	.40		80.0	.74		60.0	.66	
Item 6	40.0	.23		20.0	.00		80.0	.58		45.7	.27	
Item 7	20.0	.38		40.0	.33		20.0	.14		26.7	.27	
Item 8	80.0	.78		40.0	.48		40.0	.14		53.3	.30	
Item 9	60.0	.44		80.0	.55		80.0	.74		73.3	.43	
Item 10	100.0	1.00 <sup>a</sup>		100.0	1.00 <sup>a</sup>		100.0	1.00 <sup>a</sup>		100.0	1.00 <sup>a</sup>	
Item 11	20.0	.00		60.0	.75		40.0	.47		40.0	.48	
Item 12	40.0	.63		40.0	.21		40.0	.29		40.0	.47	
<b>4SDM</b>	<b>67.5</b>	<b>.63</b>	<b>.94</b>	<b>55.0</b>	<b>.50</b>	<b>.86</b>	<b>62.5</b>	<b>.50</b>	<b>.71</b>	<b>61.7</b>	<b>.55</b>	<b>.87</b>
Item 1	60.0	.38		80.0	.69 <sup>a</sup>		80.0	.74		73.3	.53	
Item 2	80.0	.76		60.0	.55 <sup>a</sup>		40.0	.21		60.0	.44	
Item 3	100.0	1.00		60.0	.44		80.0	.74		80.0	.78	
Item 4	100.0	1.00		40.0	.40		100.0	1.00		80.0	.79	
Item 5	60.0	.58		20.0	.00		40.0	.12 <sup>a</sup>		40.0	.35	
Item 6	100.0	1.00		40.0	.48		60.0	.55		66.7	.68	
Item 7	40.0	.35		60.0	.57		20.0	.00		40.0	.42	
Item 8	0.0	.00		80.0	.84		80.0	.69		53.3	.42	

<sup>a</sup> Prevalence-adjusted kappa (PAK)

Abbreviations: 4SDM = four-step SDM instrument; ICC = intraclass correlation; OPTION12 = 12-item observing patient involvement scale





# Chapter 6

## **The effects of a blended communication skills training for general practitioners and hospital nurses on skills to support shared decision making about palliative cancer treatment: A one-group pre-posttest study**

This chapter is submitted for publication as:

Bos-van den Hoek DW, Smets EMA, Ali R, Baas-Thijssen MCM, Bomhof-Roordink H, Helsper CW, Stacey D, Tange D, van Laarhoven HWM, Henselmans I. The effects of a blended learning for general practitioners and nurses on skills to support shared decision making with patients about palliative cancer treatment: A one-group pre-posttest study.

## ABSTRACT

**Objective:** To examine the effects of a newly developed blended CST on general practitioners' (GPs) and nurses' skills in supporting shared decision making (SDM) about palliative cancer treatment.

**Methods:** In a pre-posttest study, healthcare professionals (HCPs) participated in the blended CST (i.e. e-learning and (online) training session). HCPs filled out surveys at T0 (baseline), T1 (after e-learning), and T2 (after full blended CST). They engaged in simulated consultations at T0 and T2. The primary outcome was observed SDM support (Triple-S and DSAT-10). Secondary outcomes included knowledge about and attitude towards SDM support, and satisfaction. Repeated measures General Linear Models were conducted.

**Results:** 33 HCPs (17 GPs and 16 nurses) participated. SDM support significantly improved after CST when measured with the Triple-S (medium effect); but not with the DSAT-10 (small effect). The CST improved observers' overall rating of SDM support (medium effect), HCPs' knowledge about SDM support (large effect), and HCPs' beliefs about their capabilities (medium effect). HCPs evaluated the CST positively.

**Conclusion:** Blended CST for HCPs in supporting SDM in palliative cancer care improves their skills in simulated consultations, their knowledge, and their confidence.

**Practice implications:** The scalability of this online CST is promising for widespread implementation of interprofessional SDM.

## INTRODUCTION

Shared decision making (SDM) is advocated when discussing treatment with patients diagnosed with incurable cancer, as difficult trade-offs must be made that require patients' personal considerations [1, 2]. In the SDM process, healthcare professionals' (HCPs) expertise about treatment options as well as patients' values and appraisals of option features and consequences are exchanged to jointly make decisions regarding patients' treatment [2-5]. Patients with cancer may benefit from SDM [6-8] and want to be involved in their treatment decision making [9, 10], also in the palliative stage [11, 12]. The increasingly distributed and interdisciplinary nature of delivery of care has raised attention for interprofessional SDM [13, 14], which assumes that different "healthcare professionals collaborate to achieve SDM with the patient, either concurrently or sequentially" [13, p.20]. The interprofessional SDM model distinguishes between a primary physician, who initiates the SDM process, and a decision coach [13, 15, 16], who supports patients in participating in decision making [17].

In the Netherlands, patients with incurable cancer make treatment choices with their medical specialist. Yet, in this healthcare system, both GPs and hospital oncology nurses may take on the role of decision coach. GPs are accessible, have longstanding relationships with patients, operate in a familiar setting, advocate a holistic approach to health problems, and have expert knowledge about guiding patients in the terminal stage [18-20]. As part of the hospital's multidisciplinary oncology team, nurses in inpatient and outpatient care provide patients with treatment information, build relationships with patients, and focus strongly on their psychosocial wellbeing [21, 22]. This may position GPs and nurses with a knowledgeable and valuable perspective on the care needs of individual patients [23]. In line, the majority of (incurable) cancer patients and survivors indicated a need for involvement of GPs and nurses after a cancer diagnosis [24].

Three interdependent strategies to support patients in SDM about advanced cancer treatment decisions were identified in previous research amongst GPs and hospital nurses [20, 25]. First, these HCPs may *check the quality of a decision* by exploring whether patients are conscious that there is a choice to make, they are sufficiently informed about the different options, including refraining from disease-targeted treatment, and are making a patient-centred decision. The second strategy, *complementing SDM*, entails contributing to the SDM process by increasing choice awareness, clarifying information, or supporting preference construction. The third strategy, *enabling SDM*, allows HCPs to organise additional activities to ensure that the SDM process will continue beyond their direct involvement, e.g. by acting as an oncologist-patient intermediary or by organising or helping preparing upcoming conversations.

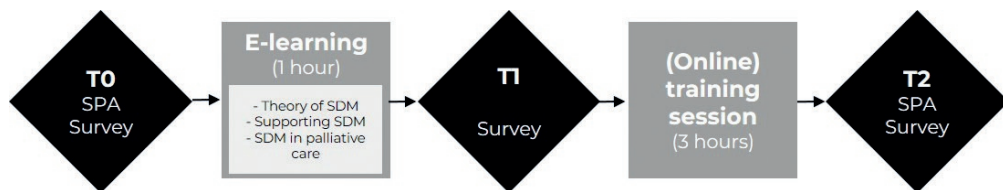


However, not all GPs and nurses seem aware of their potential supporting role in SDM about palliative cancer treatment or label their behaviour as such [20, 25]. For increasing role awareness and making their involvement more conscious and hence more effective, GPs and nurses require specific knowledge and communication skills [20, 25-27], which could be met through continuing education programmes [28]. Some training efforts showed promising effects on SDM behaviour by GPs [29, 30] as well as on decision coaching by nurses [31-35]. However, to our knowledge, communication skills training (CST) focused on supporting SDM about palliative cancer treatment does not yet exist. We developed a blended CST programme for GPs and nurses, based on the previously described strategies for SDM support [20, 25]. A blended learning format (i.e. asynchronous e-learning combined with synchronous instructor-led training sessions [36]) was adopted because of its flexibility and (cost)effectiveness [37-39].

For successful widespread implementation of SDM in clinical practice, evidence on the effects of CST programmes and formats on such topics is needed [28, 40-43]. Therefore, the aim of this study is to establish the effects of this blended CST. We hypothesise that the online blended CST will improve SDM support for decisions about palliative cancer care. The primary outcome is observed SDM support in simulated consultations. Secondary outcomes include observed support of SDM in each of the three strategies separately, knowledge of and attitude towards support of SDM, and HCPs' evaluation of the blended CST.

## METHODS

This study adopted a one-group pre-posttest design (Figure 6.1). In this report, the STROBE guidelines [44] were followed where applicable.



**Figure 6.1.** Study design

*Abbreviations: SDM = shared decision making; SPA = standardised patient assessment*

## Setting and participants

### *Sample size*

The study was powered to detect a large effect (Cohen's  $d=0.80$ ) in each separate discipline, in accordance with previous findings of similar CST [45, 46]. This required a sample size of fifteen GPs and fifteen nurses (G\*Power 3.1.9.2,  $\alpha=0.05$ ,  $\beta=0.80$ ; paired t-test). For each discipline, recruitment was continued until at least fifteen HCPs were recruited.

### *Recruitment of GPs and hospital nurses*

GPs were recruited among GP educators who supervise GPs-in-training and participate in continuing medical education meetings in GP training centres of academic hospitals in The Netherlands. GP training centres were approached to incorporate the CST in their educational meetings. When they agreed, GP educators could voluntarily enrol and were subsequently invited to participate in the evaluation study. Nurses with an oncology specialisation, caring for cancer patients, and employed by a Dutch hospital were eligible. They were approached at medical oncology departments of both academic and non-academic hospitals and through a newsletter of the nurse trainer.

### *Ethics*

The Human Ethics Committee of the Amsterdam UMC, location AMC provided ethical clearance for this study and local permission was obtained at all hospitals of participating nurses. HCPs were informed about the study by e-mail and signed informed consent before the first study activity took place. Both GPs and nurses collected continuing medical education accreditation points through participation.

## Communication skills training (CST)

The CST format was blended, consisting of e-learning modules (total of 1 hour) and one guided online (3 hours) or in-person (3.5 hours) training session. Because most training sessions took place online, we assume a training session lasting 3 hours in the remainder of this chapter. The blended CST addressed skills in supporting SDM (i.e. ability to apply the three strategies of supporting SDM: checking the quality of a decision, complementing and enabling SDM [20, 25]), attitude (i.e. awareness, motivation and personal preferences/barriers), and knowledge. The blended CST adopted several behaviour change techniques recommended for implementation of SDM [47, 48], among which providing information and instruction, prompting intention formation and goal setting, modelling the behaviour (i.e. showing tailor-made videos illustrating SDM support about palliative chemotherapy), practicing, and feedback.

There were four e-learning modules: 1) theory of SDM, 2) supporting SDM, 3) SDM in palliative care, and 4) SDM with patients with limited health literacy (optional). The training session was mainly focused on experiential learning by role-play with professional actors, prompted by short videos setting the scene. The fishbowl working format was adopted, in which one learner practiced with one of the strategies with an actor and the other participants observed and provided feedback [49, 50]. Afterwards, all participants received a consultation room tool as a follow-up prompt [47]: a pocket-size card presenting the three strategies and example phrases. See Box 6.1 for more information on the CST learning goals and content.

Training sessions were organised for small groups of either GPs or nurses ( $n=2-6$ ) and facilitated by two experienced trainers (background in either GP or nurse training). Except for one group, all training sessions were provided online due to COVID-19 restrictions, which implies this study evaluates an almost fully online format. The blended CST was pilot-tested with three GPs and three nurses in an in-person version (satisfaction scores 8.3 and 7.6 (range 1-10), respectively) and with another three GPs in an online version. Pilot findings resulted in small adjustments in e-learning modules' content as well as training sessions' methods and content. For example, more attention was needed for tailoring the conversation to patients' understanding and emotions and for HCPs' hesitations to interfere with treatment decision making.

### **Standardised patient assessments (SPAs)**

Two SPA cases for GPs reflected a patient with either metastatic gastric or oesophageal cancer who had recently met with their oncologist to discuss the start of first line palliative chemotherapy. The two cases for nurses demonstrated a patient with colorectal cancer who had just met with their oncologist to discuss the results of a scan showing recurrence and the start of second-line palliative chemotherapy. The medical situation was rather similar in both patient cases, yet their personal background differed. See Appendix 6A for more details. For each participant, the different cases were randomly assigned to either T0 (pre) or T2 (post CST). Participants received a simulated specialist's letter (GPs) or medical file (nurses), containing medical information. Three experienced professional male actors (aged 57–64 year) played all roles. They were trained and instructed to act in a standard way, namely rather passive and not overly emotional. Most SPAs took place online due to COVID-19 and were video recorded (November 2019 to June 2021). For each HCP, SPAs took place either both in-person or both online.

**Box 6.1.** Communication skills training (CST) details

**Learning objectives.** After the communication skills training (CST), the participant...

1. Attitude
  - a. Is aware of his/her potential contribution to shared decision making (SDM) in palliative cancer care
  - b. Is aware of his/her preferences and barriers to support SDM
  - c. Is willing and motivated to support SDM
  - d. Feels competent to support SDM
2. Knowledge
  - a. Knows the definition and four stages of SDM
  - b. Knows why and when SDM matters
  - c. Knows the three different strategies for SDM support
3. Skills: is able to apply the three communication strategies for SDM support, making use of the appropriate communication skills
  - a. Checking the quality of a decision
    - i. Exploring the extent to which the treatment decision is conscious
    - ii. Exploring the extent to which the treatment decision is informed
    - iii. Exploring the extent to which the treatment decision is (still) appropriate
  - b. Complementing SDM
    - i. Creating choice awareness
    - ii. Clarifying information
    - iii. Clarifying values and supporting the construction of a treatment preference
  - c. Enabling SDM
    - i. Involving others (e.g. the medical specialist)
    - ii. Support further steps (preparing questions, refer to decision aids)

**Content**

E-learning (approximately 1 hour, asynchronous)

1. Theory of SDM: theory on what SDM is as well as why and when it is important based on literature, laws and surveys by patient organisations with exercises to practice with the theory and reflect on views regarding SDM and their clinical behaviour
2. Supporting SDM: raising awareness of HCPs potential contribution to SDM by presenting theory based on literature, exercises on reasons for being involved in SDM support and highlighting the position of professional associations; theory on the three strategies to support SDM based on literature; increasing motivation to support SDM about cancer care by exercises illustrating the importance of SDM support and using videos and example questions to exercise with SDM support
3. SDM in palliative care: raising awareness about the importance and impact of SDM in palliative care based on literature; theory of specific points of attention for SDM in palliative care based on literature; increasing motivation to engage in SDM in palliative care by exercises, sometimes by using videos, to think about and reflect on one's behaviour in clinical practice and presenting available tools
4. SDM with patients with limited health literacy (optional): theory on limited health literacy (LHL) and how to recognise it based on literature and exercises; improving understanding of the challenges of SDM with LHL by theory provided by the Dutch centre of expertise on health disparities; knowledge on how to apply SDM with patients with LHL by elaborating on two communication strategies and providing concrete examples, sometimes with videos; increasing motivation to apply SDM with patients with LHL by exercises to practice communication strategies and providing example questions in plain language

(Online) training session (3/3.5 hours, synchronous)

1. Introductory round (15/25 minutes)
2. Refreshing knowledge e-learning: animation and room for questions (15/15 minutes)
3. Exploring barriers/motivation: thinking and talking in pairs (15/20 minutes)
4. Practicing skills with an actor: by means of pre-recorded videos with the start of a conversation with a patient, participants were invited to think about how they would continue the conversation and then one by one participants were asked to act it out; trainer, actor and participants were invited to provide feedback (100/135 minutes)
5. Summarising and ending (5/15 minutes); handing out consultation room tools

## Measurements

The outcomes were assessed at level one (reaction, i.e. evaluation of CST) and two (learning, i.e. self-reported changes or observed changes in simulated settings) of Kirkpatrick's Model of Training Evaluation [51].

### *Sample and SPA characteristics*

HCP characteristics were self-reported in the baseline survey (T0). SPA characteristics were registered by the researchers, except from items relating to HCPs' perception of the SPA that were queried after each SPA (T0 and T2).

### *Primary outcome*

The primary outcome was observed SDM support as assessed from video-recorded SPAs using the Triple-S, a self-developed instrument set up in this study based on the three previously identified strategies of SDM support [20, 25]. It consists of eight items, of which three focused on *checking the quality of a decision*, three on *complementing SDM*, and one on *enabling SDM*. One item focused on tailoring the conversation to patients' needs. Items were rated on 4-point Likert scales (0: not observed – 3: high standard) and a manual described how each of the categories should be coded. The total score was calculated by averaging the averages of the separate strategies (items 1-3, 4-6, and 7, respectively), and the score on item 8 and multiplying this average by 8 (range 0-24). See Appendix 6B for the instrument and Appendix 6D for more information about the validation of the Triple-S in this study. Observed SDM support was also assessed with the brief Decision Support Analysis Tool (DSAT-10) based on the Ottawa Decision Support Framework [15], which aims to analyse practitioners' use of decision support, i.e. preparing clients for decision making by providing tailored information, clarifying values, and enhancing self-help skills in decision making and implementation. The five categories of decision support were 1) decision-making status, 2) knowledge of options, 3) values associated with outcomes of option, 4) involvement of others, and 5) next steps. Sixteen criteria in these five categories were scored as absent or present and the corresponding scores calculated. The total score was the sum of scores (range 0-10). Cronbach's alpha was 0.50. Two assessors blinded to the condition (pre or post CST) were trained and conducted two calibration rounds. As interrater reliability (IRR) was considered insufficient for both the Triple-S and the DSAT-10, the assessors independently double rated all video-recorded simulated consultations. See Appendix 6C for more information on IRR.

### *Secondary outcomes*

***SDM support per strategy (T0, T2).*** The Triple-S also provided an observer score for each strategy. The total scores for the first two strategies were calculated by averaging the three corresponding items, the last strategy consisted of one item (range 0-3).

**Overall rating of SDM support (T0, T2).** The two observers rated the extent to which the HCP helped the patient in making a choice that fits the patient with one item (range 1: not at all – 10: to a very strong degree).

**Satisfaction with conversation (T0, T2).** Participants' satisfaction with communication in the conversation was assessed with the 5-item Patient Satisfaction Questionnaire (PSQ) [52] in a modified version for HCPs [53]. A sixth item was added to assess the satisfaction with patient involvement in the conversation about decision making. In accordance to the PSQ manual, responses were given on Visual Analogue Scales (VAS, range 0-100) and the overall satisfaction score was obtained by averaging the six items (range 0-100). Cronbach's alpha was 0.82.

**Clinical behavioural intentions (T0, T1, T2).** Clinical behavioural intentions towards supporting SDM was assessed with the previously validated Continuing Professional Development (CPD) reaction questionnaire [54], with 'supporting SDM' as target behaviour. The twelve items are based on the Theory of Planned Behaviour and assess the impact of continuing professional development activities on HCPs' clinical behavioural intentions. Except for one item, all items were rated on a scale of 1 (strongly disagree/never/extremely difficult/useless/harmful) to 7 (strongly agree/always/extremely easy/useful/beneficial). In accordance with the CPD manual, one item that was scored on a 5-point scale was transformed for analyses to reflect a score on a scale of 1-7 and the total score of each of the five subscales calculated by averaging the corresponding items (range 1-7). Cronbach's alpha of the subscales ranged from 0.74 to 0.86.

**Knowledge (T0, T1).** Knowledge of SDM (7 items), supporting SDM (3 items), and SDM in palliative care (2 items) was assessed by a 12-item self-developed multiple-choice test, covering the topics of the e-learning modules. No feedback on the score was provided in between both surveys. The number of correct answers represented the knowledge score (range 0-12).

**CST evaluation (T1).** HCPs' evaluation of the (online) blended CST was assessed with nineteen self-developed items; seven items on the e-learning (modules), ten on the (online) training session, and two on their combination (Table 6.6).

## Statistical analyses

All analyses were conducted in IBM SPSS Statistics 26 and 28 (IBM Corporation, Armonk, NY) by repeated measures General Linear Models (GLM). There were no missing variables. Analyses were conducted separately for each of the outcomes in the full sample of HCPs. Interaction effects for time\*discipline and post hoc analyses for each discipline were conducted in order to establish potential interdisciplinary differences. Cohen's  $d$  [55] was presented as a measure of effect size ( $d=0.20$  small,  $d=0.50$  medium, and  $d=0.80$  large [56]).

## RESULTS

A total of 33 HCPs participated. Three of five approached GP training centres organised six blended CST sessions. Of the 37 GPs enrolled in these sessions, seventeen participated in the study. Sixteen nurses from three out of twelve approached hospital oncology departments participated in three blended CST sessions. The main reason for not participating was the time burden, especially during the COVID-19 pandemic. See Table 6.1 and 6.2 for more participant and SPA characteristics.

### Effect of CST

#### *Intervention fidelity*

Thirteen GPs (76.5%) and fifteen nurses (93.8%) completed all three required e-learning modules. All HCPs attended the training session.

#### *Primary outcomes*

The blended CST had a medium effect on SDM support skills of HCPs as assessed with the Triple-S; the DSAT-10 showed a non-significant, small effect of the CST on decision support (Table 6.3 and 6.4). The correlation between both instruments was moderately positive (T0:  $r=.67$ ,  $p<.001$ ; T2:  $r=.48$ ,  $p=.004$ ).

#### *Secondary outcomes*

Regarding the three separate strategies of SDM support, the CST had a medium effect on *complementing SDM* and a non-significant, (very) small effect on *checking the quality of a decision* and on *enabling SDM*. The CST had a large effect on the knowledge of the HCPs as well as a medium effect on the observers' overall rating of SDM support and on one subscale of clinical behavioural intentions, HCP's *beliefs about their capabilities* to support SDM. A non-significant, (very) small effect of the CST was established on the other subscales of clinical behavioural intentions: *intention* to support SDM, perceptions of a *moral norm*, and *beliefs about positive consequences* of supporting SDM. *Social influence* decreased significantly after the e-learning, but this decrease disappeared after the complete blended CST. The CST had a non-significant, small effect on HCPs' satisfaction with the communication in the conversation. See Table 6.3 and 6.4 for more details.

**Table 6.1.** Participant characteristics (N=33)

Characteristics	Total	GPs (n=17)	Nurses (n=16)
Age in years, mean (SD)	48.18 (10.86)	53.29 (7.47)	42.75 (11.45)
Sex, n (%) female	23 (69.7)	7 (41.2)	16 (100.0)
Years of experience, mean (SD)	20.33 (9.51)	20.75 (8.53)	19.88 (10.72)
GP (practice) details			
Location, n (%)			
Rural	-	5 (29.4)	-
Suburban	-	7 (41.2)	-
Urban	-	5 (29.4)	-
Type, n (%)			
Solo	-	2 (11.8)	-
Duo	-	6 (35.3)	-
Group	-	9 (52.9)	-
Experience with (palliative) cancer patients <sup>a</sup> , mean (SD)			
Current number of cancer patients	-	90.63 (82.76)	-
Current number of palliative cancer patients	-	15.13 (16.11)	-
Number of consultations with cancer patients per year	-	130.60 (97.50)	-
Number of consultations with palliative cancer patients	-	29.53 (28.94)	-
Nurse details			
Hospital, n (%) academic	-	-	3 (18.8)
Function, n (%)			
RN with additional training <sup>b</sup>	-	-	5 (31.3)
Clinical nurse specialist	-	-	11 (68.8)
Type of department <sup>c</sup> , n (%) yes			
Inpatient	-	-	3 (18.8)
Outpatient	-	-	13 (81.3)
Day treatment	-	-	2 (12.5)
Experience with (palliative) cancer patients			
Years of experience with cancer patients, mean (SD)	-	-	12.63 (9.58)
Number of conversations with cancer patients per month, n (%)			
10-20	-	-	2 (12.5)
20-30	-	-	2 (12.5)
>30	-	-	12 (75.0)
Number of conversations with palliative cancer patients per month, n (%)			
0-10	-	-	2 (12.5)
10-20	-	-	4 (25.0)
20-30	-	-	6 (37.5)
>30	-	-	4 (25.0)
Years since last CST, mean (SD)	4.15 (4.58)	3.65 (5.01)	4.69 (4.16)
Days between CST and T2, mean (SD)	48.15 (34.06)	58.76 (43.86)	36.88 (12.62)

<sup>a</sup> Data of two GPs was missing; one indicated that the number of (consultations with) (palliative) cancer patients varied

<sup>b</sup> One nurse did not have an oncology specialisation

<sup>c</sup> Nurses could have been involved in multiple departments

Abbreviations: CST = communication skills training; GP = general practitioner; RN = registered nurse; SD = standard deviation; SDM = shared decision making



**Table 6.2.** Standardised patient assessment (SPA) characteristics (N=33)

Characteristics	Overall		GPs (n=17)		Nurses (n=16)	
	T0	T2	T0	T2	T0	T2
Duration of SPA <sup>a</sup> (min:sec), mean (SD)	21:42 (05:06)	20:02 (04:43)	21:25 (05:09)	21:26 (05:02)	22:00 (05:12)	18:34 (03:58)
Format of SPA, n (%) online	29 (87.9)	29 (87.9)	13 (76.5)	13 (76.5)	16 (100.0)	16 (100.0)
Actor in SPA						
Actor A, n (%)	8 (24.2)	2 (6.1)	3 (17.6)	2 (11.8)	5 (31.3)	0 (0.0)
Actor B, n (%)	12 (36.4)	17 (51.5)	7 (41.2)	9 (52.9)	5 (31.3)	7 (43.8)
Actor C, n (%)	13 (39.4)	14 (42.4)	7 (41.2)	6 (35.3)	6 (37.5)	9 (56.3)
Case used in SPA, n (%) case 1	17 (51.5)	16 (48.5)	9 (52.9)	8 (47.1)	8 (50.0)	8 (50.0)
Perceived realism (1-10), mean (SD)						
Perceived realism <sup>b</sup>	7.36 (2.28)	7.82 (1.21)	7.88 (1.69)	8.24 (0.97)	6.81 (2.71)	7.38 (1.31)
Perceived comparability	6.76 (1.90)	7.21 (1.43)	7.00 (1.73)	7.59 (1.18)	6.50 (2.10)	6.81 (1.60)
Influence of actor on perceived realism	3.69 (2.06)	4.00 (1.96)	4.08 (2.50)	4.31 (2.10)	3.38 (1.63)	3.75 (1.88)
Influence of online modality of SPA on perceived realism	4.52 (2.71)	4.66 (2.33)	4.69 (3.15)	5.23 (2.42)	4.38 (2.39)	4.19 (2.23)

<sup>a</sup> Significant difference ( $p < .05$ ) between T0 and T2 in the nurse group<sup>b</sup> Significant difference ( $p < .05$ ) between the GP and nurse group at T2

Abbreviations: GP = general practitioner; SD = standard deviation; SPA = standardised patient assessment

**Table 6.3.** Means and standard deviations per group at T0, T1 and T2 on all outcomes

Outcome (range)	Overall (N=33)			GPs (n=17)			Nurses (n=16)		
	T0	T1	T2	T0	T1	T2	T0	T1	T2
Triple-S (0-24)	13.88 (4.14)	-	15.81 (3.43)	14.20 (4.71)	-	16.24 (3.70)	13.54 (3.56)	-	15.35 (3.18)
Str. 1 – Checking SDM (0-3)	1.66 (0.58)	-	1.82 (0.54)	1.72 (0.65)	-	1.89 (0.61)	1.59 (0.52)	-	1.74 (0.45)
Str. 2 – Complementing SDM (0-3)	1.74 (0.57)	-	2.12 (0.47)	1.77 (0.67)	-	2.20 (0.50)	1.71 (0.47)	-	2.03 (0.44)
Str. 3 – Enabling SDM (0-3)	1.80 (0.79)	-	1.94 (0.70)	1.88 (0.80)	-	2.09 (0.80)	1.72 (0.80)	-	1.78 (0.58)
DSAT-10 (0-10)	3.67 (1.53)	-	4.33 (1.71)	4.06 (1.69)	-	4.56 (1.93)	3.25 (1.27)	-	4.09 (1.46)
Overall rating SDM support (1-10)	5.12 (1.84)	-	6.32 (1.56)	5.38 (2.01)	-	6.68 (1.77)	4.84 (1.66)	-	5.94 (1.25)
HCP clinical behavioural intentions <sup>a</sup> (1-7)									
Intention	6.20 (0.60)	6.09 (0.73)	6.35 (0.55)	6.03 (0.65)	6.00 (0.85)	6.24 (0.59)	6.38 (0.50)	6.19 (0.60)	6.47 (0.50)
Social influence	5.76 (0.88)	5.47 (0.87)	5.62 (0.80)	5.55 (0.90)	5.42 (0.94)	5.47 (0.71)	5.98 (0.84)	5.51 (0.83)	5.78 (0.89)
Beliefs about capabilities	5.37 (0.57)	5.35 (0.53)	5.74 (0.59)	5.25 (0.46)	5.33 (0.59)	5.63 (0.55)	5.50 (0.66)	5.38 (0.49)	5.85 (0.63)
Moral norm	6.00 (0.63)	6.15 (0.71)	6.12 (0.56)	5.94 (0.68)	6.15 (0.91)	6.12 (0.45)	6.06 (0.57)	6.16 (0.44)	6.13 (0.67)
Beliefs about consequences	5.97 (0.53)	6.02 (0.63)	6.08 (0.61)	5.97 (0.57)	5.97 (0.70)	6.00 (0.59)	5.97 (0.50)	6.06 (0.57)	6.16 (0.65)
HCP knowledge (0-12)	7.18 (1.93)	8.76 (1.37)	-	7.24 (2.08)	9.06 (1.25)	-	7.13 (1.82)	8.44 (1.46)	-
HCP satisfaction (0-100)	65.50 (11.09)	-	69.16 (9.40)	68.16 (11.02)	-	71.88 (5.43)	62.68 (10.78)	-	66.27 (11.82)

<sup>a</sup> Intention: behavioural intention to adopt a specific behaviour or not (2 items); social influence: the perception that persons significant to the individual have adopted the behaviour (3 items); beliefs about capabilities: HCPs' perceptions of facilitators and barriers to adopting the behaviour (3 items); moral norm: feeling of personal obligation regarding the adoption of the behaviour (2 items) and beliefs about consequences (2 items)

Abbreviations: DSAT-10 = brief decision support analysis tool; GP = general practitioner; HCP = healthcare professional; SDM = shared decision making; Str. = strategy

**Table 6.4.** GLM repeated measures – overall (N=33)

Outcome (range)		Mean change (95% CI)	F (df)	Sig.	d <sup>a</sup>	Time * type HCP
Triple-S (0-24)		1.93 (0.56, 3.29)	8.30 (1,31)	.007	0.51	.866
Str. 1 – Checking SDM (0-3)		0.16 (-0.02, 0.34)	3.24 (1,31)	.081	0.32	.865
Str. 2 – Complementing SDM (0-3)		0.38 (0.16, 0.60)	12.09 (1,31)	.002	0.61	.621
Str. 3 – Enabling SDM (0-3)		0.13 (-0.26, 0.53)	0.47 (1,31)	.497	0.12	.716
DSAT-10 (0-10)		0.67 (-0.03, 1.37)	3.85 (1,31)	.059	0.35	.619
Overall rating SDM support (1-10)		1.19 (0.61, 1.78)	17.42 (1,31)	<.001	0.74	.729
HCP clinical behavioural intentions (1-7)						
Intention	T0-T1	-0.11 (-0.38, 0.17)	0.64 (1,31)	.428	-0.14	.563
	T0-T2 <sup>b</sup>	0.15 (-0.03, 0.33)	2.53 (1.67,51.65)	.099	0.30	.741
Social influence	T0-T1	-0.30 (-0.56, -0.04)	5.55 (1,31)	.025	-0.40	.182
	T0-T2	-0.14 (-0.37, 0.08)	2.98 (2,62)	.058	-0.22	.368
Beliefs about capabilities	T0-T1	-0.02 (-0.24, 0.19)	0.05 (1,31)	.825	-0.04	.339
	T0-T2	0.36 (0.13, 0.60)	7.69 (2,62)	.001	0.56	.598
Moral norm	T0-T1	0.15 (-0.09, 0.39)	1.68 (1,31)	.204	0.23	.631
	T0-T2 <sup>b</sup>	0.12 (-0.05, 0.29)	0.94 (1.56,48.39)	.378	0.25	.800
Beliefs about consequences	T0-T1	0.05 (-0.17, 0.26)	0.19 (1,31)	.663	0.08	.663
	T0-T2	0.11 (-0.12, 0.34)	0.49 (2,62)	.616	0.17	.771
HCP knowledge (0-12)		1.57 (0.96, 2.17)	27.95 (1,31)	<.001	0.92	.396
HCP satisfaction (0-100)		3.66 (-1.32, 8.64)	2.25 (1,31)	.144	0.27	.979

<sup>a</sup> Cohen's *d* was calculated by  $M_{diff}/S_{diff}$

<sup>b</sup> Because the assumption of sphericity was violated, the Greenhouse-Geisser correction was applied

Abbreviations: CI = confidence interval; DSAT-10 = brief decision support analysis tool; GLM = general linear model; HCP = healthcare professional; SDM = shared decision making; Str. = strategy

### Outcomes in each discipline

The interaction between discipline (GPs or nurses) and time (pre or post CST) did not significantly affect any of the outcomes, meaning that there were no significant differences in CST effects between both disciplines (Table 6.4). Post-hoc analyses between GPs and nurses (Table 6.3 and 6.5) showed that the effect of the blended CST in SDM support skills was neither significant among GPs nor nurses (medium effects on Triple-S; small effects on DSAT-10). All secondary outcomes showed rather similar results across disciplines, with the exception of the CPD subscale *social influence* that decreased significantly (small effect) among nurses only.

### Experience with blended CST

HCPs graded the content of the e-learning with a 7.9 out of 10, the online training session with a 7.8, and the in-person training session with an 8.3 (Table 6.6). About 85 percent would recommend the e-learning to colleagues, while almost all would recommend either the online or in-person training session. Regarding the online modality of the training session, most HCPs indicated that the quality, usefulness, and enjoyment was equal to a hypothetical in-person modality and a slight majority experienced it to be more practical.

**Table 6.5.** GLM repeated measures – post hoc analyses between HCP groups

Outcome (range)	GPs (n=17)				Nurses (n=16)			
	Mean change (95% CI)	F (df)	Sig.	d <sup>a</sup>	Mean change (95% CI)	F (df)	Sig.	d <sup>a</sup>
Triple-S (0-24)	2.04 (-0.02, 4.10)	4.41 (1,16)	.052	0.51	1.84 (0.00, 3.69)	3.94 (1,15)	.066	0.50
Str. 1 – Checking SDM (0-3)	0.18 (-0.07, 0.43)	2.26 (1,16)	.152	0.36	0.15 (-0.14, 0.44)	1.15 (1,15)	.300	0.27
Str. 2 – Complementing SDM (0-3)	0.43 (0.07, 0.79)	6.37 (1,16)	.023	0.61	0.32 (0.05, 0.60)	6.13 (1,15)	.026	0.62
Str. 3 – Enabling SDM (0-3)	0.21 (-0.45, 0.86)	0.44 (1,16)	.515	0.16	0.06 (-0.43, 0.56)	0.07 (1,15)	.791	0.07
DSAT-10 (0-10)	0.50 (-0.51, 1.51)	1.10 (1,16)	.311	0.25	0.84 (-0.20, 1.89)	2.95 (1,15)	.106	0.43
Overall rating SDM support (1-10)	1.29 (0.45, 2.14)	10.47 (1,16)	.005	0.78	1.09 (0.22, 1.97)	7.16 (1,15)	.017	0.67
HCP clinical behavioural intentions (1-7)								
Intention								
T0-T1	-0.03 (-0.63, 0.57)	0.02 (1,16)	.897	-0.03	-0.18 (-0.57, 0.20)	1.71 (1,15)	.211	-0.33
T0-T2	0.21 (-0.21, 0.62)	0.89 (2,32)	.423	0.32	0.09 (-0.13, 0.31)	2.80 (2,30)	.076	0.29
Social influence								
T0-T1	-0.13 (-0.60, 0.35)	0.51 (1,16)	.487	-0.17	-0.47 (-0.96, 0.02)	6.71 (1,15)	.020	-0.65
T0-T2	-0.08 (-0.53, 0.38)	0.25 (2,32)	.781	-0.11	-0.21 (-0.58, 0.16)	4.08 (2,30)	.027	-0.38
Beliefs about capabilities								
T0-T1	0.08 (-0.28, 0.43)	0.35 (1,16)	.563	0.14	-0.13 (-0.57, 0.32)	0.58 (1,15)	.456	-0.19
T0-T2	0.37 (0.02, 0.73)	4.41 (2,32)	.020	0.68	0.35 (-0.16, 0.87)	3.84 (2,30)	.033	0.46
Moral norm								
T0-T1	0.21 (-0.21, 0.62)	1.77 (1,16)	.203	0.32	0.09 (-0.37, 0.56)	0.30 (1,15)	.594	0.14
T0-T2	0.18 (-0.17, 0.52)	0.93 (2,32)	.405	0.33	0.06 (-0.24, 0.36)	0.17 (2,30)	.844	0.14
Beliefs about consequences								
T0-T1	0.00 (-0.40, 0.40)	0.00 (1,16)	1.000	0.00	0.09 (-0.32, 0.51)	0.38 (1,15)	.549	0.15
T0-T2	0.03 (-0.38, 0.43)	0.03 (2,32)	.972	0.05	0.19 (-0.27, 0.65)	0.61 (2,30)	.549	0.28
HCP knowledge (0-12)	1.82 (0.84, 2.81)	15.47 (1,16)	.001	0.95	1.31 (0.54, 2.08)	13.15 (1,15)	.002	0.91
HCP satisfaction (0-100)	3.73 (-1.91, 9.36)	1.96 (1,16)	.180	0.34	3.59 (-5.29, 12.48)	0.74 (1,15)	.402	0.22

<sup>a</sup> Cohen's d was calculated by  $M_{diff}/S_{diff}$   
Abbreviations: CI = confidence interval; DSAT-10 = brief decision support analysis tool; GLM = general linear model; GP = general practitioner; HCP = healthcare professional; SDM = shared decision making; Str. = strategy

Table 6.6. Evaluation outcomes of CST

Outcome (range)	E-learning			Training session		
	Theory of SDM <sup>a</sup> (n=24)	Supporting SDM (n=31)	SDM in palliative care (n=32)	Overall (n=33)	Online (n=29)	In-person (n=4)
Rating (1-10), mean (SD)						
Content	7.54 (0.99) <sup>b</sup>	7.67 (1.18)	7.88 (0.96)	7.85 (0.87)	7.79 (0.68)	8.25 (0.50)
Usefulness	7.65 (1.02)	7.57 (1.19)	7.70 (1.45)	7.88 (0.99)	7.86 (0.74)	8.25 (0.50)
Helped supporting SDM (1-10), mean (SD)	7.75 (1.63)	7.57 (1.51)	7.97 (1.52)	-	7.66 (0.90)	8.00 (0.00)
Helped gaining knowledge <sup>b</sup> (1-10), mean (SD)	8.02 (1.40)	7.71 (1.33)	7.84 (1.43)	-	-	-
Time spent (in minutes), n (%)						
0-15	3 (11.5)	2 (6.7)	2 (6.1)	-	-	-
15-30	15 (57.7)	13 (43.3)	12 (36.4)	-	-	-
30-45	7 (26.9)	11 (36.7)	17 (51.5)	-	-	-
45-60	-	3 (10.0)	1 (3.0)	-	-	-
>60	1 (3.8)	1 (3.3)	1 (3.0)	-	-	-
Recommendation to colleagues, n (%)						
Yes	-	-	-	28 (84.8)	28 (96.6)	4 (100.0)
Maybe	-	-	-	4 (12.1)	1 (3.4)	0 (0.0)
No	-	-	-	1 (3.0)	0 (0.0)	0 (0.0)
Would colleagues use CST to improve knowledge (e-learning)/skills (training session), n (%)						
Yes	-	-	-	22 (66.7)	25 (86.2)	4 (100.0)
Maybe	-	-	-	10 (30.3)	4 (13.8)	0 (0.0)
No	-	-	-	1 (3.0)	0 (0.0)	0 (0.0)
Assessment of combination e-learning and training session (1-10), mean (SD)						
Fit					7.52 (0.79)	8.00 (0.82)
Quality combination					7.62 (0.73)	8.00 (0.82)

Assessment of online instead of in-person modality of training session <sup>c</sup>				
	median (IQR)	worse, n (%)	equal, n (%)	better, n (%)
Quality (1-10)	5.0 (5.0-6.5)	5 (17.2)	17 (58.6)	7 (24.1)
Usefulness (1-10)	5.0 (5.0-6.0)	2 (6.9)	22 (75.9)	5 (17.2)
Enjoyment (1-10)	5.0 (4.0-6.0)	10 (34.5)	14 (48.3)	5 (17.2)
Practicality (1-10)	6.0 (5.0-8.0)	5 (17.2)	11 (37.9)	13 (44.8)
Preferring in-person over online modality (1-10)	7.0 (5.0-8.0)	-	-	-

<sup>a</sup> GPs of one institution (n=7) did not make this module as theory of SDM was discussed in another part of the course

<sup>b</sup> In the e-learning evaluation, this item was assessed on a scale of 1-7 and transformed to reflect a range of 1-10

<sup>c</sup> Four participants received an in-person training session and were not asked these questions; all items were queried on a scale of 1-10 and three items afterwards also transformed into three categories: online modality is considered (1-4), equal (5-6), or better (7-10) worse than in-person modality

Abbreviations: CST = communication skills training; IQR = interquartile range; SDM = shared decision making; SD = standard deviation

## DISCUSSION AND CONCLUSION

This study demonstrated the effects of a blended CST in SDM support about palliative cancer treatment decisions for GPs and nurses. Using a pre-posttest design, we found a medium-sized, significant effect of the blended CST on observed skills in supporting SDM in simulated consultations when using a study-specific instrument (the Triple-S), and only small, non-significant improvements with the DSAT-10. In addition, the blended CST significantly improved HCPs' knowledge as well as HCPs' specific skill of complementing SDM, their beliefs about their capabilities, and observers' overall rating of SDM support in simulated consultations. The effect of the CST did not differ between GPs and nurses. HCPs evaluated the – often completely online – blended CST positively.

The difference in Triple-S and DSAT-10 observations is noteworthy. The definition of decision support is rather similar for both instruments [57]. However, the DSAT-10 evaluates decision support in the setting in which decision coaches knowingly *prepare* patients for decision making in advance of a clinical consultation with the oncologist as conceptualised in the Ottawa Decision Support Framework [17], while the Triple-S evaluates SDM support strategies where HCPs *facilitate* SDM during regular care regardless of any preconceived decision making context [20, 25]. The correlation between both instruments was moderately positive, indicative of the overlap between both conceptualisations of SDM support. The correlation decreased after CST, suggesting that the differences between both concepts became more apparent after a CST focussed on Triple-S strategies. The larger effect detected by the Triple-S also implies that the CST was mainly suitable to transfer skills related to the three SDM support strategies in the regular care setting.

Strikingly, a larger effect of the CST was found on the observers' overall rating of SDM support in contrast with the smaller effects detected by the Triple-S and DSAT-10, which assessed HCPs' behaviour in a seemingly more detailed and objective manner. This finding seems in line with previous argumentation that an overall rating may better capture complex behaviour such as supporting SDM [58, 59], as it provides a more holistic view of all facets of that behaviour. Dimensions important for supporting SDM may be interwoven and specific items may not completely match the end goal of supporting SDM.

Evidence about the impact of decision coaching in clinical practice is scarce and may differ between GPs and nurses, as they have different responsibilities and expertise. A Cochrane review studied the effects of decision coaching by HCPs, among which nurses, genetic counsellors, and psychologists, in clinical practice and concluded that such coaching may improve patients' knowledge when combined with evidence-based information (e.g. patient decision aids), without any adverse effects, e.g. decision regret or anxiety

[60]. However, they conclude further research is needed to establish the effectiveness of decision coaching for a broader range of outcomes [60]. In general practice, experience has been gained regarding ‘time out consultations’ (TOCs), i.e. actively scheduled GP-patient consultations after diagnosis to prepare for final treatment decisions. These studies showed that more such consultations took place and these were appreciated by patients [61-63]. However, neither the content of the consultations changed nor the patient-perceived degree of SDM improved [62, 63]. Strengthening GPs’ SDM support skills may enhance the effect of these TOCs. Besides, timing may matter. Patients may perceive SDM more negatively if a TOC takes place after a decision with the medical specialist has already been made and the possibility to apply SDM has passed [62]. Future research should look more closely at such short and long-term effects of SDM support for cancer patients on the complete interprofessional SDM process, including the decision-making consultation between the oncologist and the patient.

In addition, evidence for the effect of CST for HCPs in clinical practice is scarce and uncertain [28, 41, 64]. Likewise, the current study did not include the effect of CST on HCPs behaviour in clinical practice nor on patient outcomes, i.e. on Kirkpatrick’s Model of Evaluation [51] levels three and four, respectively. We showed that HCPs can learn skills to support SDM in SPAs, yet not if they will apply these strategies in clinical practice with patients. Future research should focus on intermediate and long-term endpoints as well [65, 66]. In addition, it would be beneficial to establish the minimum clinically important difference (MCID) of SDM measures, including the Triple-S. We do not know whether the found effects of the blended CST are relevant for clinical practice. Establishing such MCID with, for example, an anchor-based approach is complicated, as it requires having patients compare the behaviour of HCPs before and after an intervention [67].

Some limitations of this study should be considered. First, this study lacks a control group and a causal effect of CST cannot be guaranteed. Second, the primary outcome was assessed with a newly developed instrument that was not previously validated. Third, the learning took place only in an educational and simulated setting, not in clinical practice.

Hence, the learning circle of Kolb [68] was not completed and it may be that HCPs needed more time or additional training to effectively apply these skills [69]. Fourth, the SPAs and training sessions mostly took place online due to COVID-19 pandemic restrictions, of which the definite implications are still to be determined. Some literature indicates no differences in effect between digital and traditional learning [70], while others found that participants of online Objective Structural Clinical Examinations performed worse than those participating on-site [71]. Lastly, it is uncertain to what extent these findings are generalisable to all nurses and GPs, since many nurses ( $n=10$ ) were working in the same hospital and all GPs in our sample were GP trainers, which might be a selected group.



The results have implications for practice. Effective training of HCPs in SDM support is important for widespread implementation of interprofessional SDM [32]. The largely online format of the blended CST was generally well appreciated in the current study. This is promising, given the scalability of online CST [72]. Other facilitators of interprofessional SDM may be training the whole interprofessional team simultaneously [73, 74] and stimulating a collaborative and supportive environment to SDM training and implementation [69, 74]. Furthermore, patients may be educated about the possibility of receiving support of GPs or nurses in decision making [69], for example by oncologists or cancer patient organisations actively advocating its potential added value.

In conclusion, training GPs and nurses through blended CST can improve their SDM support skills, knowledge, and confidence. These first results are promising and provide good starting points for further developing and strengthening the foundations laid in training HCPs in interprofessional SDM. Through improving interprofessional SDM, patients with incurable cancer may reach better treatment decisions that match their values and preferences best at their end of life.

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## **APPENDIX 6A. STANDARDISED PATIENT ASSESSMENT (SPA) CASES PROVIDED TO PARTICIPANTS**

### **Case 1. Mr. van Beek**

#### **GPs**

Mr. van Beek (58 years old) will visit you for a (digital) consultation. He has a gastric carcinoma that has metastasised to his shoulder. Mr. van Beek has been visiting your practice for about 15 years now. He consulted you about having symptoms relating to hypertension around five years ago. You remember that you talked about his lifestyle at the time: he works a lot and likes to drink a few glasses of wine at the weekend. Back then, you advised him to take up a sport and you prescribed Metoprolol. A few weeks ago, mister van Beek came by for research a few times. When the complaints did not disappear, you referred him to the hospital. You have received a letter from the hospital's medical oncologist. Subsequently, you invited mr. van Beek to discuss the diagnosis and treatment. Have the conversation as you normally would. The conversation has the duration of a double consultation (20 minutes). During this consultation, no physical examination will be performed.

#### **Nurses**

Mr. van Beek (58 years old) was diagnosed with colon carcinoma that had metastasised to his peritoneum about nine months ago. At the time, he started first-line chemotherapy (oxaliplatin, capecitabine, and bevacizumab). Mr. van Beek just had a consultation with the medical oncologist regarding the results of the latest scan that was performed. Unfortunately, the results do not look good: the metastases are growing in number and size. The consultation between the medical oncologist and mr. van Beek resulted in the decision to start a new treatment. In many hospitals, if a patient receives bad news and/or a decision is made to start a new treatment, a nurse will have a conversation with the patient to support them emotionally. The nurse can take time to discuss the conversation between the patient and the oncologist. Right now, mr. van Beek visits you to discuss the conversation with the oncologist. In preparation, you have read the information below in the medical file of mr. van Beek. You don't know him very well. Decide for yourself what you would like to discuss. Have the conversation as you normally would. The conversation lasts a maximum of 30 minutes. In this conversation, no physical examination will be performed.

## Case 2. Mr. van Es

### *GPs*

Mr. van Es (63 years old) will visit you for a (digital) consultation. He has a PA-proven oesophageal carcinoma that has metastasised to his lungs. Mr. van Es has been a patient in your practice for quite some time, yet he does not come in for consultation often. In 2013, mr. van Es's wife passed away from stomach cancer. You remember this period being particularly difficult for him. Mr. van Es did visit you before the referral. You immediately referred him to the hospital. Subsequently, he was examined. You have received a letter from the medical oncologist and you invited mr. van Es to discuss his diagnosis and treatment. Have the conversation as you normally would. The conversation has the duration of a double consultation (20 minutes). No physical examination will be performed.

### *Nurses*

Mr. van Es (63 years old) was diagnosed with colon carcinoma that had metastasised to his liver about a year ago. At the time, he started first-line chemotherapy (oxaliplatin, capecitabine, and bevacizumab). Mr. van Es just had a consultation with the oncologist regarding the results of the latest scan. It doesn't look good, the metastases are growing in number and size. The consultation between the medical oncologist and mr. van Es resulted in the decision to start a new treatment. In many hospitals, if a patient receives bad news and/or a decision is made to start a new treatment, a nurse will have a conversation with the patient to support them emotionally. The nurse can take time to discuss the conversation between the patient and the oncologist. Right now, mr. van Es visits you to discuss the conversation with the oncologist. In preparation, you have read the information below in the medical file of mr. van Es. You don't know him very well. Decide for yourself what you would like to discuss. Have the conversation as you normally would. The conversation lasts a maximum of 30 minutes. In this conversation, no physical examination will be performed.

## **Treatment possibilities for metastasised stomach and oesophagus cancer**

For patients with metastasised stomach and oesophagus cancer, the chemotherapy suggested by the oncologist is CapOx. On average, patients without this chemotherapy live 4-5 months after diagnosis and with chemotherapy 11 months. The potential benefit is therefore 6 months on average. Side effects of this chemotherapy are blood count changes, nausea or vomiting, tiredness, diarrhoea, tingling or numbness in the fingers/feet, hand-foot syndrome, and muscle cramps. An alternative treatment option is to focus treatment on relieving symptoms only (best supportive care), for example pain killers or short-term radiation. Advantages are achieving optimal quality of life, not having to visit the hospital

often, and not taking medicines that may make you feel sick. Disadvantages are that there is no substantial inhibition of the disease and limited chances of life extension.

### **Treatment possibilities for metastasised colon cancer**

For patients with metastasised colorectal cancer, the second-line chemotherapy suggested by the oncologist is a combination of irinotecan, 5-FU, leucovorin, and cetuximab. This treatment can be given to patients 8-12 times (i.e. 4-5 months). After this cycle, the treatment can be continued as maintenance therapy with 5-FU/folonic acid, and cetuximab. The potential benefit from the chemotherapy is in the order of months but the range is large. Most common side effects of this chemotherapy are cholinergic syndrome during or shortly after administration (abdominal cramps, heavy sweating, watery eyes, salivation, visual disturbances, or bradycardia), diarrhoea, general malaise, nausea and vomiting, hair loss, leukopenia, liver function disorder, stomatitis (irritated mucosa in the mouth and throat), abnormal pigmentation, skin abnormalities, hypomagnesaemia, nail abnormalities/cuticle inflammation, headache, fever, interstitial pneumonitis (rare), and fall in blood pressure. An alternative treatment option is to focus treatment on relieving symptoms only (best supportive care), for example pain killers or short-term radiation. Advantages are achieving optimal quality of life, not having to visit the hospital often, and not taking medicines that may make you feel sick. Disadvantages are that there is no substantial inhibition of the disease and limited chances of life extension.



## APPENDIX 6B. TRIPLE-S

### Development

We assumed a formative measurement model. First, based on three strategies of supporting SDM identified in qualitative studies among GPs [20] and nurses [25], three domains to define the SDM support construct were selected: *checking the quality of a decision*, which means asking questions to check if there are any doubts or deficiencies for making high-quality decisions, *complementing SDM*, which entails adding to the SDM process to reach a high-quality decision, and *enabling SDM*, including organising activities to ensure that the SDM process will continue beyond one's direct involvement. Also, another classification was used to formulate items: the three aspects of high-quality decisions, i.e. decisions that are conscious, informed, and patient-centred [17, 75].

Second, items were created to reflect the three strategies of supporting SDM and the three aspects of a high-quality decision. Item 1 – 3 reflect *checking the quality of a decision* focused on how conscious (item 1), informed (item 2), and patient-centred (item 3) the decision (to be made) is. Similarly, item 4 – 6 focus on *complementing SDM* and the three components of a high-quality decision. Item 7 focuses on *enabling SDM* from a general perspective as there are many ways to do this. After discussions with the research team and first experiences in the CST pilot, item 8 was added to assess whether HCPs tailor the conversation to patient needs instead of their own agenda and prevent patients from getting confused by the conversation. Multiple discussions with the research team took place and the first set of items was pilot tested with two pilot SPAs. During the process, the items and response category specifications were refined, response categories were expanded from two to three, item 8 was reduced from two items to one item, and the option 'not applicable' was added to items 4 – 7. If a HCP checks the quality of a decision (items 1 – 3) sufficiently and does not establish any needs or omissions, the other two strategies (*complementing SDM* and *enabling SDM*) might not be applicable. If items 1 – 3 are insufficiently queried, it is uncertain whether the other two strategies were applicable or not. The 'not applicable' cannot be scored in such cases.

### Manual and scoring

A manual accompanying the Triple-S was set up, containing background on the Triple-S and the study context as well as a description of each of the items and response categories. Overall, scoring was as follows: 0 if the behaviour was not at all visible, 1 if the behaviour was minimally visible, 2 if sufficiently visible, and 3 if optimally visible. For each item, the manual also described specific instructions for each response category. Items were assessed independently of each other. Additionally, it was explained that the order in which strategies were shown was not taken into account and that item 1 – 3 (talk about the quality

of the decision) assess what is discussed in the consultation, no matter who – the patient or the HCP – initiates the discussion, while the other items (4 – 8) assess HCP behaviour only.

The total score of the Triple-S was calculated by first averaging the items corresponding to each of the three strategies. The average of items 1-3 represented the score of *checking the quality of decision* (range 0-3), the average of items 4-6 the score of *complementing SDM* (range 0-3), and item 7 *enabling SDM* (range 0-3). This way, the strategies all weigh equally in the total score. Second, the scores for each strategy and item 8 were averaged and this score multiplied by 8 to reflect a score on a scale of 0-24.

The manual was developed in a simulated setting, and should be further developed for use in a clinical context. For example, items 4 – 7 have a ‘not applicable’ option that can be scored if, by *checking the quality of a decision*, the HCP does not identify any hesitations or needs that require follow-up. In the current study context, however, these items were all considered applicable regardless of the HCP’s checking behaviour, as the observers knew there were hesitations and needs to identify in this standardised simulated setting. In a clinical setting with real patients, observers obviously need to rely purely on what is discussed, not on what they know of the patient and the situation. Furthermore, as it was not relevant in the current study, we have not fully thought through how the score of the ‘not applicable’ option should count towards calculating the total score; for example, whether it should receive the highest possible score or be ignored when calculating the total score. A difficulty may be that it is complicated to distinguish situations where an HCP sufficiently or insufficiently *checks the quality of a decision*, making it clear whether or not the option ‘not applicable’ is possible at all. This all may complicate scoring and calculating total scores, which deserves attention in future studies.

		Not at all	Minimal	Sufficient	Good	
1	The quality of the decision is checked by inquiring whether the patient is aware of the existence of a choice in which they have a say	0	1	2	3	
2	The quality of the decision is checked by inquiring whether the patient has sufficient information about the options and the possible benefit and burden of those options	0	1	2	3	
3	The quality of the decision is checked by inquiring whether the decision is in line with the patient's values and preferences	0	1	2	3	
4	The healthcare professional complements SDM by creating choice awareness	0	1	2	3	n/a
5	The healthcare professional complements SDM by clarifying information	0	1	2	3	n/a
6	The healthcare professional complements SDM by exploring patient's values and preference construction	0	1	2	3	n/a
7	The healthcare professional enables SDM by ensuring a conscious, informed and aligned decision is taken beyond the healthcare professional's direct involvement	0	1	2	3	n/a
8	The healthcare provider aligns with the patient's needs throughout the conversation about the treatment decision	0	1	2	3	

This tool is protected by copyright but is available to use, provided you a) cite the reference in any questionnaires or publications; b) do not charge for or profit from them; and c) do not alter them. Please note that the Triple-S is not developed for use in English (no forward-backward translation applied). Please do contact the authors if you want to use the Triple-S and for the accompanying manual.  
Contact: [i.henselmans@amsterdamumc.nl](mailto:i.henselmans@amsterdamumc.nl)

## APPENDIX 6C. INTERRATER RELIABILITY (IRR)

### Assessor training

One author (DB) and one psychologist (employed at a GP training institute with experience in assessing SDM skills and providing communication skills training in a medical setting) were first trained to rate the standardised patient assessments (SPAs). They first studied the study-specific manuals of the two instruments and discussed them. They independently rated three video-recorded SPAs (two GPs and one nurse) from the pilot. After rating these SPAs, the assessors compared their scores and discussed inconsistencies to reach a common understanding of the items and response categories. Study-specific manuals were extended if needed.

### Assessor calibration

To establish interrater reliability (IRR) between the assessors, two calibration rounds took place in which the assessors double coded five SPAs with both the DSAT-10 and the Triple-S. No distinction was made between GPs and nurses. The IRR of both instruments was calculated after each calibration round and was considered sufficient if the intraclass correlation (ICC) of the total score and the weighted kappa ( $\kappa$ ) across items was higher than .60, reflecting substantial agreement [76]. In addition, the average of the weighted kappas of the items was calculated and reported, but not included in decision making about IRR. Weighted kappas were prevalence-adjusted by balancing the matrix [77] if needed when row and column totals contained zeros due to low number of coded consultations and skewed distributions of ratings within items. After each calibration round, items with scores with  $\kappa < .60$  were discussed and manuals extended if needed. After the first set of SPAs ( $n=5$ ), the IRR was moderate for the Triple-S (ICC=.80, average  $\kappa=.47$ ) and fair for the DSAT-10 (ICC=.34, average  $\kappa=.32$ ). After the second set of SPAs ( $n=5$ ), the IRR was fair for the Triple-S (ICC=-.074,  $\kappa=.27$ ) and moderate for the DSAT-10 (ICC=.82,  $\kappa=.52$ ) [76]. Overall, in the calibration phase ( $n=10$ ) the IRR was considered fair for the Triple-S (ICC=.59,  $\kappa=.37$ ) and the DSAT-10 (ICC=.57,  $\kappa=.30$ ), which was lower compared to previous studies ( $\kappa=.55-.58$  [15, 79]). See Appendix 6C. Table 1.

### Double coding SPAs

As the ICCs and kappas were not considered sufficient for independent coding after two calibration rounds, the remaining SPAs ( $n=56$ ) were double coded. After each 10<sup>th</sup> consultation, the double coded SPAs were discussed. For the Triple-S, items with scores >1 point difference were discussed until consensus on one score was reached and scores with 1 point difference between assessors were averaged. For the DSAT-10, for all ten points to be awarded it was calculated whether the assessors differed in their assessment (yes/no). If the total of amount of points that differed was >2 (the standard deviation of the average

total scores of both assessors), all items of which the total score differed were discussed until consensus was reached. The other items were averaged.

### **Overall IRR**

As is shown in Appendix 6C. Table 1, the overall ICC of the total scores between the assessors of the 66 SPAs was .67 (Triple-S) and .43 (DSAT-10). The overall average kappas of all items were .37 (Triple-S) and .33 (DSAT-10). Both reflect fair agreement [76]. Of both instruments, all items had  $\kappa < .60$ , except for one item of the DSAT-10. No significant differences between assessors were found for the Triple-S (T0:  $p = .325$ ; T2:  $p = .631$ ), indicating no assessor bias. Regarding the scoring of the DSAT-10, one assessor seemed more strict than the other (e.g. T0:  $M_1 = 3.21$ ,  $SD_1 = 1.65$ ;  $M_2 = 4.55$ ,  $SD_2 = 2.11$ ) and a paired sample t-test between the DSAT-10 scores of both assessors showed significant differences (two-sided p-value, T0:  $p < .001$ ; T2:  $p = .005$ ).

**Appendix 6C. Table 1.** Interrater reliability in the calibration phase and overall

	Calibration (n=10)		Overall (N=66)	
	$\kappa$	ICC	$\kappa$	ICC
<b>Triple-S</b>	.37 <sup>a</sup>	.59	.37 <sup>a</sup>	.67
Checking the quality of a decision				
Item 1 – inquiring whether patient is choice aware	.62		.43	
Item 2 – inquiring whether patient has sufficient information	.13		.28	
Item 3 – inquiring whether decision aligns with patient values	.26		.39	
Complementing SDM				
Item 4 – HCP creates choice awareness	.60		.28	
Item 5 – HCP clarifies information	.51		.49	
Item 6 – HCP constructs patient preferences	.49		.51	
Enabling SDM				
Item 7 – HCP enables SDM	.42		.24	
Item 8 – HCP aligns with patient's conversational needs	-.04		.31	
<b>DSAT-10</b>	.30 <sup>a</sup>	.57	.33 <sup>a</sup>	.43
Decision-making status				
Item 1 – uncertainty about making a specific decision	.05		.39	
Item 2 – timing for when decision needs to be made	.55		.31	
Item 3 – stage of decision making	.80 <sup>b</sup>		.79 <sup>b</sup>	
Knowledge of options				
Item 4a – assess knowledge of options	1.00 <sup>b</sup>		.09	
Item 4b – provide information on options	.20		.36	
Item 5a – assess knowledge of benefits	.20		.25	
Item 5b – provide information on benefits	.20		.31	
Item 6a – assess knowledge of harms	.05		.18	
Item 6b – provide information on harms	.38		.56	
Values associated with option outcomes				
Item 7 – discuss values associated with benefits across options	.00		.35	
Item 8 – discuss values associated with harms across options	.21		.49	
Involvement of others				
Item 9a – assess preferred decision making role and others' involvement and their opinions	.40		.37	
Item 9b – intervene to handle needs regarding decision-making role and others involvement and their opinions	.00		.20	
Item 10a – assess other's pressure/support	.74		.29	
Item 10b – intervene to handle pressure or support needs	.00		.24	
Next steps				
Item 11 – summarize steps to meet decision-making needs	.05		.16	

<sup>a</sup> The average kappa were calculated by averaging the kappas of each item

<sup>b</sup> Prevalence-adjusted kappa (PAK)

Abbreviations: HCP = healthcare professional; ICC = intraclass correlation; SDM = shared decision making

## APPENDIX 6D. VALIDATION TRIPLE-S

For validation of the Triple-S, the instrument's reliability, convergent validity, and responsiveness were examined. Most of these concepts were already discussed earlier in this chapter, but the results are repeated in this Appendix focused on validation.

### Reliability

As is elaborated on in Appendix 6C, sufficient interrater reliability (IRR) was not established in the calibration phase. Therefore, all standardised patient assessments (SPAs) were double coded. In the full sample, IRR was considered sufficient if the intraclass correlation (ICC) and the average weighted kappa ( $\kappa$ ) were higher than .60, reflecting substantial agreement [77]. The ICC between the assessors of the 66 SPAs was .67 (95% CI: .51-.78), which was substantial. The overall average  $\kappa$  was .37, reflecting only fair agreement. All items had  $\kappa < .60$ , ranging from .24 to .51. See Appendix 6C. Table 1 for more details. No significant differences between assessors' scores of the Triple-S were found (T0:  $p = .325$ ; T2:  $p = .631$ ).

### Convergent validity

Convergent validity of the Triple-S was assessed by correlating Triple-S with DSAT-10 scores and with observers' overall rating of SDM support, i.e. the extent to which the HCP helped the patient reach an appropriate decision. The Triple-S measures the observed SDM support, where HCPs facilitate SDM during regular care regardless of any preconceived decision making context, based on three strategies: *checking the quality of a decision*, *complementing SDM*, and *enabling SDM*. The DSAT-10 evaluates decision support in the setting at which a decision coach knowingly *prepares* patients for decision making in advance of a clinical consultation with the oncologist as conceptualised in the Ottawa Decision Support Framework, i.e. preparing clients for decision making by providing tailored information, clarifying values, and enhancing self-help skills in decision making and implementation. Since they measure a comparable construct, we expected them to correlate well. The cut-off point considered required to demonstrate convergent validity was  $r = .50$  [79, 80]. The correlation between the Triple-S and the DSAT-10 was moderately positive (T0:  $r = .67$ ,  $p < .001$ ; T2:  $r = .48$ ,  $p = .004$ ). The correlations between the Triple-S and the observers' overall rating of SDM support were strongly positive (T0:  $r = .89$ ,  $p < .001$ ; T2:  $r = .78$ ,  $p < .001$ ). The lower correlations on T2 are possibly due to the fact that the Triple-S measured more strictly what was taught in the CST.

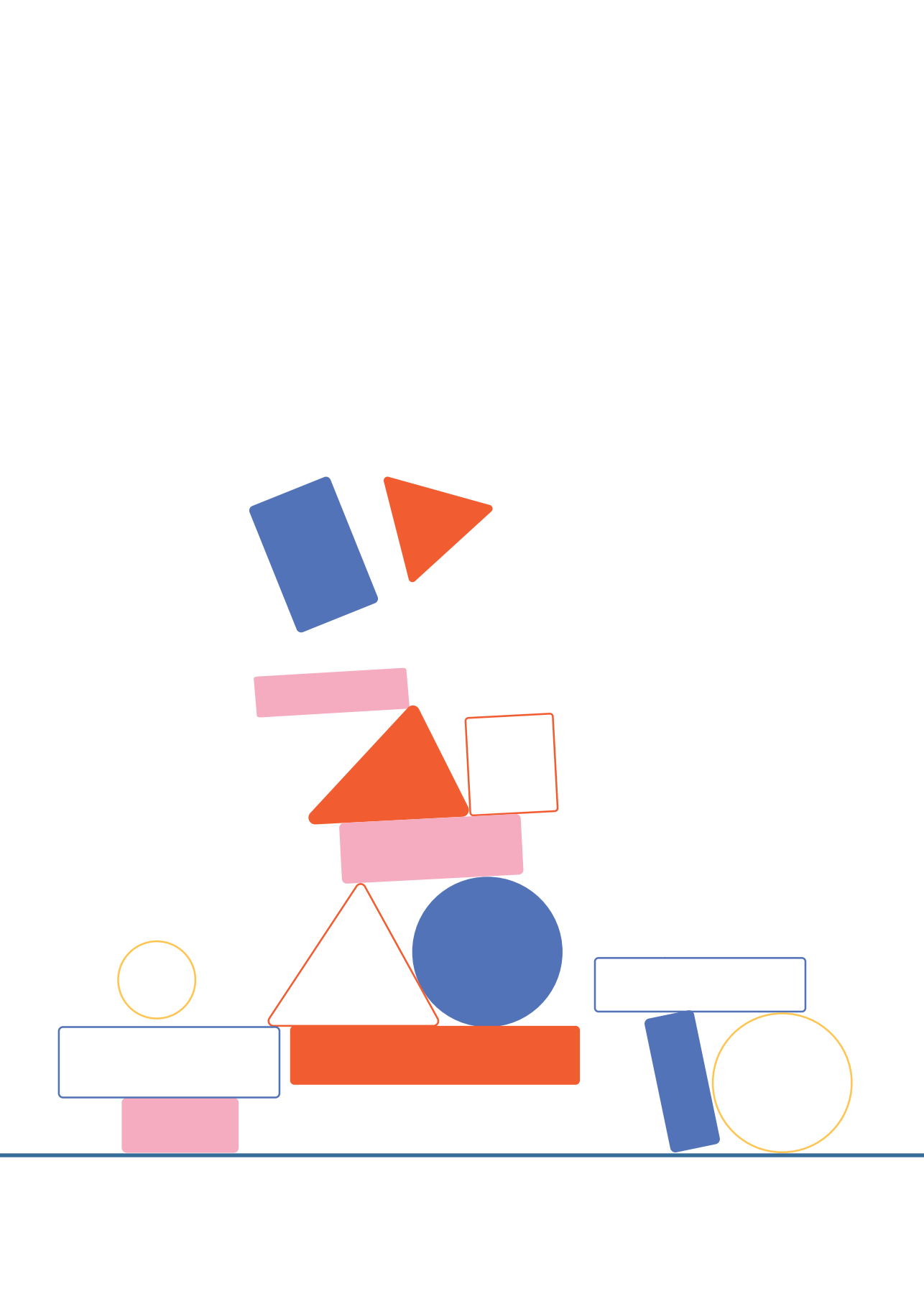
### Responsiveness

The study showed that the mean improvement of the Triple-S score was 2.04 points after the CST, a statistical significant change ( $p = .002$ ). This demonstrates the Triple-S was able

to measure improvement over time. When looking at the individual strategies, only the Triple-S's second strategy *complementing SDM* increased significantly. A limitation of this study's setup is that the Triple-S was used for establishing an effect of the intervention and for establishing responsiveness of the Triple-S simultaneously.

In conclusion, the Triple-S shows fair applicability in the context of rating SDM support skills in video-recorded SPAs. It seems that two assessors are needed to double code the degree of SDM support.





# Chapter 7

## **Through the eyes of patients: The effect of training general practitioners and nurses on perceived shared decision making support**

This chapter is submitted for publication as:

Bos-van den Hoek DW, Smets EMA, Ali R, Tange D, van Laarhoven HWM, Henselmans I. Through the eyes of patients: The effect of training general practitioners and nurses on perceived shared decision making support.

## ABSTRACT

**Objective:** To examine the effects of training general practitioners and nurses in shared decision making (SDM) support as perceived by cancer patients and survivors.

**Methods:** Using an experimental design, so-called analogue patients (AP) each assessed a video-recorded simulated consultation of a healthcare professional (HCP) conducted before or after a CST in SDM support. The primary outcome was APs' perceived SDM support with self-developed items. Secondary outcomes included AP-reported SDM, satisfaction with the communication, conversation appreciation and helpfulness as well as decision-making satisfaction and confidence, and an overall rating of SDM support. Additionally, patient and HCP characteristics associated with AP-perceived SDM support were examined.

**Results:** APs ( $n=131$ ) did not significantly differentiate trained from untrained HCPs in their perceptions of SDM support nor in secondary outcomes. Agreement between APs' observations was poor. The higher the perceived comparability of the consultation with APs' previous personal experiences, the higher their rating of SDM support.

**Conclusions:** The CST did not affect cancer patients' and survivors' perceived SDM support.

**Practice implications:** The clinical relevance of the CST in SDM support needs to be established. The variation in APs' observations suggests patients differ in their perception of SDM support, stressing the importance of patient-tailored SDM support.

## INTRODUCTION

Advanced cancer patients may need to make treatment decisions that depend on their personal evaluation of the benefits and harms of treatment options and, hence, require shared decision making (SDM). For example, they may need to choose between starting or forgoing systemic therapy, as treatment outcomes are uncertain and possibly limited while the burden of side effects may be high [1, 2]. SDM involves both the healthcare professional (HCP) and the patient, exchanging information about treatment options as well as patient values and preferences, to reach consensus about the preferred treatment [3-6]. Patients generally make decisions about cancer treatment with medical specialists. However, general practitioners (GPs) and nurses may have a complementary, supporting role in SDM [7-10]. A recent survey among patients and survivors showed that they appreciate the involvement of GPs and nurses after a cancer diagnosis [11, 12].

Attention for such interprofessional SDM and decision support by GPs and nurses has increased over the past years [13-15]. Research identified three strategies HCPs may deploy to support SDM: 1) *checking the quality of a decision*, i.e. exploring whether patients are conscious of the existence of a decision, informed about the different options, and whether their values and preferences are incorporated into the treatment decision, 2) *complementing SDM*, i.e. contributing to the SDM process by increasing choice awareness, clarifying information or supporting preference construction, and 3) *enabling SDM*, i.e. organising activities to ensure that the SDM process will continue beyond HCPs' direct involvement [16, 17].

Research shows that training can strengthen SDM support knowledge and skills of HCPs [18-21]. We previously evaluated a communication skills training (CST) in SDM support for GPs and nurses by having expert observers assess video-recorded simulated consultations conducted before and after the CST. These observers established a medium-sized significant improvement in SDM support behaviour after CST [21]. Former research, however, has shown that patients and trained observers evaluate SDM behaviour of clinicians differently [22, 23]. This stresses the necessity of exploring patient perspectives. Little is known about if and how patients experience support of GPs and nurses in decision making about cancer treatment after such CST programmes. While SDM support conversations might help patients make decisions [24], such attempts of HCPs might also go unnoticed, or not facilitate or even hinder making a high-quality decision [25]. Acquiring insights in if a CST for GPs and nurses affect not only ratings of trained observers, but also patients' perceptions of SDM support would help understanding whether the CST may indeed benefit patients in making treatment decisions.

The aim of this study is to examine the effect of the CST for GPs and nurses on cancer patients' and survivors' perceived shared decision making (SDM) support when observing video-recorded simulated consultations. The primary outcome is SDM support as perceived by these so-called analogue patients (APs), which includes the perceived degree of SDM supportive behaviours of HCPs and the perceived benefit of this behaviour for patients to feel more empowered to make a treatment decision. Secondary outcomes included self-reported SDM, satisfaction with the communication, conversation appreciation and helpfulness as well as decision-making satisfaction and confidence, and an overall rating of SDM support. Besides, the study aimed to examine which AP and HCP characteristics are associated with AP-perceived SDM support.

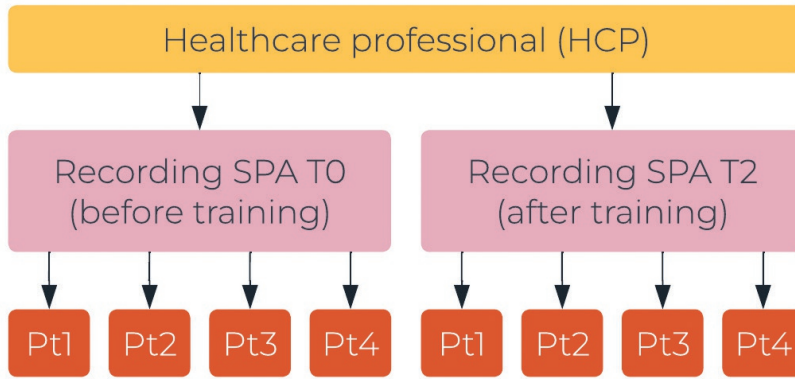
## METHODS

### Design

We previously conducted standardised patient assessments (SPAs) before and after a CST in SDM support for GPs and nurses [21]. The video-recorded SPAs were assessed by trained observers to evaluate the CST's effectiveness. In the current experimental study design, video recordings ( $n=32$ ) of SPAs of GPs ( $n=8$ ) and nurses ( $n=8$ ) conducted before (SPA T0) and after (SPA T2) the CST were assessed by at least four cancer patients or survivors ( $N=132$ ). See Box 7.1 for more information on the SPAs and Figure 7.1 for the study design. The assessments took place between June 2021 to March 2022. The STROBE guidelines [26] were followed where applicable in this report.

#### **Box 7.1.** Standardised patient assessments (SPAs)

HCPs in the video-recorded SPAs were either GPs or hospital nurses. GPs were GP educators who participate in continuing medical education meetings at GP training centres of Dutch academic hospitals. Nurses had an oncology specialisation and cared for patients with cancer in a Dutch hospital. Seventy percent was clinical nurse specialist. In the SPAs, GPs met a patient with either metastatic gastric (case 1) or oesophageal (case 2) cancer. The patient had had a conversation with the oncologist about starting palliative chemotherapy. Nurses met a patient with metastatic colorectal cancer (both cases) who just had a conversation with the oncologist regarding the results of the latest scan, which turned out to be poor, and the start of second-line palliative chemotherapy. Although the personal background of the patient cases differed, the medical situation was rather similar. See Appendix 6A for more details. Cases were randomly assigned to the SPA either before or after training. Before the start of the SPA, HCPs received a simulated specialist's letter (GPs) or medical file (nurses), containing standard medical information. Three experienced professional male actors played all roles (actor A: 63 years; actor B: 57 years; actor C: 64 years). They were trained and instructed to act in a standard way, to be rather passive, and not overly emotional. As a result of COVID-19 related restrictions, all SPAs took place online.



**Figure 7.1.** Study design

*Abbreviations: Pt = analogue patient; SPA = standardised patient assessment*

## Setting, participants, and recruitment

The study was powered to establish a medium effect, i.e. participants' ability to discriminate between trained and untrained HCPs on SDM support, of the CST (Cohen's  $d=0.50$ ) and required 128 participants (G\*Power,  $\alpha=0.05$ ,  $\beta=0.80$ , t-test). Participants were eligible if they were (previously) diagnosed with cancer and at least 50 years old, to increase engagement with the patient in the SPA. Cancer patients and survivors acted as analogue patients (APs), i.e. untrained viewers providing their perception of the interaction while taking on the patient role [27]. APs can be used if real patient observations are not possible but one is interested in subjective patient observations [27, 28], as APs' and clinical patients' perceptions of communication largely overlap [28]. Participants were recruited through the patient panels of PanelCom and Kanker.nl, both targeting (ex)cancer patients. Also, snowballing was applied by asking participants who had completed the study to invite eligible people in their network. Recruitment continued until at least 128 participants completed a survey. Invitation e-mails were sent and interested participants received participant information prior to receiving the online survey invitation. In the survey, all participants signed informed consent and a confidentiality agreement. Twenty gift vouchers were raffled among the participants. The Human Ethics Committee at the Amsterdam UMC location AMC provided ethical clearance for the study.

## Study procedures

A random selection of video-recorded SPAs (before and after the CST) from eight GPs and eight nurses was made, after verifying HCPs' consent and checking the quality of the video-recorded SPAs. The video recordings were anonymised and uploaded in a safe digital environment. The APs' online survey contained a web link to the recorded SPA that was randomly assigned to them. They were instructed that they were going to watch

a simulated conversation between a HCP and a patient (an actor). Personal and medical background information of the patient case was shared briefly as well as the context in which the conversation took place. APs were asked to engage with the patient while watching the video recording and to pay particular attention to how the HCP and patient talked about the treatment decision. Before and after watching the SPA, APs filled out a part of the survey.

## **Measurements**

### ***Baseline characteristics***

APs reported their age (in categories), sex, educational level, and medical background, i.e. whether they have (had) cancer, whether the cancer is curable, year of (first) diagnosis, type of cancer, and type of treatment. In addition, APs' preferred decisional role was measured with the Control Preferences Scale (CPS, a 1-item measure with five different treatment decision-making roles [29]), which was adjusted for analyses to reflect an active, shared, or passive patient role [30]. APs' attitude towards striving for quantity or quality of life was assessed with the Quantity Quality Questionnaire (QQQ), an 8-item survey for assessing patient attitudes concerning trade-offs between quality of life and quantity of life [31]. Responses were given on a 5-point Likert scale (1: I strongly disagree – 5: I strongly agree). Two subscales were constructed by adding the respective item scores: striving for length of life and quality of life (4 items each). Lastly, one item assessed whether APs ever had such a conversation about the cancer treatment decision with their GP or nurse (yes/no) and, if yes, another item assessed APs' perception of the comparability of the SPA with their own experience (1: not at all – 10: very much).

### ***Fidelity and validity check***

The digital environment in which APs watched the video-recorded SPAs provided analytic information on how many times the SPA was watched and for how long, in quartiles. This information was reviewed to gain insight in the fidelity of viewing SPAs, but could not be linked to APs' identification numbers. Moreover, interpretation should be cautious, as missing (parts of) viewings could also mean the AP did not turn on cookies or had internet connection issues. Regarding the validity of the procedure, engagement with the video was measured, using the validated 9-item Dutch shortened Video Engagement Scale (VES-sf) [32, 33]. This reflected "the extent to which participants are able to view, immerse, and imagine themselves being in the video and potentially being emotionally touched by the video" [32, p.2]. One item relating to whether participants paid attention was used as a screener, as this was considered a prerequisite to engage in the research and may bias results if too low [32]. Items were rated on a 7-point Likert scale (1: completely disagree – 7: completely agree) and averaged with higher scores reflecting greater engagement. In

addition, two sub scales were constructed: immersion and emotional impact, which both were calculated by averaging the corresponding four items [32].

### **Primary outcome**

Since no patient-reported observational instrument on SDM support exists, 13 self-developed items were used to assess SDM support (Appendix 7A). Six items focused on the perceived *HCP behaviour*, based on the three strategies of SDM support [16, 17]: checking the quality of a decision (1 item), complementing SDM (4 items), and enabling SDM (1 item). An example was ‘In this conversation, the HCP helped to make it clear that there is a choice between several treatment options’. Seven items focused on the perceived *patient benefit* of SDM support, i.e. being more empowered to make a treatment decision after the consultation. These benefits referred to three aspects important for making high-quality treatment decisions [34]: being choice aware (2 items), informed (2 items), and able to make a decision aligned with patient values (3 items). For example, one item stated ‘If you were the patient, after this conversation it would be clearer to you what you think of the pros and cons of the treatment(s)’. All items were rated on a 6-point Likert scale (0: completely disagree – 5: completely agree). Two total scores were calculated: *SDM support – HCP behaviour* and *SDM support – patient benefit*. These were calculated by averaging the items corresponding to each strategy or quality aspect, respectively, and subsequently averaging these three scores (range 0-5). The items were pilot tested with the first participants which resulted in some small refinements only.

### **Secondary outcomes**

Next to self-developed items, the validated 3-item CollaboRATE [35] was administered, which assesses *patient-reported SDM*. The items were introduced slightly different: ‘Imagine you were the patient...’. Items, e.g. ‘how much effort was made to include what matters to you most in choosing what to do next’, were rated on a 10-point Likert scale (0: made no effort at all – 9: made every effort), summed, and transformed to reflect a score on a range of 0-100. Secondly, *satisfaction with the communication in the consultation* was assessed with the 5-item Patient Satisfaction Questionnaire (PSQ) [36-38]. Items were slightly adapted to fit the analogue patient setting, e.g. how well the HCP addressed the needs of the patient, and assessed on a Visual Analogue Scale (VAS, range 0-100). The total score of the PSQ was the average of the five items (range 0-100). Four additional study-specific items focused on the participants’ *decision-making satisfaction*, i.e. how satisfied they would be with the way the HCP spoke about the treatment decision, *conversation appreciation*, i.e. how much they would appreciate this conversation with the HCP, perceived *conversation helpfulness*, i.e. to what extent the conversation with the HCP would have helped in making a treatment decision, and *decision-making confidence*, i.e. how confident they are that a good decision has been or will be made. These items were also



assessed on a VAS (range 0-100). Lastly, one global item assessed the overall rating of SDM support, i.e. the degree to which the HCP assisted the patient in making an appropriate decision, with a Likert scale response (1: not at all – 10: to a very strong degree).

## Statistical analyses

First, Linear Mixed Models (LMM) were computed for exploring whether APs differentiated trained from untrained HCPs while accounting for the hierarchical structure of the data (cancer patients and survivors (level 1) within training condition (time, level 2) within HCPs (level 3)). There was no missing data. A random factor for the HCP level was used. If the variance between HCPs was too low, this random factor was removed and AP assessments were treated as independent observations that were not nested. Effect size was presented by Cohen's  $d$  ( $d=0.20$  small,  $d=0.50$  medium,  $d=0.80$  large effects [39]). In addition, the intraclass correlations between APs' assessments were calculated with one-way random-effects models as each SPA was assessed by a different set of raters [40]. Next, HCP discipline and its interaction with training status (HCP discipline\*before/after training) were added to the LMMs to examine possible differences between GPs and nurses. Post hoc analyses were conducted for GPs and nurses separately. Subsequently, it was investigated which variables were associated with SDM support. Characteristics relating to APs' decision-making preferences (i.e. preferred decisional role and striving for quality and length of life), APs' similarities with the SPA patient (i.e. age, sex, patient vs survivor, palliative vs curative, corresponding type of cancer (yes/no), and chemotherapy (yes/no)), SPA HCP characteristics (i.e. sex, discipline, and years of experience) and APs' video engagement (i.e. VES sub scales immersion and emotional impact, ever had such a conversation, and comparability) were added to the model as fixed factors one by one and maintained if  $p < .20$ . Non-significant variables ( $p > .05$ ) were eliminated from the model one by one for simplification. All analyses were performed in IBM SPSS Statistics 26 (IBM, Armonk, NY).

## RESULTS

### Participant and video details

APs ( $N=132$ ) were recruited through PanelCom ( $n=106$ , response rate 23.6%),  $n=19$  through Kanker.nl (response rate 7.6%), and  $n=7$  by snowballing. Reasons for non-response were unknown. One AP was excluded from analyses as the VES screener item was  $\leq 2$ , making the final sample size  $N=131$ . Most APs were aged 60-69 (47.3%), female (60.3%), survivors (58.0%), and over half had received chemotherapy (61.1%). Within the group of participants who were currently having cancer, most were in the palliative phase (80.0%). See Table 7.1 for more participant details. As one respondent did not meet the screener criterion of the

VES and was excluded from further analyses, video recordings of SPAs ultimately were assessed by three ( $n=1$ ), four ( $n=27$ ), or five ( $n=4$ ) APs. Ninety-three percent ( $n=122$ ) of the respondents had watched their assigned SPA in full. See details in Appendix 7B.

## Evaluating SPAs before and after training

APs did not significantly differ in their assessments of SPAs of HCPs before and after CST on both primary outcomes. Effect sizes were small (Table 7.2). The intraclass correlations between APs for SDM support reflected poor agreement (*SDM support – HCP behaviour*: .17 (before training) and -.02 (after training); *SDM support – patient benefit*: -.01 (before training) and .13 (after training)). The secondary outcomes did not significantly differ between SPAs before and after training either ( $p$ -values ranging from .361 to .545 with very small negative effect sizes).

## Differences between HCP disciplines

It appeared that the by APs observed effects of CST in *SDM support – patient benefit* as well as on the overall rating of SDM support differed significantly between GPs and nurses (interaction term HCP discipline\*before/after training:  $p=.034$  and  $p=.049$ , respectively). Post hoc analyses within each HCP discipline separately showed that effect sizes of GPs were larger than those of nurses (Cohen's  $d=0.17$  vs.  $-0.06$  and  $0.20$  vs.  $-0.18$ , respectively), but none were significant. None of the effects on the other primary and secondary outcomes differed between disciplines (Table 7.3).

**Table 7.1.** Participant and video characteristics (N=131)

<b>Analogue patient characteristics</b>	
Cancer patient, <i>n</i> (%) vs. survivor	55 (42.0)
I can still be cured, <i>n</i> (%)	6 (10.9)
I (probably) cannot be cured, <i>n</i> (%)	44 (80.0)
I don't know, <i>n</i> (%)	5 (9.1)
Years since diagnosis, mean (SD)	9.17 (6.11)
Type of cancer, <i>n</i> (%)	
Breast cancer	33 (25.2)
Colon cancer	21 (16.0)
Prostate cancer	13 (9.9)
Lymphoma	12 (9.2)
Leukemia	11 (8.4)
Esophageal cancer	6 (4.6)
Multiple myeloma	6 (4.6)
Lung cancer	5 (3.8)
Stomach cancer	2 (1.5)
Skin cancer	2 (1.5)
Other type of cancer	20 (15.3)
Type of treatment, <i>n</i> (%) (multiple answers possible)	
Surgery	93 (71.0)
Chemotherapy	80 (61.1)
Radiation	68 (51.9)
Hormonal therapy	33 (25.2)
Immunotherapy	21 (16.0)
Targeted therapy	13 (9.9)
Stem cell transplantation	6 (4.6)
Other type of treatment	4 (3.1)
No treatment	6 (4.6)
Age, <i>n</i> (%)	
50-59	36 (27.5)
60-69	62 (47.3)
70-79	31 (23.7)
80 or older	2 (1.5)
Sex, <i>n</i> (%) female	79 (60.3)
Educational level, <i>n</i> (%)	
Low	20 (15.3)
Medium	35 (26.7)
High	76 (58.0)
Preferred decisional role, <i>n</i> (%)	
Active	44 (33.6)
Shared	74 (56.5)
Passive	13 (9.8)
Trade-off between quality and quantity of life (0-16), mean (SD)	
Striving for length of life	6.66 (3.06)
Striving for quality of life	12.32 (2.75)
Recruitment source, <i>n</i> (%)	
PanelCom	105 (80.2)
Kanker.nl	19 (14.5)
Snowballing	7 (5.3)
<b>Video recording characteristics</b>	
Ever had a similar conversation, <i>n</i> (%)	51 (38.9)
Comparability with own experience (1-10), mean (SD)	4.96 (2.62)
Video engagement (1-7), mean (SD)	4.81 (1.22)
Immersion	4.45 (1.42)
Emotional impact	5.18 (1.17)

Abbreviations: SD = standard deviation

**Table 7.2.** Raw means (SDs) and linear mixed model outcomes<sup>a</sup>

Outcome (range)	T0 <sup>b</sup> (n=65)	T2 <sup>b</sup> (n=66)	Effect of CST (before/after)		
			b (95% CI)	F (df)	Sig. d <sup>c</sup>
SDM support – HCP behaviour (0-5)	2.84 (1.08)	2.98 (1.14)	0.14 (-0.24, 0.52)	0.51 (1,115.96)	.478
SDM support – patient benefit (0-5)	2.69 (1.10)	2.72 (1.11)	0.03 (-0.35, 0.41)	0.02 (1,115.27)	.890
SDM support – overall <sup>d</sup> (1-10)	6.02 (2.18)	5.76 (2.62)	-0.26 (-1.08, 0.57)	0.38 (1,131)	.538
CollaboRATE <sup>d</sup> (0-100)	68.44 (24.32)	65.44 (26.02)	-3.00 (-11.64, 5.64)	0.47 (1,131)	.493
PSQ (0-100)	64.71 (23.98)	60.89 (26.37)	-3.87 (-12.23, 4.49)	0.84 (1,115.52)	.361
Decision-making satisfaction (0-100)	63.05 (28.39)	59.09 (32.35)	-3.98 (-14.32, 6.35)	0.58 (1,115.70)	.447
Conversation appreciation (0-100)	65.31 (30.24)	61.27 (33.55)	-4.12 (-14.75, 6.51)	0.59 (1,115.66)	.444
Conversation helpfulness (0-100)	57.15 (29.89)	53.15 (31.73)	-3.93 (-13.91, 6.05)	0.61 (1,115.60)	.437
Decision-making confidence (0-100)	67.49 (24.87)	64.88 (28.13)	-2.67 (-11.40, 6.05)	0.37 (1,115.62)	.545

<sup>a</sup> These were outcomes of basic models without any covariates or interaction terms<sup>b</sup> T0: before CST; T2: after CST<sup>c</sup> Cohen's d was calculated by  $b/((\sqrt{n}) * SE)$ <sup>d</sup> The variance at HCP level was 0 and the random factor for HCP level was removed from the mixed model

Abbreviations: CI = confidence interval; CST = communication skills training; HCP = healthcare professional; PSQ = patient satisfaction questionnaire;

SD = standard deviation

**Table 7.3.** Differences between GPs and nurses

Outcome (range)	Time*HCP group sig.	GPs (n=67)					Nurses (n=64)						
		T0 <sup>a</sup> (n=33)	T2 <sup>a</sup> (n=34)	b (95% CI)	F (df)	Sig.	d <sup>b</sup>	T0 <sup>a</sup> (n=32)	T2 <sup>a</sup> (n=32)	b (95% CI)	F (df)	Sig.	d <sup>b</sup>
SDM support – HCP behaviour (0-5)	.171	2.72 (1.16)	3.12 (1.16)	0.39 (-0.16, 0.94)	2.01 (1,59.23)	.162	0.17	2.97 (1.01)	2.83 (1.13)	-0.13 (-0.65, 0.39)	0.25 (1,56.68)	.617	-0.06
SDM support – patient benefit <sup>c</sup> (0-5)	.034	2.60 (1.09)	3.02 (1.08) <sup>d</sup>	0.42 (-0.10, 0.94)	2.58 (1.67)	.113	0.20	2.78 (1.13)	2.39 (1.07) <sup>d</sup>	-0.39 (-0.92, 0.15)	2.12 (1,56.29)	.151	-0.18
SDM support – overall <sup>c</sup> (1-10)	.049	5.73 (2.13)	6.26 (2.50)	0.54 (-0.58, 1.65)	0.93 (1.67)	.339	0.12	6.31 (2.22)	5.22 (2.69)	-1.09 (-2.31, 0.12)	3.26 (1,64)	.076	-0.23
CollaboRATE <sup>c</sup> (0-100)	.107	64.76 (26.34)	68.63 (21.58)	3.87 (-7.68, 15.42)	0.45 (1.67)	.506	0.08	72.23 (21.80)	62.04 (30.02)	-10.19 (-23.08, 2.71)	2.49 (1,64)	.119	-0.20
PSQ (0-100)	.061	65.30 (22.86)	69.09 (21.94) <sup>d</sup>	3.79 (-6.93, 14.51)	0.50 (1,59.12)	.482	0.09	64.12 (25.45)	52.18 (28.17) <sup>d</sup>	-11.95 (-24.78, 0.89)	3.48 (1,56.25)	.067	-0.23
Decision-making satisfaction <sup>c</sup> (0-100)	.215	64.00 (26.92)	66.29 (27.88)	2.29 (-10.88, 15.46)	0.12 (1.67)	.729	0.04	62.06 (30.22)	51.44 (35.34)	-10.65 (-26.73, 5.43)	1.76 (1,56.14)	.190	-0.17
Conversation appreciation <sup>c</sup> (0-100)	.078	67.55 (27.30)	72.62 (28.92) <sup>d</sup>	5.07 (-8.44, 18.59)	0.56 (1.67)	.456	0.09	63.00 (33.28)	49.22 (34.33) <sup>d</sup>	-13.79 (-30.20, 2.61)	2.84 (1,56.29)	.098	-0.21
Conversation helpfulness (0-100)	.066	59.88 (26.93)	64.82 (28.11) <sup>d</sup>	4.98 (-8.05, 18.02)	0.58 (1,59.30)	.448	0.09	54.34 (32.87)	40.75 (31.01) <sup>d</sup>	-13.42 (-28.50, 1.67)	3.17 (1,56.42)	.080	-0.22
Decision-making confidence (0-100)	.227	70.06 (22.52)	72.56 (22.82) <sup>d</sup>	2.50 (-8.34, 13.33)	0.21 (1,59.47)	.646	0.06	64.84 (27.19)	56.72 (31.18) <sup>d</sup>	-8.15 (-22.06, 5.75)	1.38 (1,56.23)	.245	-0.15

<sup>a</sup> T0: before CST; T2: after CST<sup>b</sup> Cohen's d was calculated by  $b/((\sqrt{n}) * SE)$ <sup>c</sup> The variance at HCP level was 0 and the random factor for HCP level was removed from the mixed model; for all variables except for SDM support – overall and CollaboRATE, the variance was only 0 for the GP group and removed from that model<sup>d</sup> Significant differences between GPs and nurses ( $p < .05$ )

Abbreviations: CI = confidence interval; GP = general practitioner; HCP = healthcare professional; PSQ = patient satisfaction questionnaire; SD = standard deviation; SDM = shared decision making

## Variables associated with SDM support

Tables 7.4 presents the variables associated with *SDM support* – *HCP behaviour* and *patient benefit*, respectively. For both outcomes, only comparability with previous personal experiences with conversations with a GP or nurse about cancer treatment decisions (if any) was significantly associated ( $F(1,51)=18.34$ ,  $p<.001$ ,  $d=0.60$ ;  $F(1,51)=15.73$ ,  $p<.001$ ,  $d=0.56$ ). This implies that the more comparable the SPA was with the AP's own experiences with conversations with GPs or hospital nurses about the cancer treatment decision, the higher the AP's assessment of the SPA.

**Table 7.4.** Final model SDM support

	HCP behaviour		Patient benefit	
	<i>b</i> (95% CI)	Sig.	<i>b</i> (95% CI)	Sig.
Intercept	1.75 (1.08, 2.42)	<.001	1.57 (0.90, 2.25)	<.001
Training condition				
Before (ref)				
After	-0.11 (-0.67, 0.44)	.690	-0.22 (-0.79, 0.34)	.434
Comparability	0.21 (0.11, 0.32)	<.001	0.23 (0.12, 0.34)	<.001

*Intercept* = average SDM support score of a (hypothetical) subject scoring 0 for each variable in the model  
*Abbreviations:* CI = confidence interval; HCP = healthcare professional; SDM = shared decision making

## DISCUSSION AND CONCLUSION

### Discussion

This experimental study demonstrated that cancer patients and survivors, i.e. analogue patients (APs), did not differentiate trained from untrained HCPs when evaluating SDM support. Although trained observers established a medium effect of the CST in SDM support behaviour of HCPs [21], this effect was apparently not sufficiently large to be observed by APs or it was not meaningful enough to them. In line, correlations between trained observers' and APs' assessments were low ( $-.08 \leq r \leq .48$ ;  $.055 \leq p \leq .982$ ). This corroborates previous research on SDM as rated by observers and patients [20, 22, 23, 41-44]. APs may observe and prioritise differently than observers, underscoring the necessity of evaluating outcomes on patient level in clinical practice [45, 46]. Hence, the clinical relevance of the CST still needs to be established [46, 47]. Possibly, such CST and evaluation outcomes should be better adapted to patients' wishes and needs, by, for example, developing CST and evaluation criteria in co-creation with patients.

APs were not more satisfied with the communication of trained HCPs. Moreover, satisfaction scores in general were lower compared to previous studies in a clinical setting, e.g. in internal medicine outpatient consultations [38] and in SDM conversations with

oncologists [48]. Possibly, APs are more critical of shown communication, as they are not evaluating their own HCP. Besides, not all patients may appreciate involvement of GPs or hospital nurses in decision making about cancer care, being it before or after a CST. Previous research has indicated various patient experiences regarding involvement of GPs and nurses: patients reported to experience decision support by GPs as comforting [49] and valuable for SDM [24] but also to prefer or expect specialist-led care [50]. Moreover, exposing patients to SDM means exposing them to uncertainty and responsibility, which may not be beneficial to all patients [25, 51]. In the current study, a few APs indicated in their open answers confusion about the responsibilities of medical specialists and HCPs like GPs or nurses. Some felt that topics discussed were the responsibility of the medical specialist, as they initially discuss and eventually make the treatment decision with the patient. In addition, some APs worried that the conversation might have raised more questions and uncertainty. Patients' varying experiences regarding SDM support were corroborated by the poor agreement between APs' observations in this study, which was much lower compared to the agreement between trained observers in the previous study evaluating the CST's effectiveness (Triple-S: .67 [21]). This all stresses the importance of tailoring the amount and content of SDM conversations to patients' needs and wishes. Future research should further look into different patients' experiences and needs regarding SDM support.

Next to that APs differed largely in their observations and appreciation of SDM support, other reasons for their lack of distinction between trained and untrained HCPs may be of a more methodological nature. APs may have reported their satisfaction with general communication skills of HCPs rather than SDM support behaviour, as was reported in previous research [52]. Besides, although we used standardised patients in the SPAs, these conversations varied considerably in content other than SDM support. Also, responses between the different actors varied. Other issues may be related to APs' engagement and ability to empathise with the patient in the video, although VES scores were comparable to previous research based on video recordings [32]. The simulated context, the content as well as the online modality of SPAs may not have been representative of APs' personal experiences. Similarly, the sometimes suboptimal quality of the recorded SPAs may have affected immersion. The implications of video quality on APs' immersion and perceptions are not yet empirically tested [53]. Related, in clinical practice, SDM support is often part of a larger SDM process with multiple conversations and HCPs [13, 54]. Since the SPA only showed one conversation with one HCP, it may have been complicated for APs to consider whether this SDM support benefited the patient in their specific context and in the long run.

Although both GPs and nurses are important to support SDM in the interprofessional SDM process, they have different responsibilities and expertise in the healthcare system [7, 55]. APs assessed GPs' SDM support behaviour typically higher, which corresponds with findings of the prior CST evaluation by observers. Possibly, APs may more clearly observe SDM support by GPs or, in some way, value it higher. Another possible explanation may be that the SPA cases may have been less applicable to the individual nurse's situation, as nurses' responsibilities differ largely between functions and hospitals. For example, some nurses have more decisional responsibility or more knowledge about certain cancer types than others, because of different organisational structures. This may have caused that the conversations for nurses were less appropriate and comfortable, which APs may have sensed in some way.

This experimental study design, having APs assess SPAs used for the evaluation of CST, should be further developed and refined. Strengths are the possibility to explore APs' perceptions, increased reliability of ratings as multiple APs assess the same HCP, prevention of observing ceiling effects, i.e. high share of participants with maximum scores on the observed variable, reuse of collected data, the possibility to compare APs' with observers' assessments, and providing the opportunity to make statements about clinical relevance. A possible disadvantage is that there may be large differences between APs' hypothetical experiences and experiences of real patients regarding SDM support. APs may also have (unconsciously) included previous experience when assessing the conversations, which is supported by the fact that the one variable associated with their evaluation of SDM support was comparability with previous experiences. Patients who did not have a comparable experience were more critical, which may imply they used their own experience as the standard. Interesting research topics could be to explore whether APs can better differentiate trained HCPs if a larger training effect was established by observers, making the topic of interest more clearly visible, and, if possible in terms of the GDPR, recordings of clinical consultations with real patients could be used to increase representativeness and immersion.

Next to the aforementioned methodological limitations, another limitation worth mentioning may be selection bias, as only cancer patients and survivors interested in (patient-provider communication) research participated. For example, compared to a 2015 review [30], the share of patients who wanted an active (34% vs. 28%) or shared (57% vs. 44%) decisional role was somewhat higher in our sample. Related, a bias may be present in the randomly selected sample of HCPs part of the current study. When compared with the total sample of HCPs in the prior CST evaluation study, this smaller sample had similar overall effect sizes on SDM support scores as rated by trained observers but effect sizes were relatively low for nurses and high for GPs when compared to the full sample.



Therefore, conclusions on differences between GPs and nurses should be interpreted cautiously. Lastly, it remains uncertain how engaged APs were while watching the SPAs.

## **Conclusion**

This experimental study shows that a CST for GPs and hospital nurses did not affect cancer patients' and survivors' perceived SDM support when assessing video-recorded simulated consultations. Since this was one of the first studies trying to gain insight in patient perceptions regarding SDM support in an experimental study design, future research on this topic is needed as well as further development of the study design.

## **Implications**

As patients did not pick up any training effect, the clinical relevance of CST in SDM support for GPs and nurses still remains to be established. The large variation in cancer patients' and survivors' assessments of SDM support suggests patients differ in their perception of SDM support. Hence, HCPs should tailor their (offering of) SDM support to patients' needs and wishes. It is important to better understand the reasons underlying this study's findings. Future research should explore experiences of patients with SDM support by means of other research methodologies. Qualitative studies would provide more insight into patients' perceptions of SDM support from GPs and nurses, for example by having APs thinking aloud while watching an SPA. Studies with video vignettes, i.e. videos that are systematically manipulated for characteristics of interest and respondents' judgments being elicited by surveys [56, 57], could systematically explore whether and what characteristics of SDM support patients prefer.

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## APPENDIX 7A. QUESTIONNAIRE

*The following statements ask for your opinion about the conversation between the healthcare professional (HCP) and patient you just saw. You are asked to engage with the patient in the video. Please circle the number that reflects to what extent each statement applies according to you. Your impression is most important.*

	Totally disagree	Mostly disagree	Disagree	Agree	Mostly agree	Totally agree
<i>Patient benefit</i>						
1a. If you were the patient, after this conversation you would know better that you can choose from several treatment options.	0	1	2	3	4	5
1b. If you were the patient, after this conversation you would know better that the treatment decision depends on what you want.	0	1	2	3	4	5
2a. If you were the patient, after this conversation you would know more about the treatment options you can choose from.	0	1	2	3	4	5
2b. If you were the patient, after this conversation you would know more about the pros and cons of those treatment options.	0	1	2	3	4	5
3a. If you were the patient, after this conversation it would be clearer to you what you consider important in the coming period.	0	1	2	3	4	5
3b. If you were the patient, after this conversation it would be clearer to you what you think of the pros and cons of the treatment(s).	0	1	2	3	4	5
3c. If you were the patient, after this conversation it would be clearer to you which treatment(s) suits you best.	0	1	2	3	4	5
<i>HCP behaviour</i>						
4. In this conversation, the HCP asked questions about what the patient knows about the treatment choice he should make.	0	1	2	3	4	5
5a. In this conversation, the HCP helped to make it clear that there is a choice between several treatment options.	0	1	2	3	4	5
5b. In this conversation, the HCP helped to understand the information about the treatment options.	0	1	2	3	4	5
5c-I. In this conversation, the HCP helped to find out what is important for the patient in the coming period.	0	1	2	3	4	5
5c-II. In this conversation, the HCP helped to find out what the patient thinks about the pros and cons of the treatment(s).	0	1	2	3	4	5
6. In this conversation, the HCP helped the patient with what needs to be done after the conversation in order to make a good treatment decision.	0	1	2	3	4	5

This tool is protected by copyright but is available to use, provided you: a) cite the reference in any questionnaires or publications; b) do not charge for or profit from them; and c) do not alter them. Please note that this tool is not developed for use in English (no forward-backward translation applied). Please do contact the authors if you want to use the tool. Contact: [i.henselmans@amsterdamumc.nl](mailto:i.henselmans@amsterdamumc.nl)

## Appendix 7B. Fidelity of viewing SPAs

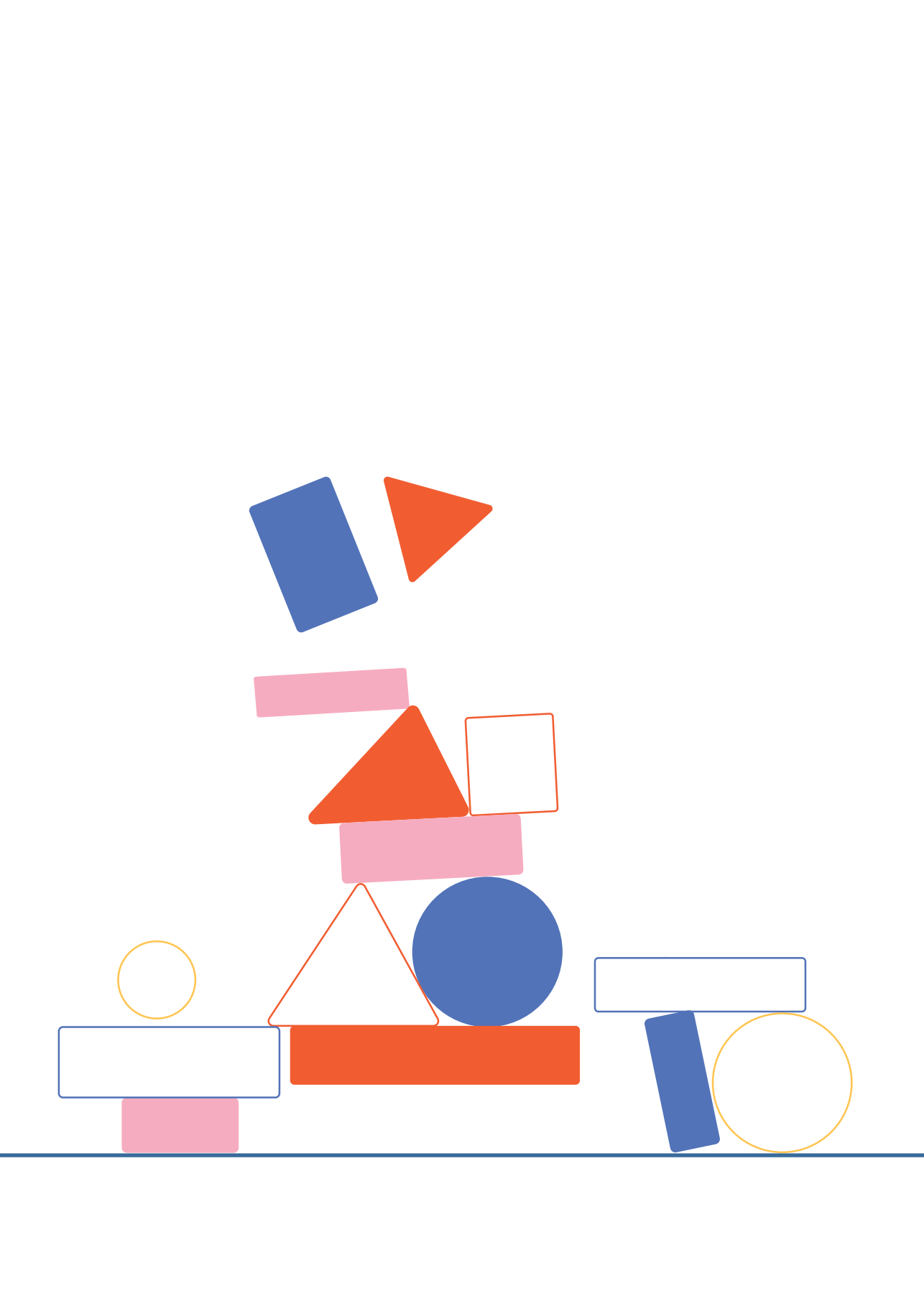
**Table 1.** Video analytics

# Video	# HCP	Type HCP	Time	# APs	% watched
1	1	GP	T0	4	3 100%; 1 50%
2			T2	4	3 100%; 1 missing
3	2	GP	T0	4	4 100%
4			T2	4	4 100%
5	3	GP	T2	4	4 100%
6			T0	5	4 100%; 1 missing
7	4	GP	T2	4	4 100%; 1 25%
8			T0	4	3 100%; 1 50%
9	5	GP	T2	5	5 100%
10			T0	4	2 100%; 1 75%; 1 missing
11	6	GP	T0	4	3 100%; 1 missing
12			T2	5	5 100%
13	7	GP	T2	4	4 100%
14			T0	4	3 100%; 1 75%
15	8	GP	T0	4	4 100%
16			T2	4	4 100%
17	9	Nurse	T0	4	4 100%
18			T2	4	3 100%; 1 75%
19	10	Nurse	T2	4	4 100%
20			T0	4	4 100%
21	11	Nurse	T0	3 <sup>a</sup>	3 100%
22			T2	4	4 100%
23	12	Nurse	T2	4	4 100%
24			T0	4	4 100%
25	13	Nurse	T2	4	4 100%
26			T0	4	4 100%
27	14	Nurse	T0	4	4 100%
28			T2	4	3 100%; 1 25%
29	15	Nurse	T2	4	4 100%
30			T0	4	4 100%
31	16	Nurse	T0	5	5 100%
32			T2	4	4 100%

*Note: Missing could mean several things, e.g. the AP did not watch or the AP did not turned on cookies. Similarly, for any other data points indicating that the video was not watched 100%, this could be due to internet connection issues*

<sup>a</sup> One AP was excluded from analyses as the VES screener item  $\leq 2$

Abbreviations: AP = analogue patient; GP = general practitioner; HCP = healthcare professional; T0 = before CST; T2 = after CST



# Chapter 8

## General discussion



For patients with incurable cancer, shared decision making (SDM) is of great relevance to ensure they receive appropriate care. Yet, SDM is not always implemented to the full and, although they can make an important contribution to SDM in palliative cancer care, the role of general practitioners (GPs) and hospital nurses has received little attention. By involving these healthcare professionals (HCPs) in the SDM process, an interprofessional approach to SDM is adopted. Interprofessional SDM assumes that “at least two HCPs from different professions collaborate to achieve SDM with the patient, either concurrently or sequentially” [1, p.20]. The overall aim of the research described in this dissertation was to effectively promote interprofessional SDM in palliative cancer care through communication skills training (CST) for HCPs, i.e. medical oncologists, GPs, and hospital nurses (registered oncology nurses and nurse practitioners). More specifically, we aimed to 1) gain insight into the role of GPs and hospital nurses in the SDM process by two interview studies (**chapter 2 and 3**), and 2) establish the effects of CST in (supporting) SDM about palliative cancer care by a review of reviews (**chapter 4**) and three CST effect studies (**chapter 5, 6 and 7**). This final chapter of the dissertation will first highlight and interpret the main findings of the previous chapters, addressing the role of GPs and hospital nurses, the effects of CST (ingredients), the methodology, implementation of interprofessional SDM, and the significance of interprofessional SDM to patients. Subsequently, implications for practice and research as well as final conclusions will be presented.

## **The role of GPs and hospital nurses**

In part I, we aimed to understand the role of HCPs other than the primary physician in the SDM process about palliative cancer care. Interviews among GPs (**chapter 2**) and hospital nurses (**chapter 3**) identified SDM-related practices that we categorised into three strategies to support SDM: 1) *checking the quality of a decision*, i.e. querying a patient’s choice awareness, level of being informed, and/or their values and treatment preferences, 2) *complementing SDM*, i.e. adding to the SDM process by, for example, increasing choice awareness or constructing patients’ treatment preferences, and 3) *enabling SDM*, i.e. organising additional activities to ensure continuation of the SDM process beyond a HCP’s direct involvement. Some of these practices were previously described in literature about GPs’ and hospital nurses’ roles and tasks in cancer care. For example, they were reported to educate patients about treatment and advocate on behalf of their patients [2-5]. However, these role descriptions were not directly placed in the context of interprofessional SDM. Moreover, previous descriptions mostly paralleled with activities involved in *complementing SDM* (e.g. providing information) and *enabling SDM* (e.g. advocating for patients), but the literature rarely referred to activities that involved GPs and nurses *checking the quality of a decision*. The latter is an important addition to discover any decision hesitations or needs before intervening, thereby putting HCPs in a monitoring role. Besides, previous research on decision coaching mainly focused on the setting in

which patients are referred to a decision coach in advance of a clinical consultation with the primary physician with whom the final decision is made [6], while we focused on the regular care setting where the decision-making context is not always fully determined as such before the HCP meets the patient. This means that any HCP can take on the role of decision coach. As far as we know, this is the first research conjoining an interprofessional approach to SDM with previously identified role descriptions in cancer care and strategies to engage in interprofessional SDM in the regular care setting.

Although GPs and hospital nurses described practices indicative of a potential significant role in the SDM process, they did not consider their contribution to SDM to be self-evident (**chapter 2 and 3**). Possibly, GPs' and hospital nurses' involvement in the SDM process is impeded by unclear expectations, a lack of structured processes, and worries about role boundaries, i.e. the responsibilities and degree of involvement of the different HCPs [7, 8]. A related issue is whether HCPs perceive themselves and each other as part of the same team that collaborates, as this is a central assumption of the interprofessional SDM model [1]. In Dutch secondary and tertiary care, hospital nurses and oncologists are part of the same hospital team. In contrast, GPs operate in primary care and – particularly in urban regions with multiple hospitals – may not always be considered part of the team. Indeed, multiple studies identified the culture, collaboration, and information exchange between HCPs within a team as factors influencing GPs' and nurses' involvement in decision support [9-11]. Although previous research indicated that both medical specialists and patients recognised the added value of decision support by GPs [11], we need to comprehend their perspectives on interprofessional SDM better. By understanding their and other stakeholders' perspectives, potential barriers and facilitators for GPs' and hospital nurses' involvement can be identified and targeted.

## Effects of CST (ingredients)

In part II of this dissertation, the overall aim of the studies was to establish the effects of CST for HCPs in SDM about palliative cancer care. We adopted a blended learning format, which combines online asynchronous with instructor-led synchronous learning [12], as its potential for medical education has increasingly been recognised [13, 14]. The research in this dissertation showed that blended CST for medical oncologists in applying SDM in palliative cancer care had a large positive effect on observed SDM in simulated consultations. The training also improved the observed individual stages of SDM and oncologists' confidence in their SDM skills, SDM knowledge, and satisfaction with the communication in the consultation (**chapter 5**). The blended CST for GPs and hospital nurses on supporting SDM in palliative cancer care was based on the three strategies for supporting SDM identified in the studies described in part I. This training had a medium effect on observed SDM support in simulated consultations when assessed with a study-

specific instrument (**chapter 6**). In addition, HCPs' knowledge and confidence increased after training. These results imply that blended learning formats of CST may improve SDM skills of HCPs in palliative cancer care. Other research also established positive effects of e-learning and blended CST in healthcare [15-19], although definite conclusions on the effectiveness of such learning compared to conventional learning cannot be drawn due to the large heterogeneity across studies [20].

Despite establishing positive effects of the blended CST in SDM when assessed by observers, cancer patients and survivors did not significantly differentiate trained from untrained HCPs and were not more satisfied with the communication of trained HCPs. Hence, we carefully concluded that the effects of CST for GPs and hospitals nurses in SDM support were not sufficiently large to be observed by cancer patients and survivors, or the effects were not meaningful enough to them (**chapter 7**). This corroborates previous research that also established differences between observers' and patients' assessments of SDM behaviour by HCPs [21-24] and stresses the value of using evaluation instruments that account for both observers' and patients' perspective, such as MAPPIN'SDM [25] or iSHARE [26]. Moreover, these results raise questions about the clinical relevance of this CST. Future research should establish 'minimal important differences' to determine which effect sizes of CST in SDM (support) are considered meaningful [27]. One way to do this is by an anchor-based method to determine the smallest effect size of interest [27]. Individuals give a subjective global rating of change after an intervention such as CST, after which they are categorised into groups who perceived no, a little, or substantial change. Of those who experienced a little positive or negative change, the mean change scores of the outcome of interest, e.g. SDM (support), are established, providing the smallest effect size of interest [27]. This minimal important difference could then be adopted as a criterion for the clinical relevance of interventions.

In response to our own call to look into effective ingredients of CST (**chapter 4**), we compared two CST formats (**chapter 5**): a previously evaluated intensive face-to-face CST, which demonstrated large effects in the simulated and clinical setting [28, 29], and the blended CST for oncologists. Blended CST effects seemed smaller. However, there were several methodological limitations in comparing both formats, such as differences in the modality of the simulated consultations (in-person vs. online), observers, and SDM baseline scores. Besides, although the content, setting, and evaluation outcomes were similar in both evaluation studies, the interventions differed in length (10 vs. 4 hours), format (entirely face-to-face vs. blended) and modality (in-person vs. online). This makes it hard to pinpoint what exactly caused the face-to-face CST to be more effective than the blended CST. Non-inferiority studies are needed to robustly establish whether either format is (un)acceptably less efficacious. Also, valid comparisons between CST formats

require standards. However, consensus seems to be lacking on, for example, a shared definition of SDM [30], SDM's core competencies that should be targeted in CST in SDM [31], and on descriptions of types of formats [12]. A lack of standardisation is also visible in SDM evaluation instruments, which were found to vary largely and to strongly focus on information provision behaviour and less on other key elements of SDM [32, 33]. Comparisons may be hindered if consensus about the previously mentioned aspects is assumed but does not exist in research practice.

While COVID-19 forced us to organise the training session of the blended CSTs largely online instead of in-person (**chapter 6 and 7**), this design change yielded interesting and novel insights with implementation opportunities. We shortened the online programme of the training session (3.5 vs. 3 hours) and made some minor adjustments. Fortunately, many parts could be preserved, among which repeating theory, discussing in pairs one's role in as well as the relevance and potential barriers of interprofessional SDM, and experiential learning with an actor. Next to establishing positive effects of online CST on skills, knowledge, and confidence, most participants also evaluated the online modality as positive as a – hypothetical – in-person modality. This is interesting from a crisis resilience and implementation point of view, as online training may better be feasible and implementable in case of restrictions in meeting in-person and in the available (travel)time of HCPs.

After exploring the role of GPs and hospital nurses in SDM separately, we treated both disciplines as similarly placed in the SDM process, i.e. as decision coaches, and we developed a similar CST in SDM support for both groups. However, it can be debated whether these disciplines can be considered as equals in the context of SDM support. For example, in the interview studies (**chapter 2 and 3**), we experienced that GPs could more easily describe their contribution to SDM than nurses but were more hesitant about role boundaries. Affirmatively, in the studies including GPs and hospital nurses, we observed differences in training effects between both disciplines, from both trained observers' (**chapter 6**) and cancer patients' and survivors' (**chapter 7**) perspective, albeit these differences were generally not significant. Previous research describes that GPs typically have long lasting relationships with patients, take a holistic approach to health problems, and are experts in palliative care [34, 35], equipping them for deliberating on treatment by taking into account a patient's specific context and facilitating early integration of palliative care and the transition to the terminal phase. Hospital nurses are part of the oncology team, provide oncological care, and assess patients' coping with treatment [2, 36], enabling them to monitor whether treatment continues to be appropriate for the patient after the start of treatment and to consult easily with the primary physician. Although both HCP disciplines have great potential in contributing to interprofessional SDM, future

research should look more in-depth into their differences. It could be that these differences are larger than we realised and, related to that, GPs and nurses possibly have different training and implementation needs.

By demonstrating the positive effects of (online) blended CST and comparing two CST formats, the results of this dissertation are a step forward in the scientific basis for CST in SDM and its effective ingredients. First, both the face-to-face as well as the (online) blended CST format improve SDM skills of oncologists. Hence, one may choose which format (face-to-face vs. blended) and modality (in-person vs. online) is preferred and fits learners' needs and wishes best. Second, implementation of CST in interprofessional SDM may be facilitated, as shorter, partly asynchronous, and entirely online CST may be better feasible. Future research should make efforts to establish ideal balances between efficacy and feasibility. Also, the effects of CST should be investigated more specifically, that is to investigate, for example, which training ingredients, i.e. intensity, format, and content, are most suitable for which type of communication behaviour and for which HCP group. For example, e-learning may be less suitable for nurses, given that they evaluated the e-learning less positive than GPs (7.6 vs. 8.1). By establishing such differences, CST can even better meet the varying needs of learners. Lastly, it may be beneficial to explore whether simultaneous training of involved stakeholders in interprofessional SDM has added value [37]. This way, awareness of each other's contribution, identification of barriers and facilitators relating to collaboration, and the unity as interprofessional SDM team can be emphasised.

## Methodology

We found low certainty of evidence for the effectiveness of CST and its specific ingredients, i.e. intensity, format, and content, while the implementation of CST was widely advocated and specific ingredients were recommended (**chapter 4**). Therefore, we emphasised the importance of more homogeneous and high-quality research on CST effects. Despite this conclusion, we used a one-group pre-posttest design rather than a randomised controlled trial in the studies evaluating CST in this dissertation (**chapter 5 and 6**). This design was adopted because of problems with recruitment during the COVID-19 pandemic (**chapter 5**) and the explorative nature of the study on the effects of CST in SDM support (**chapter 6**). It has previously been argued that randomised controlled trials are inappropriate for evaluating programmes that have not reached maturity [38]. Hence, we consider the found effects a first exploration of new training formats (blended instead of face-to-face) and content (SDM support by HCPs other than the primary physician). Nevertheless, we cannot exclude confounding effects of, for example, participant characteristics on the training evaluation outcomes or learning effects of the simulated consultations rather than the training. It is challenging to set up robust CST evaluation research. A main issue is

establishing sufficiently large sample sizes due to low uptake, the limited time span and resources of research projects, and the lack of clarity on minimal important differences to determine the required power and sample size. We recommend to limit the study load and maximise the potential gain for study participants as much as possible, set up research projects with sufficient resources, and establish the minimal important differences for SDM measures [27].

Other methodological considerations in CST evaluations regard the levels on which outcomes were evaluated and the focus of analysis. First, our review of reviews showed that the evidence of CST on patients' outcomes were scarce and inconsistent and could therefore not be demonstrated (**chapter 4**). More authors stressed the importance of evaluating outcomes on the long term and on patients [39-41]. Nevertheless, we evaluated our trainings on two levels of Kirkpatrick's Model of Training Evaluation [42] only: *reaction*, i.e. HCPs' experiences with the CST, and *learning*, i.e. self-reported or observed changes in knowledge, attitude, or behaviour in simulated settings. We did not include evaluation outcomes on level of *behaviour*, i.e. changes in HCPs' behaviour in clinical practice, and *results*, i.e. impact on patient outcomes. Second, we focused on standalone simulated SDM consultations during analysis. In reality, however, SDM often does not take place in single encounters, especially when assuming interprofessional SDM where SDM takes place with multiple collaborating HCPs both during and outside multiple consultations [1, 43-45]. It is currently unknown what the effect is of SDM support conversations by GPs or hospital nurses on forthcoming conversations between patients and oncologists. Moreover, little is known about the effects of (CST in) SDM on outcomes later in the disease trajectory. Possibly, once SDM has been applied, it may become easier for patients to engage in SDM in future decisions [46]. Future research evaluating CST in SDM should preferably concentrate on the complete interprofessional SDM process, including all HCPs involved. If we better understand the impact of (CST in) SDM in clinical practice and on patients, being it either positive or negative, we can contribute to a better basis of evidence for SDM, which is urgently needed [47, 48]. Eventually, we will be better able to attune CST and SDM more to patients' wishes and needs.

In order to evaluate CST in SDM support in the regular care setting, we developed, used, and validated a new instrument: the Triple-S. We assumed a formative measurement model, which was based on the three strategies of supporting SDM identified in the research described in part I of this dissertation and the three aspects of high-quality decisions: decisions being conscious, informed, and patient-centred [6]. Regarding reliability, we found substantial agreement between raters after coding all simulated consultations. Convergent validity was assessed and demonstrated by correlating the Triple-S with the DSAT-10 (an instrument for decision coaching in assigned decision coaching conversations

[49]) scores and with an overall rating of SDM support by observers. Responsiveness was established by the statistically significant improvement of SDM support after the evaluated CST in SDM support. All in all, we concluded that the Triple-S showed fair applicability in the context of rating SDM support in video-recorded simulated consultations. However, a limitation was that we simultaneously used the Triple-S for establishing an effect of the intervention as well as its responsiveness. In addition, the Triple-S was developed and used in the simulated setting only. Further development and validation is needed in the clinical setting.

It remains questionable whether the findings of the research in this dissertation, which largely took place in the palliative cancer care setting, can be extrapolated to other settings. First, palliative cancer care decisions are almost by definition preference-sensitive as the gain of disease-targeted treatment is often uncertain and limited, while its burden may be high [50]. In other settings, where clear preference-sensitivity is less likely, it may be less straightforward for HCPs to engage in interprofessional SDM [51]. Second, it was found that most patients prefer more active participation in treatment decision making in later stages of their cancer trajectory [52-54], possibly influencing HCPs' SDM behaviour as well as patients' perceptions of SDM (support). Third, complicating aspects to the SDM conversation in the palliative compared to the curative (cancer) setting may be the wish of both the HCP and the patient to maintain hope and not giving up [22, 55, 56] and patients' fear of decisional regret [22] or their approaching death [56, 57]. It has also been suggested that, particularly in palliative cancer care, the input of other HCPs that the primary physician may be necessary to introduce conversations about the quality and the end of life [55, 56]. For example, nurses may be more inclined than physicians to express their doubts about continuing disease-targeted treatment [56]. This all makes interprofessional SDM of great potential in the palliative cancer care setting and it should be explored whether these results can be generalised to other settings, both non-oncological and non-palliative.

A last methodological consideration is that COVID-19 restrictions forced us to conduct the simulated consultations online instead of in-person, as we originally planned. The implications thereof for the evaluation of CST are insufficiently clear. Possibly, learners can apply and demonstrate acquired skills better in in-person than online simulated consultations. A study on Objective Structural Clinical Examinations (OSCEs) found that those participating in online examinations performed worse than those participating in-person [58]. Other studies generally reported positive experiences with online OSCEs [59-62] and virtual patients [63]. In our experience, online simulated consultations are easier to implement compared to in-person simulated consultations, resulting in better use of project resources. Actors as well as research team members facilitating simulated consultations save time and money by not having to travel to hospitals or GP practices.



However, although we expected most HCPs to be fairly used to online conversations with patients due to COVID-19 restrictions, in their evaluation of how realistic the simulated consultation was compared to their own experiences, HCPs rated the influence of the online modality as having had more influence on this score than the influence of the patient being an actor. This may have affected the validity of the simulated consultations. We also experienced some technical issues. For example, sound or image was sometimes lost due to internet connection problems. All in all, online simulated consultations may have advantages, but it is important to determine their impact on research outcomes.

## Implementation of interprofessional SDM

This dissertation showed that effective CST in SDM in palliative cancer care can help HCPs to demonstrate more SDM (support) behaviour in simulated consultations and acquire knowledge and confidence in their skills (**chapter 6 and 7**). This all may promote implementation of interprofessional SDM. However, (interprofessional) SDM is complex and requires changes on all levels of the healthcare system, not only on those of HCPs [64]. Literature has described that, next to the individual (micro) level at which the patient and HCPs operate, the interprofessional SDM model has two other levels: the meso level, representing healthcare teams and organisations, and the macro level, including health policies, social context, and professional organisations [1]. These levels influence decision-making encounters at the individual level. This means that, to implement interprofessional SDM, factors at these other levels should be favourable too. Literature has identified many barriers and facilitators HCPs [65] and patients [66] experience to engage in (interprofessional) SDM at these different levels as well. For implementing interprofessional SDM, factors such as a collaborative team culture towards interprofessional SDM and access to sufficient resources to participate in interprofessional SDM should be targeted to make GPs' and nurses' contribution better coordinated and more effective.

Importantly, GPs and hospital nurses should be involved sooner, ideally before the decision is made, and more systematically into the interprofessional SDM process. This will require structural changes in the way healthcare is organised. Efforts such as 'time out consultations' [67, 68], i.e. actively scheduled GP-patient consultations after diagnosis to prepare for final treatment decisions, are promising in this regard. However, HCPs may benefit from effective training, for example by the CST described in this dissertation, to effectively conduct such SDM support conversations. Also, the timing and sequence of these and other conversations may matter. Currently, cancer care pathways focus on rapid diagnosis and start of cancer treatment [68]. However, this impedes patients from having ample time to deliberate on the treatment decision or to consult with a decision coach before making a final decision. Perfors *et al.* [68] evaluated the effects of structural patient-GP decision coaching conversations for cancer treatment decisions. They conclude that



about eighty percent of the planned conversations took place after the treatment decision was already made with the oncologist. It was also reported that patients experienced less instead of more SDM after such time out consultations with the GP, with patients reporting even lower scores of SDM if the time out consultation took place after the possibility to engage in SDM had already passed. A possible explanation can be that patients perceive SDM more negatively if they are made aware of SDM after a decision has been made but did not experience involvement in the decision themselves. In a commentary, we argued that such decision coaching conversations nevertheless can have added value because it raises awareness about SDM and creates an opening for GPs to support in making subsequent decisions, including decisions about stopping treatment [69]. However, it seems important to be aware that the order of conversations and the time between diagnosis and final treatment decision can make a difference for patients.

Next to targeting HCPs by CST, we developed and evaluated other interventions promoting SDM as well. First, so-called Els Borst-conversations were organised, which are interprofessional conversations between HCPs, e.g. medical specialists and hospital nurses, and patients about their experiences with SDM in palliative cancer care. We evaluated the effects of these conversations on HCPs' attitude towards the implementation of SDM (support). We found small to medium non-significant effect sizes on attitudes. Nevertheless, all participants experienced these conversations as useful and valuable. See for more details **Appendix A**. Second, we developed two conversation aids for patients with incurable cancer and their informal caregivers. These conversation aids aim to help patients and their informal caregivers to contemplate on different topics: 1) wishes and needs in the last phase of life and 2) deciding on whether to start with disease-targeted treatment in preparation of the consultation about the treatment decision. The conversation aids were made available online via Kanker.nl, i.e. a Dutch online platform about cancer, and the website of the Dutch Federation of Cancer Patient Organisations (NFK). We explored the one-year reach of these aids and, by means of surveys, the profile of online users, how they found the aids online, and their satisfaction with the aids. We found that the webpages containing the conversation aids were visited over 25,000 times and that the conversation aids were downloaded over 2,200 times. The target group, i.e. incurable cancer patients and their informal caregivers who searched actively and at their own initiative for information about life, care, and treatment wishes in the last phase of life, was reached well. However, it remains unknown whether the group that perhaps needed the aids most was sufficiently reached. Online users of the aids were satisfied with the content, comprehensibility, and the potential for use in clinical practice (**Appendix B**). Both interventions showed potential for improving SDM, but their implications for interprofessional SDM should be explored further.

## Significance of interprofessional SDM to patients

Patients may vary in how they experience interprofessional SDM. In the study exploring cancer patients' and survivors' perceptions of SDM support, agreement between patients was low, indicating that patients had diverging views on the observed consultations (**chapter 7**). Something we should consider is that interprofessional SDM may not always be exclusively beneficial to all patients and may even be experienced as burdensome by some. First, SDM implies imposing patients to uncertainty and giving them responsibility [70-74]. For effective SDM, transparent and elaborate communication is required about harms and benefits of treatment options, including prognosis. Information about these topics is often based on uncertain, unpredictable, or unknown evidence in palliative cancer care, which complicates HCPs' information provision and patients' comprehension and considerations thereof. In addition, it is uncertain which probabilities for response to treatment apply to individuals and what effects the illness or treatment has on an individual's personal life [72, 75]. Such uncertain and confrontational information may be distressing [73]. In the case of interprofessional SDM, SDM support might also induce confusion about the responsibilities of different HCPs and about the SDM process or the treatment decision itself.

Second, SDM may be burdensome for some patients in some situations, e.g. they may not prefer or not be ready for sharing decisional responsibility [52, 74, 76-78]. Not all patients want to be involved in decision making about their treatment [52, 78] and there still is little concordance between patients' perceived and preferred role [78, 79]. HCPs should therefore elicit patients' preferred decision-making role during the SDM process at the right moment [64], that is create awareness and provide information about the pros and cons of options before engaging in a discussion about patients' preferred role in decision making as patients may otherwise base their role preference on incomplete information. More importantly, patients are vulnerable and dependent on their physician [70, 73, 80]. Specific attention is needed for patients with limited health literacy, as they face multiple challenges with SDM, among which HCPs using medical jargon and patients feeling insecure about participating [64, 81, 82]. Burdening patients by confronting them with uncertainty and responsibility can cause SDM to conflict with instead of abide to ethical principles of care, such as non-maleficence and beneficence [76, 83]. Although some literature indicates no link between SDM and adverse outcomes [84], there is indefinite evidence that patients may become anxious, dissatisfied with the decision six months after consultation, and experience increased decisional conflict [47, 85]. This all emphasises the importance of regarding SDM a means to an end [86]. The primary goal of SDM is not to allow patients to make decisions for themselves, but to allow for a treatment decision that fits this patient best. This requires an exchange of information and considerations between the HCP and patient, yet not necessarily a transfer of decision-making responsibility from the HCP to the patient. We

should make an effort to better understand patients' perceptions of interprofessional SDM and how to implement interprofessional SDM that benefits all patients.

### **Implications for practice and research**

The results presented in this dissertation have implications for clinical practice and research. A first implication is that the conceptualisation of the three strategies to support SDM may provide HCPs guidance on how to coach patients in SDM about their cancer care and consequently contribute to interprofessional SDM. It can help them recognise that tasks related to SDM support may already be part of their duties and behaviour. As HCPs did not consider their contribution to interprofessional SDM self-evident, HCPs' awareness of their role in interprofessional SDM may increase by being informed about this conceptualisation, and, by that, make their contribution more effective.

The CST in SDM (support) for both medical oncologists as well as GPs and hospital nurses appeared to increase their skills, knowledge, and confidence to engage in SDM (support). It is promising that a blended format of CST showed positive effects, although effects seemed smaller when compared with a more intensive, face-to-face format of CST. Furthermore, we did not anticipate that we would establish the effects of an entirely online CST format. Fortunately, the online format was well appreciated by participants. The positive effects of both the blended format as well as the online modality are promising for the feasibility and scalability of these CSTs. Furthermore, successful promotion of interprofessional SDM seems to be complex; CST alone will probably not suffice. Continuous efforts should be made to understand the complexity of this interprofessional SDM better, identify high-impact interventions, and establish their effects, especially on patient and on long term outcomes.

Although we established positive effects of the blended CST in SDM (support) in the simulated setting, we also challenged the clinical relevance of such CST as patients did not differentiate trained from untrained HCPs in SDM support. Before concluding that such training attempts are futile, we should acknowledge that we do not fully understand the impact in clinical practice yet. Underlying reasons for patients' lack of distinction as well as minimal important differences should still be established. Perhaps co-designing CST with patients would help improve CST in such way that it helps HCPs better align with patients' wishes and needs [87].

As patients seem to differ in their experiences of SDM support and SDM may not always be beneficial to all patients, interprofessional SDM needs to be tailored to patients' wishes and needs. It is essential SDM is regarded a means to an end, with the aim to respect patient autonomy and deliver care concordant with patients' values and preferences [86].

Future research should provide more insight into patients' underlying reasons for whether wanting or needing SDM (support) conversations. Possibly, HCPs can be provided with guidance on how to tailor (the offering of) SDM (support). At the same time, it may benefit patients if they are better educated about what SDM (support) entails, so that they are more empowered in deciding on their decisional role preferences and participate in interprofessional SDM accordingly.

The results in this dissertation provide some direction as to how effective CST and different formats thereof may be, but the evidence is not very strong. As there still is much heterogeneity between studies, more consensus is needed on the concept of interprofessional SDM, essential competencies, CST formats, and the criteria for evaluation of CST to be able to make fair comparisons between outcomes of evaluation studies. Open science and sharing of data on evaluation outcomes can accelerate such comparisons. Besides, large follow-up evaluation studies with long term and patient outcomes can contribute to establishing the impact of (CST in) interprofessional SDM, both negative and positive, to prevent detrimental burdening of patients and promote that incurable cancer patients receive appropriate care in line with their values and wishes in their last phase of life.

## Final conclusions

Interprofessional shared decision making (SDM) has great potential in the palliative cancer care setting. This dissertation shows that healthcare professionals such as general practitioners and hospital nurses can have an important supporting role in SDM in palliative cancer care. Besides, the dissertation demonstrates that blended communication skills training (CST) makes healthcare professionals from different disciplines skilled, conscious, and motivated to engage in interprofessional SDM in palliative cancer care, thereby contributing to the promotion of interprofessional SDM. Yet, research designs and homogeneity across studies should be improved to draw definite conclusions and the clinical relevance of the CST programmes still needs to be established. It is important to keep in mind that patients' wishes and needs regarding SDM (support) may differ and, to prevent any possible adverse effects, tailoring of SDM (support) conversations may be needed. Additionally, for successful implementation of interprofessional SDM, CST only might not suffice. Other interventions focused on all involved stakeholders at different levels of the healthcare system may be required. All together, these efforts may contribute to better interprofessional SDM, ultimately benefitting incurable cancer patients receiving care aligned with their end-of-life wishes.

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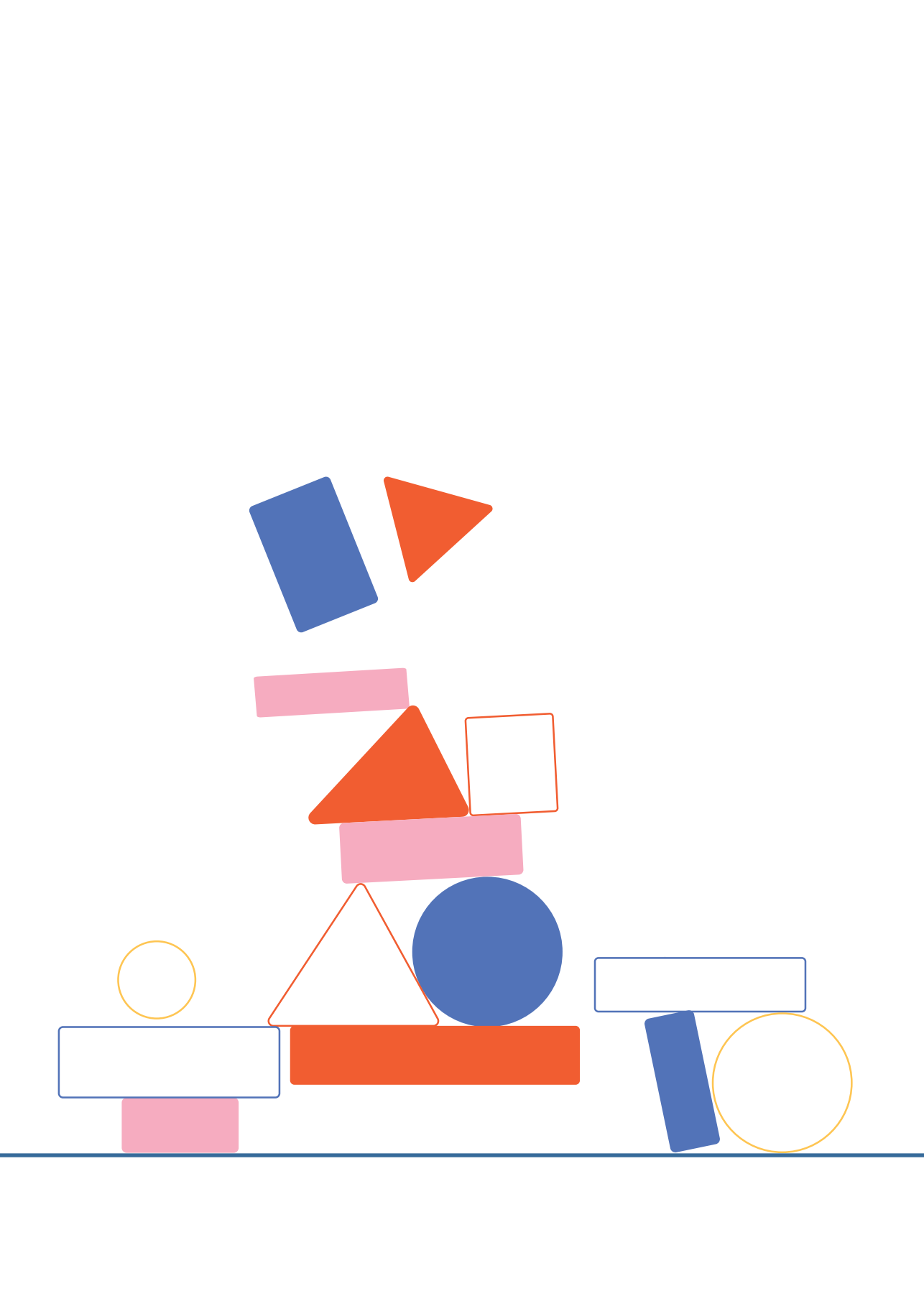


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# Chapter 9

## English summary

## **PROMOTING INTERPROFESSIONAL SHARED DECISION MAKING – COMMUNICATION SKILLS TRAINING IN PALLIATIVE CANCER CARE**

Shared decision making (SDM) is essential for patient-centred care for patients with incurable cancer as there often is no single best treatment strategy. However, SDM is not always optimally applied in clinical practice. Also, the role of general practitioners (GPs) and hospital nurses in SDM about palliative cancer treatment is still underexposed. This dissertation focused on the effective promotion of interprofessional SDM in palliative cancer care through communication skills training (CST) for healthcare professionals (HCPs). We first examined the supporting role of GPs and hospital nurses in SDM and subsequently aimed to establish the effects of CST in (supporting) SDM about palliative cancer care. The following research questions were addressed:

1. How do GPs and hospital nurses perceive their role in SDM about palliative (cancer) care?
2. What are the effects of CST in SDM (support) about palliative cancer care?
  - What is the current evidence for the effectiveness of CST for HCPs in cancer care?
  - What are the effects of (online) blended CST in (supporting) SDM about palliative cancer care for medical oncologists, GPs, and nurses?

To answer these research questions, we conducted six studies. In the first part of this dissertation, we described two qualitative interview studies in which we explored how GPs and nurses perceived their role in the SDM process about palliative life-prolonging (cancer) treatment. In the second part, we investigated the effects of CST in SDM in four studies. First, we conducted a review of reviews that summarised the evidence for the effectiveness of CST in cancer care as well as for effective features of CST, i.e. intensity, format, and content. Second, we evaluated the effects of (online) blended CST for 1) medical oncologists, and 2) GPs and nurses in (supporting) SDM about palliative cancer care in two one-group pre-posttest studies. Last, in an experimental study, we examined the effect of training GPs and nurses on cancer patients' and survivors' perceived SDM support.

### **PART I. THE ROLE OF GPs AND HOSPITAL NURSES**

We conducted two qualitative interview studies on the role of both GPs (**chapter 2**) and hospital nurses (**chapter 3**) in SDM about life-prolonging (cancer) treatment. We found that both groups described practices that potentially support SDM and we classified them into three strategies: 1) *checking the quality of a decision*, i.e. querying a patient's choice

awareness, level of knowledge about the options, and/or the match between the decision and patients' values and preferences, 2) *complementing SDM*, i.e. educating patients about the choice, providing additional information, or supporting preference construction, and 3) *enabling SDM*, i.e. organising additional activities to ensure continuation of the SDM process beyond a HCP's direct involvement. Hospital nurses experienced varying degrees of influence in decision making. GPs struggled with their role boundaries in relation to the role of medical specialists in SDM but recognised their added value. Preconditions for SDM support were good collaboration with medical specialists, sufficient information and transfer of information, sufficient time, a positive culture towards their involvement, a trusting relationship with patients, and patient-centred communication. This conceptualisation of GPs' and nurses' involvement could provide a more conscious and effective contribution of these HCPs in interprofessional SDM.

## PART II. EFFECTIVE CST IN SDM

Effective communication in cancer care demands HCPs to possess higher order communication skills, which can be advanced by CST. Although the number of empirical studies on CST has grown, controversies abound. In a review of reviews, we summarised the current evidence and opinion on effective CST for HCPs in cancer care (**chapter 4**). Based on nine reviews, we concluded that CST can probably improve some aspects of HCPs' communication skills, but that the certainty of evidence is too limited to draw definite conclusions on the effectiveness of CST and its effective ingredients, i.e. intensity, format, and content, because of heterogeneity in studies and effects. Nevertheless, we found that implementation of CST is widely advocated. These findings stressed the importance of standardised, high-quality research on CST effects.

To promote SDM in palliative cancer care and to establish the effects of CST in SDM, we developed and evaluated the effects of an online blended CST (i.e. e-learning and online training session) for oncologists and compared this online blended with a previously studied more extensive, entirely face-to-face CST format focused on the same content (**chapter 5**). A one-group pre-posttest design was adopted, in which seventeen medical oncologists (in training) conducted simulated consultations and completed surveys. Observed SDM in the simulated consultations was the primary outcome and improved significantly after the online blended CST (large effect), as did most secondary outcomes: individual stages of SDM (medium-large effect), postponement of the decision (medium effect), and oncologists' satisfaction (large effect), confidence (medium effect), as well as knowledge (medium effect). Consultation duration was not affected significantly. Medical oncologists evaluated the blended CST satisfactory and the online equal to an in-person

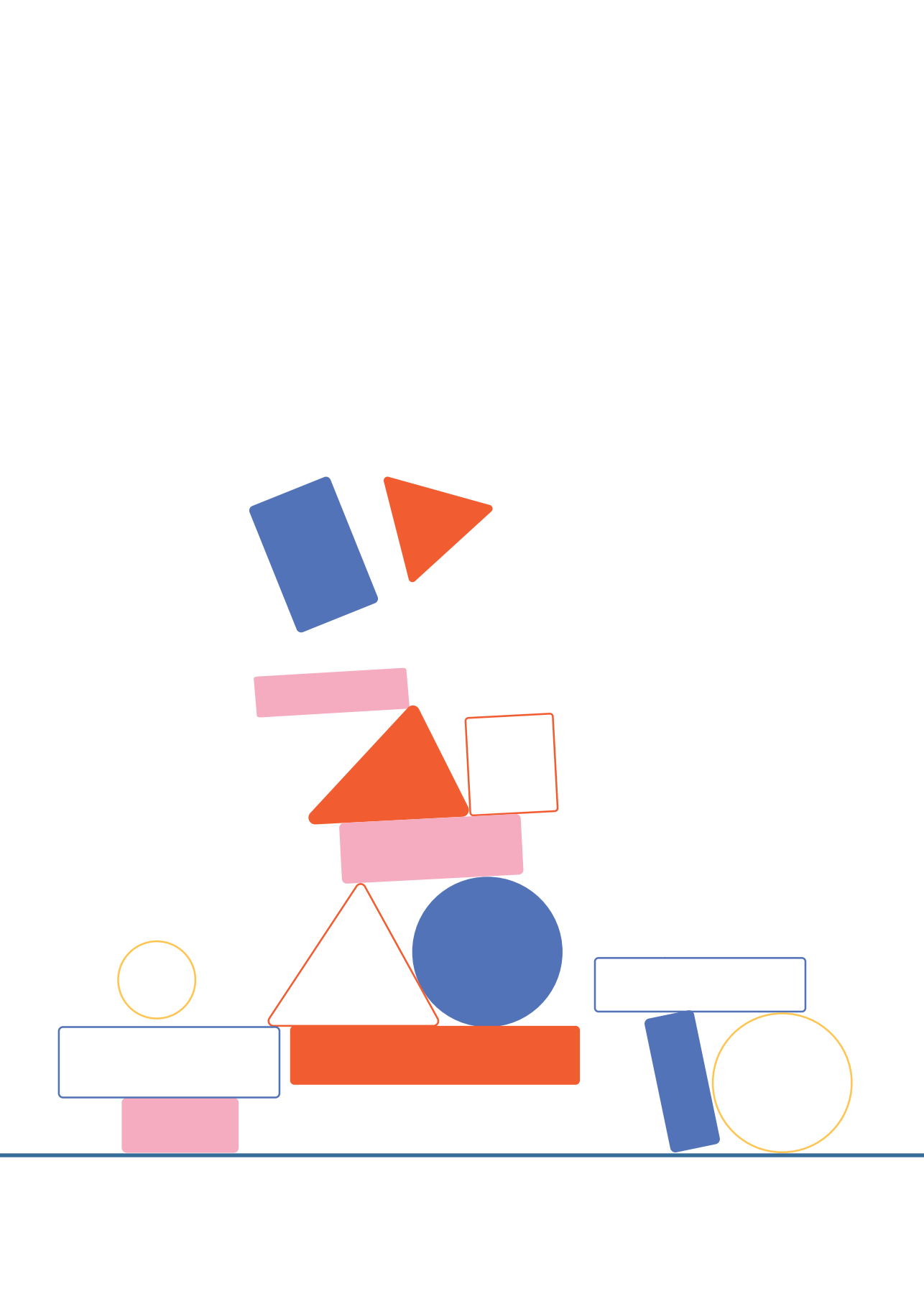
training modality. In addition, outcomes of the current evaluation of the blended CST were compared with those of the previously evaluated face-to-face CST. When compared with the face-to-face CST, blended CST effects seemed smaller. The availability of different effective formats provides opportunities for tailoring CST to the wishes and needs of learners.

As healthcare and decision making increasingly take place across disciplines and over multiple encounters, attention for interprofessional SDM and decision support has been raised. We developed and evaluated CST for GPs and hospital nurses in supporting SDM based on the three strategies identified in the first part of this dissertation (**chapter 6**). In this one-group pre-posttest study, 33 HCPs (17 GPs and 16 nurses) participated in simulated consultations and filled out surveys. The primary outcome, observed SDM support, increased significantly after CST with a study-specific instrument for SDM support (medium effect), but not with an existing measuring instrument for decision coaching (small effect). HCPs' knowledge (large effect) and beliefs about capabilities (medium effect) as well as observers' overall rating of SDM support (medium effect) increased significantly after CST. These effects were largely similar in GPs and nurses. HCPs evaluated the CST positively. The results provide good starting points for further developing and strengthening the foundations laid in training HCPs in interprofessional SDM.

Observers and patients assess SDM behaviour of HCPs differently. Little is known about if and how patients perceive SDM support by GPs and nurses. It might benefit patients, but it may also hinder making high-quality decisions. In an experimental study, we aimed to examine the effects of the CST for GPs and nurses on cancer patients' and survivors' perceived SDM support (**chapter 7**). Video recordings of simulated consultations from GPs and nurses before and after the CST from the study described in chapter 6 were watched and assessed by 131 cancer patients and survivors. In a survey, they were asked to which degree the consultation helped the portrayed patient making a treatment decision and to which degree the portrayed HCP demonstrated SDM supportive behaviour. It was shown that the assessments of simulated consultations of HCPs before and after CST by cancer patients and survivors did not significantly differ, meaning that they did not differentiate trained from untrained HCPs. Also, cancer patients and survivors were not more satisfied with the communication of trained HCPs. The agreement among cancer patients and survivors who watched the same consultation was poor. Future research is thus needed to establish the clinical relevance of the training programme on SDM support and to better understand cancer patients' needs, wishes, and expectations regarding SDM support and interprofessional SDM.

In the last chapter, we put the findings of this dissertation in perspective and conclude that, as GPs and hospital nurses play an important supporting role in SDM, interprofessional SDM has great potential value in the palliative cancer care setting and CST is helpful in promoting its implementation. Yet, to draw definite conclusions about CSTs' effects, research designs and homogeneity across studies should be improved. As patients may differ in their needs and wishes, HCPs should tailor SDM (support) to arrive at treatment decisions most appropriate for each individual incurable cancer patient.





# Chapter 10

**Nederlandse samenvatting (Dutch summary)**

## **HET VERBETEREN VAN INTERPROFESSIEEL SAMEN BESLISSEN – COMMUNICATIETRaining IN DE PALLIATIEVE KANKERZORG**

Samen beslissen is belangrijk voor goede zorg voor patiënten met ongeneeslijke kanker, omdat zij vaak uit meerdere behandelingen kunnen kiezen. Helaas gebeurt samen beslissen in de praktijk nog niet altijd. Ook is er nog te weinig aandacht voor de bijdrage die huisartsen en ziekenhuisverpleegkundigen kunnen hebben bij samen beslissen over de behandeling. Het onderzoek in dit proefschrift richtte zich op het verbeteren van interprofessioneel samen beslissen in de palliatieve kankerzorg door zorgverleners te trainen. Interprofessioneel samen beslissen betekent dat meerdere zorgverleners samenwerken in samen beslissen om met de patiënt tot een goed besluit over de behandeling te komen. We onderzochten eerst de rol van huisartsen en ziekenhuisverpleegkundigen bij samen beslissen en daarna de effecten van communicatietraining in (het ondersteunen van) samen beslissen in de palliatieve kankerzorg. Daarvoor hadden we de volgende onderzoeksvragen:

1. Hoe zien huisartsen en ziekenhuisverpleegkundigen hun rol in samen beslissen in de palliatieve (kanker)zorg?
2. Wat zijn de effecten van communicatietraining in (het ondersteunen van) samen beslissen over de palliatieve kankerzorg?
  - Wat is op dit moment het bewijs voor de effecten van communicatietraining voor zorgverleners in de kankerzorg?
  - Wat zijn de effecten van (online) blended communicatietraining in (het ondersteunen van) samen beslissen in de palliatieve kankerzorg voor medisch oncologen, huisartsen en ziekenhuisverpleegkundigen?

Om deze onderzoeksvragen te beantwoorden, hebben we zes studies uitgevoerd. In het eerste deel van dit proefschrift beschreven we twee interviewstudies. We vroegen huisartsen en ziekenhuisverpleegkundigen hoe zij hun rol zien bij samen beslissen over de palliatieve (kanker)behandeling. In het tweede deel beschreven we de effecten van communicatietraining voor zorgverleners op samen beslissen in vier studies. Eerst hebben we op basis van de literatuur een overzicht gemaakt van het bewijs voor de effecten van (kenmerken van) communicatietraining voor zorgverleners in de kankerzorg. Daarna onderzochten we de effecten van (online) blended communicatietraining op (het ondersteunen van) samen beslissen in de palliatieve kankerzorg in twee voor-na studies voor 1) medisch oncologen en 2) huisartsen en ziekenhuisverpleegkundigen. Ten slotte onderzochten we in een experimentele studie de effecten van het trainen van huisartsen en ziekenhuisverpleegkundigen op de ervaren ondersteuning van samen beslissen door (ex) patiënten met kanker.

## DEEL 1. DE ROL VAN HUISARTSEN EN ZIEKENHUISVERPLEEGKUNDIGEN

We hebben twee interviewstudies uitgevoerd naar de rol van huisartsen (**hoofdstuk 2**) en ziekenhuisverpleegkundigen (**hoofdstuk 3**) bij samen beslissen over de palliatieve (kanker) behandeling. We ontdekten dat beide groepen gedrag benoemden waarmee zij samen beslissen kunnen ondersteunen. We hebben dat gedrag ingedeeld in drie strategieën voor ondersteuning van samen beslissen: 1) *signaleren* van de kwaliteit van de beslissing (vragen of de patiënt de keuze begrijpt, genoeg informatie heeft en de keuze past bij wat hij/zij belangrijk vindt en wil), 2) samen beslissen *aanvullen* (patiënten informatie geven over de keuze en de behandelingen of helpen uitzoeken wat hij/zij belangrijk vindt en wil) en 3) samen beslissen *faciliteren* (ervoor zorgen dat het samen beslissen proces doorgaat na het gesprek). Ziekenhuisverpleegkundigen verschilden in hoeveel invloed zij ervoeren bij samen beslissen. Huisartsen hadden moeite met wat hun rol bij samen beslissen is in vergelijking met de rol van medisch specialisten. Toch zagen huisartsen ook toegevoegde waarde in hun eigen bijdrage aan samen beslissen. Voorwaarden voor het ondersteunen van samen beslissen waren een goede samenwerking met medisch specialisten, genoeg informatie, genoeg tijd, een positieve houding naar de betrokkenheid van huisartsen en verpleegkundigen, een goede relatie met patiënten en communicatie met aandacht voor de patiënt. De resultaten uit deze studies kunnen huisartsen en ziekenhuisverpleegkundigen meer bewust maken van hun rol en hen helpen bij interprofessioneel samen beslissen.

## DEEL 2. COMMUNICATIETRAINING IN SAMEN BESLISSSEN

Gesprekken met patiënten met kanker vragen om goede communicatievaardigheden van zorgverleners. Communicatietraining kan daarbij helpen. In de afgelopen jaren is er veel onderzoek gedaan naar de effecten van communicatietraining. Toch zijn er nog steeds veel onduidelijkheden. We hebben een overzicht gemaakt van de literatuurstudies (*reviews*) over het bewijs voor de effecten van en adviezen voor communicatietraining voor zorgverleners in de kankerzorg (**hoofdstuk 4**). Uit negen *reviews* bleek dat er bewijs is voor een positief effect van communicatietraining, maar dat dit bewijs niet sterk is omdat studies van elkaar verschilden. Ook is er geen overtuigend bewijs voor het effect van verschillende kenmerken van communicatietraining, zoals de duur, vorm en inhoud. Toch werd er vaak geadviseerd om communicatietraining te gebruiken in de opleiding van zorgverleners. Deze resultaten maken duidelijk dat onderzoek naar de effecten van communicatietraining meer op elkaar moet lijken om de uitkomsten beter te kunnen vergelijken. Ook moet het onderzoek van hoge kwaliteit zijn.

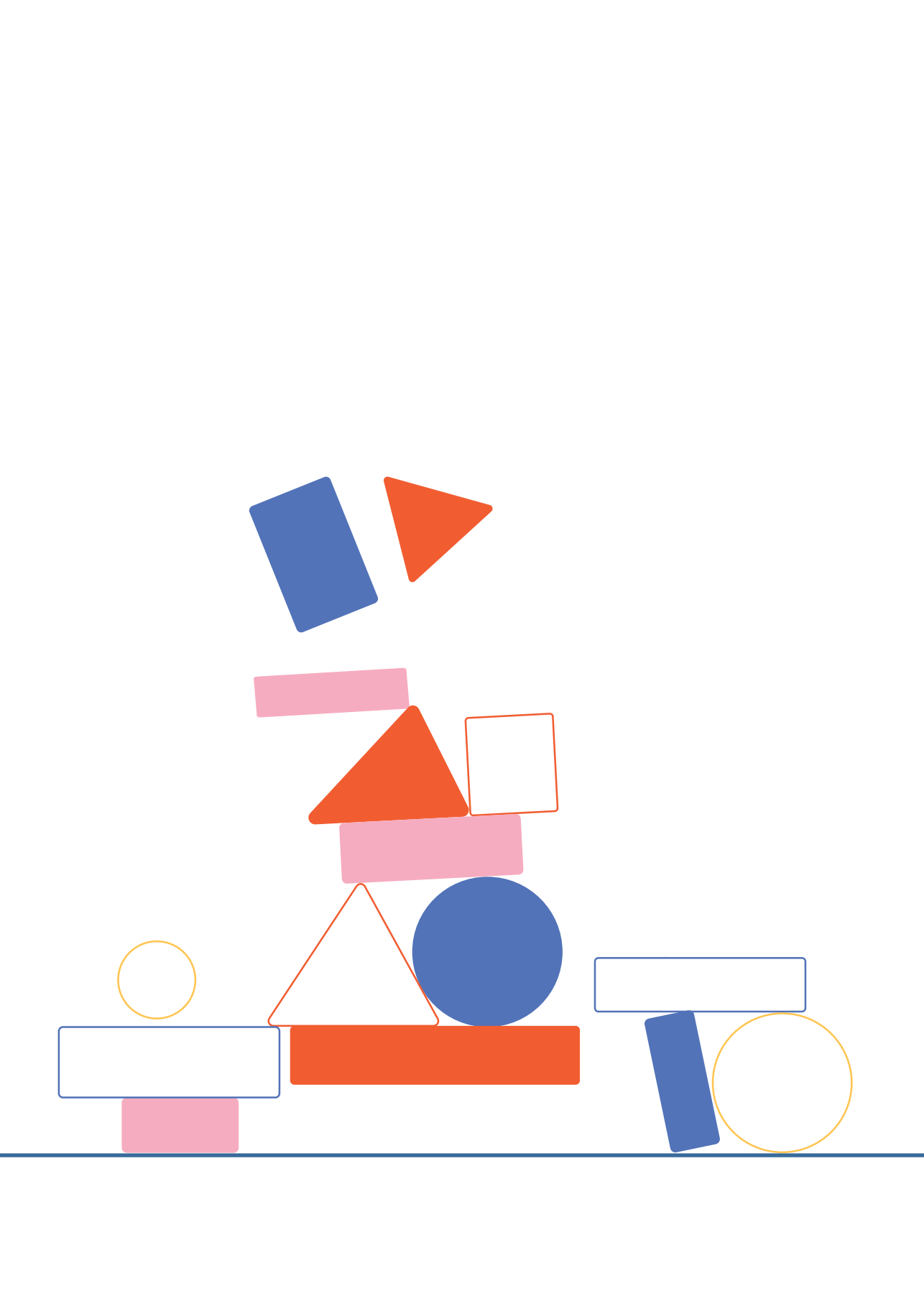
Om samen beslissen in de palliatieve kankerzorg te verbeteren, is communicatietraining voor zorgverleners hierover nodig. We ontwikkelden een online blended communicatietraining over samen beslissen in de palliatieve kankerzorg voor medisch oncologen en onderzochten de effecten (**hoofdstuk 5**). De blended communicatietraining bestond uit een e-learning en een online trainingsbijeenkomst. In een voor-na studie deden zeventien medisch oncologen (in opleiding) mee. Voor en na de communicatietraining deden zij een gesprek met een acteur die een patiënt speelde. Dit noemen we simulatieconsulten. Ook vulden de medisch oncologen vragenlijsten in. De belangrijkste uitkomst was de score die beoordelaars gaven aan het samen beslissen gedrag van de oncologen in de simulatieconsulten. Deze score verbeterde na de online blended communicatietraining (groot effect). Daarnaast verbeterde na de training ook de score op de losse fasen van samen beslissen (gemiddeld tot groot effect), werd de beslissing vaker uitgesteld (gemiddeld effect) en verbeterde de tevredenheid over de communicatie (groot effect), het vertrouwen (gemiddeld effect) en de kennis (gemiddeld effect) van medisch oncologen. De duur van het simulatieconsult veranderde niet na de training. Oncologen waren tevreden over de training en vonden een online trainingsbijeenkomst even goed en leuk als een face-to-face trainingsbijeenkomst. Ook hebben we de uitkomsten van deze training vergeleken met de uitkomsten van een langere en helemaal face-to-face communicatietraining, die eerder werden onderzocht. Vergeleken met de face-to-face communicatietraining leken de positieve effecten van de online blended communicatietraining kleiner. De beschikbaarheid van verschillende vormen van communicatietraining die goed werken biedt mogelijkheden om de training aan te passen aan wat trainingsdeelnemers willen en nodig hebben.

Steeds meer zorgverleners zijn betrokken bij de zorg voor patiënten. Ook keuzes over zorg worden steeds vaker gemaakt samen met meerdere zorgverleners, in meerdere gesprekken. Daardoor is er meer aandacht gekomen voor interprofessioneel samen beslissen en het ondersteunen van samen beslissen. We ontwikkelden en onderzochten de effecten van een blended communicatietraining voor huisartsen en verpleegkundigen over het ondersteunen van samen beslissen over palliatieve kankerzorg (**hoofdstuk 6**). Deze training ging vooral over de drie strategieën voor het ondersteunen van samen beslissen die in het eerste deel van dit proefschrift zijn beschreven. In deze voor-na studie deden 33 zorgverleners (17 huisartsen en 16 ziekenhuisverpleegkundigen) mee. Voor en na de training deden zij simulatieconsulten en vulden vragenlijsten in. De belangrijkste uitkomst was de score die beoordelaars gaven aan het samen beslissen ondersteuningsgedrag van de zorgverleners in de simulatieconsulten. Na de training verbeterde deze score op een scorelijst voor het ondersteunen van samen beslissen die speciaal werd ontwikkeld voor deze studie (gemiddeld effect), maar niet op een bestaande scorelijst voor coaching bij het nemen van beslissingen (klein effect). De kennis over samen beslissen (groot effect) en het vertrouwen in eigen vaardigheden voor het ondersteunen van samen beslissen (gemiddeld effect) van zorgverleners verbeterden na de training. Ook het rapportcijfer dat de beoordelaars

gaven aan de manier waarop de zorgverleners samen beslissen ondersteunden verbeterde na de training (gemiddeld effect). We vonden geen grote verschillen in uitkomsten tussen huisartsen en verpleegkundigen. Zorgverleners waren positief over de training. De resultaten bieden een goede start voor het verder ontwikkelen en onderzoeken van het opleiden van zorgverleners in interprofessioneel samen beslissen.

We weten dat neutrale beoordelaars en patiënten verschillen in hoe zij samen beslissen gedrag van zorgverleners scoren. We weten nog weinig over of en hoe patiënten het ondersteunen van samen beslissen door huisartsen en verpleegkundigen ervaren. Betrokkenheid van een huisarts en/of verpleegkundige kan patiënten helpen, maar misschien ook in de weg staan bij het nemen van goede beslissingen over zorg. In een experimentele studie wilden we onderzoeken wat de effecten zijn van de communicatietraining voor huisartsen en verpleegkundigen op de ervaren ondersteuning van samen beslissen door (ex)patiënten met kanker (**hoofdstuk 7**). We gebruikten de video-opnames van de simulatieconsulten van huisartsen en verpleegkundigen voor en na de training uit de studie beschreven in hoofdstuk 6. Deze simulatieconsulten werden bekeken en beoordeeld door 131 (ex)patiënten met kanker. In een vragenlijst werd hen gevraagd hoe goed het gesprek de patiënt in de video-opname zou helpen bij het nemen van een beslissing over zorg. Ook werd gevraagd hoe goed de zorgverlener in de video-opname gedrag liet zien dat samen beslissen ondersteunt. De resultaten maakten duidelijk dat (ex)patiënten met kanker de simulatieconsulten van zorgverleners na de training niet anders scoorden dan consulten voor de training. Dit betekent dat ze geen verschil zagen tussen getrainde en ongetrainde zorgverleners. Ook waren (ex)patiënten met kanker niet méér tevreden over de communicatie van getrainde zorgverleners. Er waren grote verschillen tussen de scores van (ex)patiënten met kanker die naar hetzelfde simulatieconsult hadden gekeken. Vervolgonderzoek zal moeten bekijken wat de waarde is van de communicatietraining over het ondersteunen van samen beslissen in de praktijk. Ook is het belangrijk om beter te begrijpen wat kankerpatiënten willen, nodig hebben en verwachten van interprofessioneel samen beslissen.

In het laatste hoofdstuk (**hoofdstuk 8**) hebben we onze kijk op de resultaten van dit proefschrift beschreven. We vinden dat uit het proefschrift blijkt dat interprofessioneel samen beslissen geschikt is in de palliatieve kankerzorg, omdat huisartsen en ziekenhuisverpleegkundigen een belangrijke ondersteunende rol kunnen spelen bij samen beslissen over de zorg. Communicatietraining lijkt behulpzaam bij het verbeteren van interprofessioneel samen beslissen. Om definitieve conclusies te trekken over de effecten van communicatietraining, moeten onderzoeken meer op elkaar lijken en van hoge kwaliteit zijn. Doordat patiënten kunnen verschillen in wat ze willen en nodig hebben bij het nemen van beslissingen, moeten zorgverleners (het ondersteunen van) samen beslissen op maat bieden. Zo komen ze samen met elke patiënt met ongeneeslijke kanker tot een beslissing over de behandeling die past bij zijn of haar unieke situatie.



# **ADDENDUM**



## **Appendix A – Evaluation Els Borst-conversations**

### **THE EFFECT OF ELS BORST-CONVERSATIONS ON HEALTHCARE PROFESSIONALS' ATTITUDE TOWARDS SHARED DECISION MAKING ABOUT TREATMENT FOR ADVANCED CANCER: A PRE-POSTTEST STUDY**

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#### **INTRODUCTION**

Patients with incurable cancer face treatment decisions requiring their personal considerations of the benefits and harms of treatment options. Shared decision making (SDM) facilitates treatment decision making; healthcare professionals' (HCPs) expertise about treatment options, including refraining from disease-targeted treatment, as well as patients' values and appraisals of option features are exchanged [1]. This way, they jointly arrive at a treatment decision that best suits the patient at the end of life. In the first phase after diagnosis, when disease-targeted treatment is still possible, most medical care is provided in the hospital, where the medical specialist is often in the lead. However, other HCPs, such as general practitioners (GPs) and hospital nurses, can also play an important supporting role in the SDM process [2, 3]. Observational studies demonstrated that SDM about palliative cancer treatment is not always optimally applied in clinical practice [4, 5]. Numerous efforts are made to better implement SDM [6], for example by bringing the urgency of SDM to the attention of HCPs.

One such effort is the 'Els Borst-conversation', which was developed in 2010 at the initiative of the former chairwoman of the Dutch Federation of Cancer Patient Organisations (NFK), dr. Els Borst-Eilers, in collaboration with the UMC Utrecht Cancer Centre with financial support by the Dutch Cancer Society (KWF Kankerbestrijding). Els Borst-conversations are aimed at making HCPs aware of how cancer patients and their informal caregivers experience certain events during diagnosis and treatment [7] and vice versa. In recent years, NFK organised Els Borst-conversations that mainly focused on SDM. In Els Borst-conversations, HCPs and patients with cancer with no treatment relation enter into a dialogue, led by an independent facilitator. HCPs and patients both exchange their perspectives and experiences regarding the topic of interest. This aims to lead to mutual awareness, reflection, and understanding [7]. As participants share and respond to each

other's experiences in the consultation room in a safe environment, there is a unique form of information exchange [7], which distinguishes it from, for example, mirror conversations and intervision [8, 9].

Apart from pilot [7] and cross-sectional data [10], in which participants were mostly positive, there is no scientific evidence for the effects of Els Borst-conversations. The aim of this pre-posttest survey study was to establish the effect of Els Borst-conversations on HCPs' attitude towards applying or supporting SDM about patients' palliative cancer care. The primary outcome was HCPs' attitude towards (supporting) SDM in clinical practice and we hypothesised that, after Els Borst-conversations, HCPs would find SDM more important and would have a stronger intention to apply or support SDM.

## METHODS

### Design, sample, and procedure

A one-group pre-posttest design was adopted. To establish a medium effect of the Els Borst-conversations (Cohen's  $d=0.50$ ), 34 HCPs had to be included (G\*Power 3.1.9.2,  $\alpha=0.05$ ,  $\beta=0.80$ ; paired t-test). Participants were eligible if they had contact with patients with incurable cancer; medical specialists if they consulted with patients about decisions regarding the start, continuation, or altering of palliative systemic treatment and nurses if they were employed in a hospital, had an oncology specialisation, and were usually in the position that the medical specialist made the decision with the patient. HCPs were recruited by asking hospital contacts if they were interested in organising an Els Borst-conversation about the topic of 'SDM about the palliative treatment of cancer patients'. These contact persons invited HCPs in their hospital to participate. Initially, interested participants were asked without any obligation to participate in the evaluation of the conversations; later, participation in the evaluation became part of the Els Borst-conversation offer. HCPs who participated in the evaluation were first sent an information letter. Prior to the first survey they could digitally sign informed consent. Patients (experiential experts) participating in the Els Borst-conversations were recruited through NFK and did not participate in the evaluation.

### Els Borst-conversations

Experienced cancer patients as well as a multidisciplinary group of HCPs with no treatment relationship participated in the Els Borst-conversations. In this study, the Els Borst-conversations were facilitated by a professional patient representative of the NFK. Due to the COVID-19 restrictions, conversations took place both in-person (group size of  $n=8$  HCPs and  $n=4$  patients) and online (group size of  $n=6$  HCPs and  $n=3$  patients). The discussion was guided by a general opening question ('how do you perceive SDM in

the palliative phase?’) and the four stages of SDM: 1) raising awareness about the choice, 2) explaining the options and their pros and cons, 3) exploring patient’s values and constructing treatment preferences, and 4) making or deferring the decision [1]. HCPs and patients were asked to share their positive and negative experiences with these stages. Usually, participants asked if they could share their experiences (when digital they raised their hand). Sometimes, the facilitator asked someone specifically, e.g. a participant who did not participate very actively. Some variation in the conversations occurred due to the different experiences of the participants. The conversations lasted about 1.5 hours and took place between October 2019 and March 2022.

## Evaluation outcomes

HCPs completed a survey approximately one week before and one week after the Els Borst-conversation. The primary outcome was the intention of HCPs towards their clinical behaviour as measured by a Dutch version of the Continuing Professional Development (CPD) Reaction Questionnaire [11]. The target behaviour for specialists was ‘applying SDM’ (explained as the four stages of SDM [1]) and for GPs and nurses ‘supporting SDM’ (explained as a complementary role to that of specialists in the SDM process, helping patients to make a conscious, informed, and appropriate health decision [3]). The twelve items of the CPD are based on the Theory of Planned Behaviour and assess the impact of continuing education activities on the intentions of HCPs with regard to their clinical behaviour. See Table A.1 for the constructs of the CPD. The sum score of each construct was the average of the corresponding items (scale from 1 – 7).

**Table A.1.** Continuing Professional Development reaction questionnaire (CPD) constructs

Construct	# items	Description
Intention	2	Behavioural intention to adopt a specific behaviour or not
Social influence	3	The perception that persons significant to the individual have adopted the behaviour
Belief about capabilities	3	HCPs’ perceptions of facilitators and barriers to adopting the behaviour
Moral norm	2	Feeling of personal obligation regarding the adoption of the behaviour
Beliefs about consequences	2	Beliefs about possible consequences of the behaviour for the HCP (for me it would be useful/beneficial)

HCPs were also asked about their age, sex, work experience (type of HCP, type of specialism, registration year or start and end date of their education, and the frequency with which they consulted (incurable) cancer patients), and experience with training in SDM. After the Els Borst-conversation, five evaluation questions were asked about the conversation: experience with the conversation (open), yield (multiple answers possible, see Table A.5), meaningfulness (1: not meaningful – 7: very meaningful), thoughts on the conversations as a method to gain insight in patient experience (open), and comments or suggestions (open).

## Analyses

All analyses were conducted in IBM SPSS Statistics 26 (IBM Corporation, Armonk, NY). Descriptive statistics were reported; means with standard deviations for continuous variables and absolute numbers with percentages for all categorical outcomes. Wilcoxon signed rank tests for paired groups were performed to analyse the effect of the conversations on the non-normal distribution of the data. Cohen's *d* was reported as a measure of effect size (small=0.20, medium=0.50, and large=0.80 [12]). There was no missing data. In addition, the open answers from the evaluation were qualitatively analysed to inductively identify the common and salient themes [13].

## RESULTS

In total, *n*=8 Els Borst-conversations were organised in *n*=7 hospitals and *n*=33 HCPs participated in the evaluation, including *n*=18 medical specialists, *n*=15 nurses, and no GPs. Table A.2 shows the participant characteristics.

**Table A.2.** HCP characteristics (*N*=33)

Characteristics	Total	Specialists ( <i>n</i> =18)		Nurses ( <i>n</i> =15)	
Age, mean (SD)	45.73 (11.12)	40.94 (10.34)		51.47 (9.40)	
Sex, <i>n</i> (%) female	26 (78.8)	12 (66.7)		14 (93.3)	
Function, <i>n</i> (%)	-	MD	2 (11.1)	RN	3 (20.0)
	-	Resident	2 (11.1)	RN with additional training	6 (40.0)
	-	Specialist	14 (77.8)	Clinical nurse specialist	6 (40.0)
Specialism, <i>n</i> (%) (multiple answers possible)					
Oncology	14 (42.4)	8 (44.4)		6 (40.0)	
Haematology	2 (6.1)	1 (5.6)		1 (6.7)	
Surgery	1 (3.0)	1 (5.6)		0	
Radiotherapy	2 (6.1)	2 (11.1)		0	
Geriatrics	2 (6.1)	2 (11.1)		0	
Palliative care	2 (6.1)	1 (11.1)		1 (6.7)	
Urology	1 (3.0)	1 (11.1)		0	
No <sup>a</sup>	4 (12.1)	4 (22.2)		0	
Work experience, mean (SD)	14.58 (11.51)	10.00 (8.17)		20.07 (12.75)	
Experience with consulting incurable cancer patients per month, <i>n</i> (%)					
0-10	14 (42.4)	10 (55.6)		4 (26.7)	
10-20	5 (15.2)	2 (11.1)		3 (20.0)	
20-30	8 (24.2)	2 (11.1)		6 (40.0)	
30-40	6 (18.2)	4 (22.2)		2 (13.3)	
Training experience, <i>n</i> (%) yes	2 (6.1)	2 (11.1)		0	

<sup>a</sup> Of this group 2 were MD and 2 resident (internal medicine)

Abbreviations: MD = doctor of medicine; RN = registered nurse; SD = standard deviation

HCPs did not show any significant difference in their attitude towards applying or supporting SDM after the Els Borst-conversations (see Table A.3). The effect sizes ranged from very small (*intention*, *moral norm*, and *belief about consequences*) to small (*social influence* and *beliefs about capabilities*). Post hoc analyses within each HCP group separately (specialists, applying SDM; nurses, supporting SDM) also showed no significant differences in attitude (see Table A.4a en Table A.4b). Strikingly, the construct *beliefs about capabilities* showed very different results between specialists and nurses: a non-significant medium-sized increase was found for specialists and a non-significant medium-sized decrease for nurses.

**Table A.3.** Results for total group (N=33)

CPD (range 1 – 7)	Before	After	Mean change (95% CI)	Sig.	d <sup>a</sup>
Intention	6.30	6.29	-0.02 (-0.25, 0.22)	.983	-0.01
Social influence	5.73	5.85	0.12 (-0.20, 0.44)	.232	0.30
Beliefs about capabilities	5.75	5.87	0.12 (-0.13, 0.38)	.187	0.33
Moral norm	6.24	6.27	0.02 (-0.22, 0.29)	.941	0.02
Beliefs about consequences	6.00	6.02	0.02 (-0.24, 0.27)	.855	0.05

<sup>a</sup> The calculation of Cohen's d was based on  $r_{pb} = z/\sqrt{N}$  by  $d = 2r/\sqrt{1 - r_{pb}^2}$  [14]

Abbreviations: CI = confidence interval; CPD = continuing professional development reaction questionnaire

**Table A.4a.** Results per HCP discipline (specialists, n=18)

CPD (range 1 – 7)	Before	After	Mean change (95% CI)	Sig.	d <sup>a</sup>
Intention	6.22	6.25	0.03 (-0.23, 0.29)	.942	0.02
Social influence	5.50	5.73	0.23 (-0.16, 0.62)	.172	0.47
Beliefs about capabilities	5.59	5.70	0.11 (-0.21, 0.43)	.164	0.48
Moral norm	6.08	6.19	0.11 (-0.20, 0.43)	.470	0.24
Beliefs about consequences	5.69	6.00	0.31 (-0.04, 0.65)	.075	0.62

<sup>a</sup> The calculation of Cohen's d was based on  $r_{pb} = z/\sqrt{N}$  by  $d = 2r/\sqrt{1 - r_{pb}^2}$  [14]

Abbreviations: CI = confidence interval; CPD = continuing professional development reaction questionnaire; HCP = healthcare professional

**Table A.4b.** Results per HCP discipline (nurses, n=15)

CPD (range 1 – 7)	Before	After	Mean change (95% CI)	Sig.	d <sup>a</sup>
Intention	6.40	6.33	-0.07 (-0.52, 0.39)	.856	-0.07
Social influence	5.98	6.00	-0.02 (-0.59, 0.55)	.790	-0.10
Beliefs about capabilities	5.93	6.07	0.13 (-0.32, 0.58)	.548	0.22
Moral norm	6.43	6.37	-0.07 (-0.52, 0.39)	.554	-0.22
Beliefs about consequences	6.37	6.03	-0.33 (-0.68, 0.01)	.075	-0.69

<sup>a</sup> The calculation of Cohen's d was based on  $r_{pb} = z/\sqrt{N}$  by  $d = 2r/\sqrt{1 - r_{pb}^2}$  [14]

Abbreviations: CI = confidence interval; CPD = continuing professional development reaction questionnaire; HCP = healthcare professional

Participants in the Els Borst-conversations indicated that the conversations yielded new insights from patients’ perspective and a confirmation of how they are already engaged in SDM in practice (see Table A.5). The conversations were also found to be meaningful (5.79 on a range of 1 – 7). The open answers about the Els Borst-conversations experiences and method indicated that many participants found the conversations informative and valuable, mainly by gaining insight into the experiences and needs of different patients and issues encountered by other HCPs. They also found the conversations accessible and open, which gave many opportunities to ask questions and to give and receive direct and concrete feedback. Some HCPs did not find the patients representative in terms of their background or decision-making preferences and would like to organise conversations with patients from their own hospital in order to share more concrete experiences.

**Table A.5.** Evaluation by participants

Evaluation of Els Borst-conversations	
Yield Els Borst-conversation, <i>n</i> (%) (multiple answers possible)	
New insights from a patient perspective	25 (75.8)
New insights from a HCP perspective	15 (45.5)
Confirmation of how I’m already engaging in SDM in practice	20 (60.6)
Something else	4 (12.1)
Nothing	0 (0)
Meaningful (1: not at all – 7: very much), mean (SD)	5.79 (0.86)

Abbreviations: HCP = healthcare professional; SD = standard deviation; SDM = shared decision making

DISCUSSION

The aim of this evaluation study was to establish the effect of Els Borst-conversations on HCPs’ attitude to engage in SDM in palliative cancer care. Although the Els Borst-conversations did not cause significant differences and only very small to small effects in HCPs’ attitude towards applying or supporting SDM, HCPs evaluated the Els Borst-conversations positive and meaningful.

The positive experiences of HCPs with Els Borst-conversations resonate with prior research [7, 10]. However, the results also indicate that HCPs’ attitude towards SDM did not change significantly after an Els Borst-conversation. An explanation for these null results may be that scores were already quite high prior to the conversation and, as a result, there was not much room for improvement. This may have caused ceiling effects. The high scores prior to the Els Borst-conversation may also indicate that participants in the study showed an above-average interest in SDM, implying a selection bias. Besides, we mainly found small effects, for which the study was not powered. The clinical relevance of Els Borst-conversations is yet to be determined.



Another striking finding was the difference between specialists and nurses, especially in the *beliefs about consequences* construct, but also in the other constructs. The effect for nurses was smaller and sometimes negative, while for specialists all constructs improved after the Els Borst-conversation. A possible explanation could be that the conversation was largely about interactions between patients and specialists, as the final treatment decision about the cancer treatment is the responsibility of medical specialists and medical specialists have had a greater and clearer role than nurses in the several stages of the SDM process as discussed in the conversation. Another reason for the different effects between HCP disciplines may be that the hierarchical relationship between specialists and nurses may have had a negative impact on the effects of the Els Borst-conversation for nurses. Simultaneous training of multiple HCP disciplines within teams is recommended for interventions aimed at interprofessional SDM [15, 16], yet these do need to account for the role differences across disciplines. For example, a decision coaching or SDM support model [2, 17] might match the role of nurses in SDM better than the four stages of SDM [1] adopted in the Els Borst conversations.

There are a number of limitations in the study design. Several choices regarding the organisation of Els Borst-conversations were made, of which the implications on the found effects are unknown. For example, the majority of conversations took place online due to the COVID-19 pandemic restrictions. The ratio of specialists, nurses, and patients and the type of patients present could also have influenced the results. Another choice made was the facilitator being a patient representative and not a physician, as originally recommended [7]. A physician could have used personal experiences if the conversation stalled or deviated too much from the topic of interest. However, in this interprofessional setting where both physicians and nurses were present, a patient representative might have been the best choice. Another option would have been to choose another type of healthcare professional as facilitator.

In conclusion, interprofessional Els Borst-conversations about SDM in palliative cancer care have a non-significant, very small to small effect on the attitude of HCPs towards SDM but are experienced as valuable and useful. This method can be used by hospitals to improve their quality of care and make it more patient-centred for patients with incurable cancer. More research is needed to establish the effect of Els Borst conversations on HCPs' behaviour in clinical practice.

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## **Appendix B – Evaluation conversation aids**

### **USER EVALUATION OF TWO ONLINE CONVERSATION AIDS FOR PATIENTS WITH ADVANCED CANCER AND THEIR INFORMAL CAREGIVERS**

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#### **INTRODUCTION**

Patients with incurable cancer should receive appropriate care that best suits their personal wishes and situation [1]. Therefore, it is important to carefully consider both their current and future care choices in the last phase of life.

When deciding about cancer treatment such as palliative chemotherapy, there often is no one best strategy. The patient's personal considerations with regard to possible gains and harms of treatment are therefore decisive. Shared decision making (SDM) may facilitate choosing cancer treatment based on patients' personal considerations: the healthcare professional (HCP) and patient discuss the available treatment options, the advantages and disadvantages they have, and, subsequently, patient's values and their evaluation of the pros and cons [2]. In doing so they jointly arrive at a treatment decision best fitting a patient's wishes for their final stage of life.

Advance Care Planning (ACP) can facilitate the anticipation of future decisions about care and treatment for patients with incurable cancer. ACP is "a process that supports adults (...) in understanding and sharing their personal values, life goals, and preferences regarding future medical care" [3, 4, p.826]. ACP can be enhanced by inviting patients to think about and discuss not only aspects of their physical, but also mental, social, and spiritual wellbeing. This way, patients get a better picture of their life, care, and treatment wishes, now and in the future.

Although many interventions to facilitate SDM en ACP in palliative cancer care target HCPs, there is an increasing attention for tools to support patients in thinking about and discussing life, care, and treatment wishes in their last phase of life. Important tools in SDM for patients are decision aids [5] and conversation aids [6]. A review showed that decision aids for patients may make them feel better informed and clearer about their values, and

that patients may also have a more active role in decision-making when provided with a decision aid [5]. Other patient-targeted tools are question prompt lists (QPLs), which are lists of example questions that aim to stimulate patients to ask questions, also about difficult issues such as prognosis [7-9]. In (palliative) cancer care, QPLs were found to be acceptable and useful, and to stimulate patient participation [9-12].

We have developed two different conversation aids for patients with incurable cancer and their informal caregivers, combining aspects of the previously mentioned interventions and tools: the *gesprekskaart* (conversation card) and the *gesprekswijzer* (conversation guide). The *gesprekskaart* helps patients, who know their diagnosis and know that their time is limited, and their informal caregivers to think about their wishes and needs in the last phase of life. In addition, the aid can be used in conversations between patients and informal caregivers or HCPs. The *gesprekswijzer* helps patients and their informal caregivers to think about whether or not to start or continue with disease-targeted treatment and can be used in preparation for conversations with specialists, general practitioners (GP), or hospital nurses about treatment decisions.

Conversation aids should match different patients' experiences and needs, as patients vary in their understanding of prognosis [13], information needs [14, 15], and the degree to which they want to be involved in decision-making [15-17]. Although no previous research is available on the *gesprekskaart*, a qualitative study on an earlier version of the *gesprekswijzer* showed a mixed picture of patients' experiences: some felt that a conversation aid was not necessary or did not experience a real treatment choice, while others found the *gesprekswijzer* helpful for asking questions and considering options [6]. It is important to make the conversation aids easily available to this latter group. One way to do this is to make them available online.

We evaluated the use of the conversation aids by exploring 1) the number of online natural users of the online conversation aids, i.e. persons who find the conversation aid on their own without referral by a healthcare professional or a researcher, 2) who these online natural users are and how they found the aids online, and 3) how satisfied they were with the content. The target group included incurable cancer patients and their informal caregivers, who actively searched for information about their wishes for life, care, and treatment in the last phase of life and did so at their own initiative. The *gesprekswijzer* targeted a more specific group of patients facing a treatment decision and their informal caregivers, searching information in preparation for the conversation with the HCP about this decision.

## METHOD

### Development gesprekskaart

The *gesprekskaart* has been developed by the Dutch Federation of Cancer Patient Organisations (*Nederlandse Federatie van Kankerpatiëntenorganisaties*, NFK) in cooperation with fourteen incurable cancer patients; nine of whom participated in a focus group discussion and five via an interview by telephone. They were asked about their top end-of-life questions once they had heard they were incurably ill. After that, cancer patients ( $N=654$ ) prioritised the questions by means of a survey focused on what patients with incurable cancer need [19]. In addition, experts in patients' interests and experiences, informal caregiving, nursing, health disparities, and palliative care contributed to the development of the *gesprekskaart*. Pharos, the Dutch Centre of Expertise on Health Disparities (*expertisecentrum gezondheidsverschillen*), tested the aid twice with five 'language ambassadors', i.e. experiential experts who have or had difficulty with reading and writing. Eventually, the questions on the *gesprekskaart* were written in plain language so that they can be easily understood by a large group of patients.

### Development gesprekswijzer

The *gesprekswijzer* was developed and piloted in a previous study [6]. Also, in a four-arm RCT, the effect of the *gesprekswijzer* was tested simultaneously with the effect of a training for medical oncologists on the degree of SDM in clinical consultations about palliative cancer treatment [19]. The results demonstrated that the *gesprekswijzer* had no significant effect on observed SDM compared to a control group. One of the possible causes was the length and complexity of the *gesprekswijzer*. Therefore, together with Pharos, the *gesprekswijzer* was shortened, rewritten in plain language, and tested with four language ambassadors. In addition, feedback on text and design was provided voluntarily by persons with incurable cancer affiliated with the NFK.

### Evaluation procedures

The conversation aids were published on Kanker.nl, i.e. a Dutch online platform with information about cancer, and the website of NFK, both with a hyperlink to the website of Amsterdam UMC where the conversation aids and the corresponding surveys could be found. On Kanker.nl, the conversation aids can be found on various webpages about palliative care: being in control over the care you receive, questions you can ask about being incurable or about palliative treatment, and discussing these topics with your physician. Potential participants could click on the survey on the website to participate.

Within a year, we aimed to reach a hundred people with cancer or their informal caregivers to complete a survey on one of the two conversation aids. In this year, the conversation

aids were promoted in several ways: via NFK's social media, newsletters distributed among the nineteen cancer patient organisations united within NFK and eighty walk-in centres united within the Psychosocial Oncology Institute (*Instellingen PsychoSociale Oncologie*, IPSO). Also, 750 pocket-size cards were developed and disseminated among HCPs with a QR code and a URL to the Amsterdam UMC website. HCPs could distribute these cards to patients with incurable cancer. In view of our goal to reach patients actively searching for the conversation aids at their own initiative, only the conversation aids were promoted and not the corresponding surveys for the evaluation study. After a year, we requested anonymous analytics data from the various websites to gain insight into the number of users of the conversation aids (reach; views and downloads).

## Survey and outcomes

The survey consisted of 31 topics, of which 14 about users' background characteristics, 8 about their search behaviour, and 9 about their opinion about the conversation aid. Most items were self-developed. The items on background characteristics concerned disease-related characteristics (i.e. the type of respondent (patient/informal caregiver/other), type of cancer, disease status, and whether the patient is currently under treatment), and socio-demographic characteristics (i.e. age, sex, language spoken at home, and education level). Furthermore, we assessed users' health literacy with the Health Literacy Screening Questions [20]. These consist of three items that can be scored on a 5-point Likert scale (0: never need help reading information from HCPs/very confident in filling out forms/never difficult to find out more on health – 4: always needing help/not at all sure/always hard to find out). Two items also had a 'not applicable' option, that was reported as a missing in the current study. The total score was calculated by summing the answers and was then dichotomised, with scores above 10 representing limited health literacy [21]. We also assessed decision-making characteristics, among which the user's preferred decision-making role with the Control Preferences Scale (CPS) [22], which questions the preferred treatment decision-making role by means of one item with five different decision-making roles. The items were then transformed from A/B/C/D/E to AB/C/DE to represent an active, shared, or passive preferred role. Besides, the user's information needs and attitudes towards striving for length and quality of life were included. The Quality-Quantity Questionnaire (QQQ) [23] was administered, which consists of 8 items on a 5-point Likert scale (1: strongly disagree – 5: strongly agree). Two sub scales were constructed by adding the respective item scores: striving for length of life and quality of life (4 items each). Lastly, for *gesprekswijzer* users, it was asked whether they had to decide about treatment in the near future and what the status of this treatment decision was.

For search behaviour, it was asked where the conversation aid was found, what information users searched for, and what information was found. Also, it was asked whether they found

what they were looking for, whether they had read information they rather not had seen, and, if so, which information. In addition, it was inquired if they found the conversation aid at the right moment, and, if not (completely), what would have been the right moment and why. Regarding experience and satisfaction, users' grade of the conversation aid and perception of the length and words was queried as well as whether the conversation aid would be helpful for its goal (e.g. supporting in making a treatment decision) and in general, and in conversations with either the medical specialist, GP, nurse, or patients/informal caregivers. Besides, it was inquired in which conversations the user would use the conversation aid and if the user would recommend the conversation aid. See for more information about the response categories Tables B.1-B.3. There were separate versions of the surveys for both conversation aids and for patients and informal caregivers, in which the wording was adapted to the target group.

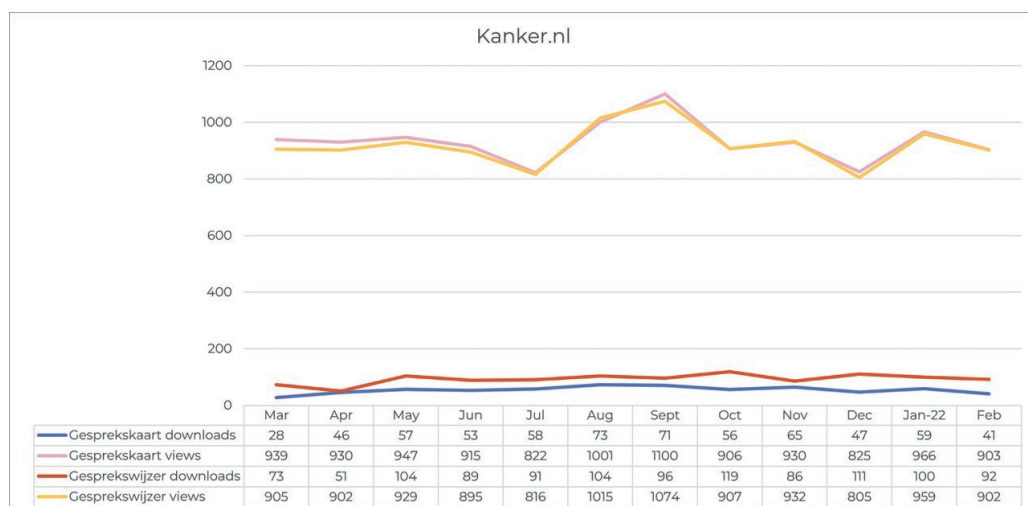
## Analysis

Analyses were done in IBM SPSS Statistics 26 (IBM Corporation, Armonk, NY). First, descriptive analyses (means with standard deviations, medians with interquartile ranges, and absolute numbers with percentages) of the items were provided. Second,  $\chi^2$ -tests, t-tests, and non-parametric tests tested differences between the two conversation aids (*gesprekskaart/gesprekswijzer*) and the type of user (patient/informal caregiver).

## RESULTS

### Reach

In the period from March 2021 to February 2022, the three different webpages on Kanker.nl containing the *gesprekskaart* were viewed 11,184 times. The *gesprekskaart* was clicked 654 times, yielding a click-through rate of 5.8%. This is the ratio of how often something is clicked to how often it is viewed. The four webpages on which the *gesprekswijzer* was located were viewed 11,041 times. The *gesprekswijzer* was clicked 1,116 times; a click-through rate of 10.1%. In Figure B.1, the fluctuation of views and downloads of the separate conversation aids on Kanker.nl over the year are shown. On the NFK website, the webpage containing both conversation aids was viewed 3,199 times in the period from March 2021 to February 2022. The *gesprekskaart* was downloaded a total of 426 times and the *gesprekswijzer* 5 times; a click-through rate of 13.3% and 0.2%, respectively.



**Figure B.1.** Overview of the number of viewed and downloaded conversation aids on Kanker.nl

## Users

Of the people who viewed one of the conversation aids, a total of 164 started the survey. This resulted in a response rate of 7.5%. Thirty-eight people completed the survey in full. It turned out that the further down the survey, the fewer people answered the questions. In Table B.1-B.3, the number of missings for each item is shown.

Approximately as many patients as informal caregivers participated in a survey ( $n=73$ , 52.5% and  $n=58$ , 41.7%, respectively; see Table B.1). Most had to deal with lung cancer ( $n=21$ , 17.2%), breast cancer ( $n=18$ , 14.8%), or prostate cancer ( $n=14$ , 11.5%), could not be cured ( $n=104$ , 85.2%), and were currently treated for cancer ( $n=76$ , 62.3%). Most people were Dutch speaking ( $n=101$ , 95.3%), between 61 and 70 years old ( $n=31$ , 29.2%), female ( $n=66$ , 62.3%), and few of them had limited health literacy ( $n=1$ , 0.9%). Regarding decision making, most preferred a shared ( $n=43$ , 45.7%) or active ( $n=42$ , 44.7%) role, had a high information need (median (IQR): 10.00 (8.8-10.0), range 1-10), and attributed more importance to the goal of quality than length of life (median (IQR): 12.00 (11.0-15.0) vs. 7.0 (4.0-10.3), respectively). Of the *gesprekswijzer* users, slightly more than half had to make a decision soon ( $n=34$ , 51.5%) and most people had already decided which treatment they wanted ( $n=42$ , 63.6%).

**Table B.1.** Background characteristics users

	<b>Total (N=164)</b>	<b>Gesprekskaart (n=57)</b>	<b>Gesprekswijzer (n=107)</b>
Informed consent, <i>n</i> (%)	148 (90.2)	53 (93.0)	95 (88.8)
<b>Disease characteristics</b>			
	<b><i>n</i>=139</b>	<b><i>n</i>=48</b>	<b><i>n</i>=91</b>
Respondent type, <i>n</i> (%)			
Patient	73 (52.5)	25 (52.1)	48 (52.7)
Informal caregiver	58 (41.7)	18 (37.5)	40 (44.0)
Healthcare professional	2 (1.4)	1 (2.1)	1 (1.1)
Other	6 (4.3)	4 (8.3)	2 (2.2)
Type of cancer <sup>a</sup> , <i>n</i> (%)			
Lung	21 (17.2)	8 (20.5)	13 (15.7)
Breast	18 (14.8)	6 (15.4)	12 (14.5)
Prostate	14 (11.5)	6 (15.4)	8 (9.6)
Colon	13 (10.7)	5 (12.8)	8 (9.6)
Lymph node	9 (7.4)	1 (2.6)	8 (9.6)
Skin	4 (3.3)	2 (5.1)	2 (2.4)
Pancreas	3 (2.5)	0	3 (3.6)
Kidney	2 (1.6)	1 (2.6)	1 (1.2)
Oesophagus	2 (1.6)	1 (2.6)	1 (1.2)
Bladder	1 (0.8)	1 (2.6)	0
Other	32 (26.2)	7 (17.9)	25 (30.1)
Do not know	3 (2.5)	1 (2.6)	2 (2.4)
Disease status <sup>a</sup> , <i>n</i> (%)			
Curative	6 (4.9)	2 (5.1)	4 (4.8)
Palliative	104 (85.2)	34 (87.2)	70 (84.3)
Do not know	12 (9.8)	3 (7.7)	9 (10.8)
Currently treatment <sup>a</sup> , <i>n</i> (%)			
Yes	76 (62.3)	22 (56.4)	54 (65.1)
No	45 (36.9)	17 (43.6)	28 (33.7)
Do not know	1 (0.8)	0	1 (1.2)
<b>Socio-demographic characteristics</b>			
	<b><i>n</i>=106</b>	<b><i>n</i>=33</b>	<b><i>n</i>=73</b>
Age <sup>b</sup> , <i>n</i> (%)			
31-40	6 (5.7)	1 (3.0)	5 (6.8)
41-50	16 (15.1)	5 (15.2)	11 (15.1)
51-60	16 (15.1)	8 (24.2)	8 (11.0)
61-70	31 (29.2)	7 (21.2)	24 (32.9)
71-80	27 (25.5)	10 (30.3)	17 (23.3)
81+	10 (9.4)	2 (6.1)	8 (11.0)
Sex, <i>n</i> (%) female	66 (62.3)	19 (57.6)	47 (64.4)

Home language <sup>b</sup> , <i>n</i> (%)			
Dutch	101 (95.3)	32 (97.0)	69 (94.5)
Turkish	2 (1.9)	1 (3.0)	1 (1.4)
Spanish	2 (1.9)	0	2 (2.7)
German	1 (0.9)	0	1 (1.4)
Education level, <i>n</i> (%)			
Low	34 (32.1)	11 (33.3)	23 (31.5)
Medium	37 (34.9)	13 (39.4)	24 (32.9)
High	35 (33.0)	9 (27.3)	26 (35.6)
Health literacy <sup>c</sup> , <i>n</i> (%) low	1 (0.9)	0 (0.0)	1 (1.4)
Health literacy <sup>b,d</sup> (0-12), median (IQR)	1.3 (0.0-3.0)	2.0 (0.5-4.5)	1.0 (0.0-3.0)
<b>Decision-making characteristics</b>			
	<i>n</i> =94	<i>n</i> =28	<i>n</i> =66
Decision-making role preference <sup>b</sup> , <i>n</i> (%)			
Active role	42 (44.7)	17 (60.7)	25 (37.9)
Shared role	43 (45.7)	9 (32.1)	34 (51.5)
Passive role	9 (9.6)	2 (7.1)	7 (10.6)
Information need (1-10), median (IQR)	10.0 (8.8-10.0)	10.0 (8.3-10.0)	10.0 (8.8-10.0)
QQQ <sup>e</sup> (0-16), median (IQR)			
Striving for length of life	7.0 (4.0-10.3)	9.0 (4.0-11.0)	7.0 (4.5-10.0)
Striving for quality of life	12.0 (11.0-15.0)	12.0 (11.0-15.0)	12.0 (11.0-15.0)
Decision soon, <i>n</i> (%) yes	-	-	34 (51.5)
Decision status on treatment, <i>n</i> (%)			
Not thinking about decision yet	-	-	9 (26.5)
Thinking about decision	-	-	8 (23.5)
Already chosen decision	-	-	17 (50.0)

<sup>a</sup> 9 missings; 4 in the gesprekskaart and 5 in the gesprekswijzer group

<sup>b</sup> Significant difference between patients and informal caregivers ( $p < .05$ )

<sup>c</sup> A higher score indicates lower health literacy; score <10 indicates adequate health literacy and score  $\geq 10$  indicates insufficient health literacy

<sup>d</sup> Significant difference between gesprekskaart and gesprekswijzer group ( $p < .05$ )

<sup>e</sup> 8 missings; 3 in the gesprekskaart and 5 in the gesprekswijzer group

Abbreviations: IQR = interquartile range; SD = standard deviation; QQQ = quality quantity questionnaire

## Search behaviour

As shown in Table B.2, the conversation aids were mainly found via Kanker.nl ( $n=61$ , 84.7%). Most people searched online for information about the disease ( $n=41$ ), absence of a cure ( $n=34$ ), and life expectancy ( $n=33$ ) and indicated that they did find ( $n=30$ , 44.8%) or somewhat found ( $n=27$ , 40.3%) what they were looking for. Nearly twelve percent indicated that they had read information that they would rather not have seen ( $n=8$ ). In open answers, some respondents indicated that they would have preferred not to see text about life expectancy, about dying while it was still too early, and that information in the conversation aid confirmed that the disease is incurable. A large majority indicated that they found the conversation aids at the right moment ( $n=42$ , 70.0%), and if they had not,



most would not have wanted to see the aids at any time ( $n=10$ , 58.8%). In open responses, users indicated as reasons for this moment being the right moment that a conversation was about to take place, the treatment had not yet started, they had accepted the incurability of the disease, or they wanted information and be prepared for anything. Of the users indicating it was somewhat the right moment, some mentioned that they were not ready yet, their loved one was not doing well, they were looking for information, or struggled with whether it all made sense. Reasons for this moment not being the right one were that the treatment was still focused on cure or had already started, or that the *conversation aid* did not provide the right answers.

**Table B.2.** Search behaviour

	Total ( <i>n</i> =82)	<i>Gesprekskaart</i> ( <i>n</i> =22)		<i>Gesprekswijzer</i> ( <i>n</i> =60)		
Location found, <i>n</i> (%)						
Internet <sup>a</sup>	74 (90.2)	18 (81.8)		56 (93.3)		
Kanker.nl	61 (84.7)	14 (77.8)		47 (87.0)		
NFK	1 (1.4)	1 (5.6)		0		
Pharos	0	0		0		
Other	10 (13.9)	3 (16.7)		7 (13.0)		
Newsletter/social media	6 (7.3)	4 (18.2)		2 (3.3)		
HCP	0	0		0		
Other	2 (2.4)	0		2 (3.3)		
Information						
Information searched   found about, <i>n</i> (%) (multiple answers possible)						
The illness	41 (50.0)	27 (32.9)	14 (63.6)	9 (40.9)	27 (45.0)	18 (30.0)
Patient experiences	15 (18.3)	9 (11.0)	6 (27.3)	4 (18.2)	9 (15.0)	5 (8.3)
Inability to be cured	34 (51.5)	21 (25.6)	12 (54.6)	6 (27.3)	22 (36.7)	15 (25.0)
Life expectancy	33 (40.2)	9 (11.0)	9 (40.9)	4 (18.2)	24 (40.0)	5 (8.3)
Treatment of the illness	28 (34.1) <sup>b</sup>	14 (17.1)	5 (22.7)	3 (13.6)	23 (38.3)	11 (18.3)
Treatment of the complaints	15 (18.3)	7 (8.5)	5 (22.7)	3 (13.6)	10 (16.7)	4 (6.7)
Other help/care	3 (3.7)	4 (4.9)	1 (4.6)	0	2 (3.3)	4 (6.7)
Other help/care for loved ones	3 (3.7)	0	1 (4.6)	0	2 (3.3)	0
Preparation conversation specialist	14 (17.1) <sup>b</sup>	16 (19.5) <sup>b</sup>	1 (4.6)	2 (9.1)	13 (21.7)	14 (23.3)
Preparation conversation nurse	5 (6.1)	3 (3.7)	1 (4.6)	0	4 (6.7)	3 (5.0)
Preparation conversation GP	5 (6.1)	2 (2.4)	1 (4.6)	0	4 (6.7)	2 (3.3)
Preparation conversation patient-caregiver	4 (4.9)	5 (6.1)	0	2 (9.1)	4 (6.7)	3 (5.0)
Taking a decision	14 (17.1) <sup>c</sup>	13 (15.8)	4 (18.2)	5 (22.7)	10 (16.7)	8 (13.3)
Last phase of life	13 (15.8)	12 (14.6)	4 (18.2)	3 (13.6)	9 (15.0)	9 (15.0)
Wishes/needs in the last phase of life	13 (15.8)	11 (13.4)	5 (22.7)	3 (13.6)	8 (13.3)	8 (13.3)
Arranging things	14 (17.1) <sup>c</sup>	9 (11.0)	2 (9.1)	3 (13.6)	12 (20.0)	6 (10.0)
Dying phase	8 (9.8) <sup>c</sup>	3 (3.7) <sup>c</sup>	1 (4.6)	0	7 (11.7)	3 (5.0)
Other	2 (2.4)	2 (2.4)	0	0	2 (3.3)	2 (3.3)
Found what they were looking for <sup>d</sup> , <i>n</i> (%)						
Yes	30 (44.8)	7 (36.8)		23 (47.9)		
No	10 (14.9)	3 (15.8)		7 (14.6)		
A little	27 (40.3)	9 (47.4)		18 (37.5)		

Info that they would rather not have seen, <i>n</i> (%)			
Yes	8 (11.9)	2 (10.5)	6 (12.5)
No	59 (88.1)	17 (89.5)	42 (87.5)
<b>Moment</b>			
	<i>n</i> =60	<i>n</i> =15	<i>n</i> =45
Right moment, <i>n</i> (%)			
Yes	42 (70.0)	10 (66.7)	32 (71.1)
No	6 (10.0)	2 (13.3)	4 (8.9)
A little	12 (20.0)	3 (20.0)	9 (20.0)
If 'no' or 'a little': when right moment, <i>n</i> (%)			
Sooner	4 (23.5)	0	4 (33.3)
Later	3 (17.6)	2 (40.0)	1 (8.3)
Never	10 (58.8)	3 (60.0)	7 (58.3)

<sup>a</sup> Within the internet group 2 missings in the gesprekswijzer group

<sup>b</sup> Significant difference between gesprekskaart and gesprekswijzer group ( $p < .05$ )

<sup>c</sup> Significant difference between patients and informal caregivers ( $p < .05$ )

<sup>d</sup> 15 missings; 3 in the gesprekskaart and 12 in the gesprekswijzer group

<sup>e</sup> 1 missing in the gesprekswijzer group

Abbreviations: GP = general practitioner; HCP = healthcare professional

## Experience and satisfaction

The conversation aids were most often rated with an 8.0; the *gesprekskaart* was scored higher (8.0) than the *gesprekswijzer* (7.5). See Table B.3. Of the people who (somewhat) viewed one of the conversation aids, most indicated that the length was just right ( $n=25$ , 61.0%) and the wording easy ( $n=21$ , 51.2%). The majority found the conversation aid completely ( $n=22$ , 53.7%) or a little ( $n=12$ , 29.3%) helpful for its purpose and completely ( $n=22$ , 53.7%) or a little ( $n=17$ , 41.5%) helpful in general. According to the users, the conversation aids seemed helpful in the conversation with the medical specialist ( $n=23$ , 56.1%) and the *gesprekskaart* particularly in the conversation with the GP ( $n=7$ , 63.6%). Most wanted to use the conversation aid in the conversation with the physician in the hospital ( $n=28$ , 68.3%) compared to conversations with the GP, nurse, between patient-informal caregiver, or in no conversation at all. In general, users recommended the conversation aids to other patients with incurable cancer and their informal caregivers ( $n=25$ , 65.8%).

**Table B.3.** Experience and satisfaction

	Total (n=55)	Gesprekskaart (n=14)	Gesprekswijzer (n=41)
Viewed, n (%)			
Yes	37 (67.3)	11 (78.6)	26 (63.4)
No	7 (12.7)	0	7 (17.1)
A little	11 (20.0)	3 (21.4)	8 (19.5)
Assessment			
	n=41	n=11	n=30
Grade (1-10), median (IQR)	8.0 (7.0-8.0)	8.0 (7.0-10.0)	7.5 (7.0-8.0)
Length, n (%)			
Too long	3 (7.3)	1 (9.1)	2 (6.7)
Exactly right	25 (61.0)	7 (63.6)	18 (60.0)
Don't know	13 (31.7)	3 (27.3)	10 (33.3)
Words, n (%)			
Easy	21 (51.2)	3 (27.3)	18 (60.0)
Difficult	1 (2.4)	0	1 (3.3)
Exactly right	15 (36.6)	6 (54.5)	9 (30.0)
Don't know	4 (9.8)	2 (18.2)	2 (6.7)
Usefulness			
Helpfulness conversation aid for its purpose <sup>a</sup> , n (%)			
Yes	22 (53.7)	8 (72.7)	14 (46.7)
No	7 (17.1)	0	7 (23.3)
A little	12 (29.3)	3 (27.3)	9 (30.0)
Conversation aid helpful in conversation with, n (%)			
Medical specialist	Yes: 23 (56.1) No: 4 (9.8) A little: 14 (34.1)	Yes: 5 (45.5) No: 1 (9.1) A little: 5 (45.5)	Yes: 18 (60.0) No: 3 (10.0) A little: 9 (30.0)
GP	-	Yes: 7 (63.6) No: 0 A little: 4 (36.4)	-
Nurse	-	Yes: 5 (45.5) No: 1 (9.1) A little: 5 (45.5)	-
Patient-informal caregiver	-	Yes: 5 (45.5) No: 1 (9.1) A little: 5 (45.5)	-
Helpfulness conversation aid in general, n (%)	Yes: 22 (53.7) No: 2 (4.9) A little: 17 (41.5)	Yes: 6 (54.5) No: 0 A little: 5 (45.5)	Yes: 16 (53.3) No: 2 (6.7) A little: 12 (40.0)
Would like to use conversation aid in conversation with, n (%) (multiple answers possible)			
Medical specialist	28 (68.3)	7 (63.6)	21 (70.0)
GP	17 (41.5)	7 (63.6)	10 (33.3)
Nurse	7 (17.1)	3 (27.3)	4 (13.3)
Patient-informal caregiver	15 (41.5)	5 (45.5)	10 (33.3)
Not	2 (4.9)	0	2 (6.7)
Recommend conversation aid to other incurable cancer patients/informal caregivers <sup>b</sup> , n (%)			
Yes	25 (65.8)	8 (88.9)	17 (58.6)
No	4 (10.5)	0	4 (13.8)
Maybe	9 (23.7)	1 (11.1)	8 (27.6)

<sup>a</sup> Aim gesprekskaart: thinking about wishes and needs in last phase of life; aim gesprekswijzer: supporting decision making about treatment

<sup>b</sup> 3 missing; 2 in the gesprekskaart and 1 in the gesprekswijzer group  
Abbreviations: GP = general practitioner; IQR = interquartile range

## Differences between groups

Users of the *gesprekswijzer* had significantly higher health literacy than those of the *gesprekskaart* ( $p=.033$ ). It was more likely that users of the *gesprekswijzer* searched for information about the treatment of the disease ( $\chi^2(1)=4.25$ ,  $p=.039$ ) and the preparation of the conversation with the medical specialist ( $\chi^2(1)=5.15$ ,  $p=.023$ ) than users of the *gesprekskaart*. It was also more likely that users of the *gesprekswijzer* found information about the preparation of the conversation with the medical specialist ( $\chi^2(1)=3.87$ ,  $p=.049$ ).

It appeared that patients who found the conversation aids were older ( $\chi^2(5)=14.88$ ,  $p=.011$ ), spoke Dutch more often ( $\chi^2(2)=7.69$ ,  $p=.021$ ), and had higher health literacy ( $p=.032$ ) than informal caregivers who found the conversation aids. In addition, patients were more likely to prefer a shared role in decision making than informal caregivers ( $\chi^2(2)=9.59$ ,  $p=.008$ ), who more often preferred an active or passive role. Patients more often searched for information about making a decision ( $\chi^2(1)=5.71$ ,  $p=.017$ ) or what needs to be arranged ( $\chi^2(1)=5.71$ ,  $p=.017$ ) than informal caregivers. On the other hand, informal caregivers more often indicated to have found information about the dying phase ( $\chi^2(1)=3.86$ ,  $p=.049$ ).

## DISCUSSION

In this evaluation study, we aimed to explore the reach of two online conversation aids, which users found and used them, how they found them, and how satisfied they were with the content. We discovered that, in total, the webpages containing the conversation aids were visited over 25,000 times and that the conversation aids were clicked about 2,200 times in a period of one year, the *gesprekskaart* about as often as the *gesprekswijzer* (1,080 vs. 1,121 times). The target group was well reached. Most users found the conversation aids in the context of the palliative phase and – according to themselves – at the right moment, and searched for what the conversation aids are intended for, e.g. preparing a treatment decision making conversation. The profile of visitors was predominantly Dutch-speaking, between 51 and 70 years of age, with high information needs and health literacy, and with a preference for an active or shared role in decision-making. This profile is understandable given that users were actively seeking online for information about preparing for a conversation or deliberating wishes for the end of life.

The question remains whether the group that perhaps needs conversation aids most was sufficiently reached by making the aids available online. Possibly, this group may require a more active (referral) role for the HCP and it is therefore important to investigate which method of presenting works best for which group. For example, patients with limited health literacy were found to prefer face-to-face information from their HCP during the

SDM process, potentially next to supportive (digital) written or visual information [24]. When starting this research project, the plan was to adjust the conversation aids as to make them available for patients with limited health literacy. However, in line with the previous findings, in a focus group with patients with limited health literacy, we soon found out they would probably not use such conversation aids by themselves, let alone search for them online.

Regarding the location where the conversation aids were found, some striking observations were made. The *gesprekskaart* was found by a relatively large proportion of users via newsletters and social media (18.2%). This may explain the popularity of the *gesprekskaart* on the NFK website, as NFK advertised their webpage in the newsletters and on social media. In confirmation, we observed spikes in the number of views of the webpages containing the conversation aids around the times when newsletters or social media posts were published. Attention through social media and newsletters might also work for other conversation aids. In addition, it is important to think carefully about where the target group is searching for information and to place the conversation aids there. The website of NFK may not be the most obvious choice, as NFK is not directly focused on the provision of information to patients and their informal caregivers. Websites of cancer patient organisations may therefore be a more logical place.

The online users were positive about the content, the comprehensibility, and the potential use in practice of the conversation aids. When compared with previous studies evaluating the *gesprekswijzer*, users' rating of how helpful the conversation aid was seemed comparable or slightly higher. In the previous studies, various aspects of the helpfulness of the *gesprekswijzer* were scored with a median of 3.0 on a scale of 1-5 ( $n=18$ ) [6] and 3.6 ( $n=81$ ) [19]. In the current study, the *gesprekswijzer* scores seem comparable (helpfulness for its specific purpose) or slightly higher (helpfulness in general) and the scores for the *gesprekskaart* even higher. This could indicate that the adjustment of the *gesprekswijzer*, mainly simplification, has improved the usefulness of the aid. It could also indicate that a different group of users have found the conversation aids, i.e. natural users searching for support as opposed to patients asked to participate in a scientific study. Furthermore, the evaluation of users' experience and satisfaction is limited by the high dropout rate. It is striking that so many people started the survey but did not finish it. People may not have been motivated enough to fully complete the survey or they were not able to evaluate the aids yet because they could or would not use it right away after downloading. Other possibilities are that the aids may have not been useful to them or may not have been what they were looking for. This could have affected results. For some people such conversation aids can also come at the wrong time or provide unwanted information. It is good to be aware of this, and add disclaimers if necessary.

There are a number of limitations of the current study design. First, we do not know whether and how carefully people viewed the conversation aids before completing the survey. Some people indicated that they had not looked at the conversation aid ( $n=7$ ), whom were excluded from the last part of the survey about experiences and satisfaction. We also do not know whether the same people filled out surveys for both conversation aids. In addition, we do not know exactly what happens in practice, for example how people search or why they do or do not opt for a certain conversation aid. To find out, qualitative research, for example by using a think aloud study design in which users are asked to speak out their thoughts and experiences, or tracking on websites would provide more insight. Finally, to translate scientific advances into public health practice, the RE-AIM (reach, effectiveness/efficacy, adoption, implementation, and maintenance) model is widely used [25]. In our study, we only examined and described the *reach* of the RE-AIM model. For successful implementation of these types of conversation aids, it would be beneficial to explore the other elements of this model as well. In this way, we could establish the clinical relevance of the conversation aids, and thus whether they help patients and informal caregivers to ultimately receive better appropriate care.

All in all, the conversation aids were well found by the intended target group. Continuous efforts should be made to determine where best to place such conversation aids and whether the online offering reaches a sufficient number of patients and informal caregivers who would benefit from such conversation aids.

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## CHAPTER 6 | THE EFFECTS OF A BLENDED CST FOR GENERAL PRACTITIONERS AND NURSES ON SKILLS TO SUPPORT SHARED DECISION MAKING WITH PATIENTS ABOUT PALLIATIVE CANCER TREATMENT: A ONE-GROUP PRE-POSTTEST STUDY

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## **CHAPTER 7 | THROUGH THE EYES OF PATIENTS: THE EFFECT OF TRAINING GENERAL PRACTITIONERS AND NURSES ON PERCEIVED SHARED DECISION MAKING SUPPORT**

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## PhD portfolio

Name PhD student: Danique Bos-van den Hoek

PhD period: June 2018 – September 2022

Name PhD supervisors: prof. dr. E.M.A. Smets and prof. dr. H.W.M. van Laarhoven

Name PhD co-supervisor: dr. I. Henselmans

1. PhD training	Year	ECTS
<b>Courses</b>		
- eBROK ('Basiscursus Regelgeving Klinisch Onderzoek'), NfU	2018	1.5
- EndNote, Graduate School for Medical Sciences, University of Amsterdam	2019	0.1
- Research Data Management, Graduate School for Medical Sciences, University of Amsterdam	2019	0.7
- Scientific Writing in English, Graduate School for Medical Sciences, University of Amsterdam	2019	1.5
- Practical biostatistics, Graduate School for Medical Sciences, University of Amsterdam	2019	1.4
- Clinical epidemiology: Randomized Controlled Trials, Graduate School for Medical Sciences, University of Amsterdam	2019	0.6
- CCA Oncology Course (not finished), Cancer Center Amsterdam	2019	2.0
- Clinical epidemiology: Observational epidemiology, Graduate School for Medical Sciences, University of Amsterdam	2020	0.6
- Research on Shared Decision-Making course, contemplating definitions and measures, pre-conference course ICCH 2020	2020	0.4
- Ethics and integrity in science, Cancer Center Amsterdam	2021	2.0
- InDesign, Cancer Center Amsterdam	2021	0.1
- Advanced topics in biostatistics, Graduate School for Medical Sciences, University of Amsterdam	2022	2.1
- Presenting in English, Graduate School for Medical Sciences, University of Amsterdam	2022	1.0
- Project management, Graduate School for Medical Sciences, University of Amsterdam	2022	0.6
<b>Seminars, workshops and master classes</b>		
- Research meetings Department of Medical Psychology Amsterdam UMC	2018-2022	3.0
- Research meetings 'supportive care' Amsterdam UMC	2021-2022	0.5
- Shared decision making working group Amsterdam UMC	2018-2022	0.5
- Patient-Provider Interaction meetings, NIVEL, Utrecht	2018-2022	0.5
- Masterclass with prof. dr. Irene Higginson, Expertisecentrum Palliatieve Zorg (EPZ) VUmc, Amsterdam UMC	2018	0.1
- Mini course Castor EDC (Electronic Data Capture System), Castor EDC and Clinical Research Unit Amsterdam UMC	2019	0.1
- Working and writing from home, Amsterdam Public Health research institute, Methodology program	2020	0.1

**Presentations/(poster)pitches/workshops**

- 'Passende zorg' – Consortiumraad Palliatieve Zorg Noord Holland – (presentation)	2018	0.5
- 'Communication skills training for healthcare professionals in oncology over the past decade: a systematic review of reviews' – ARPH Conference (presentation)	2019	0.5
- 'Gedeelde besluitvorming bij de oncologische behandeling: een multidisciplinaire focus' – NVPO Congres 2019 (workshop; twice)	2019	1.0
- 'Het SYMPHONY-project/Instrumenten ter bevordering van Gedeelde SYMPHONY project: Besluitvorming in de eerste en tweedelijns palliatieve oncologische zorg' – Symposium 'Innovatie door samenwerking in de palliatieve zorg: zorg verbonden aan onderwijs en onderzoek' by Consortium Palliatieve zorg Noord-Holland & Flevoland (pitch)	2019	0.5
- 'Shared decision making in de palliatieve oncologische zorg' – 'Clinical lesson' for anesthesia residents and Palliative Team members Amsterdam UMC (presentation)	2019	0.5
- 'General Practitioners' supporting role in SDM about cancer treatment – an interview study' – ICCH 2019 (poster with pitch)	2019	0.5
- 'Shared Decision-Making in Palliative Oncological Care. The supportive role of GPs and nurses' – ICCH 2020 (online presentation)	2020	0.5
- 'De ondersteunende rol van verpleegkundigen en huisartsen in Gedeelde Besluitvorming in de palliatieve oncologische zorg' – NVPO Conference 2020 (online presentation)	2020	0.5
- 'Shared decision making in palliative oncological care – the supportive role of GPs and nurses' – ARPH conference (online presentation)	2021	0.5
- 'Ondersteunen bij gedeelde besluitvorming' – Working group Shared Decision-Making Amsterdam UMC (presentation)	2021	0.5
- 'Shared efforts to promote shared decision-making in palliative cancer care' – CCA Award Ceremony (presentation)	2021	0.5
- 'Samen beslissen voor verpleegkundigen' – Webinar for nurses by SDM working group Amsterdam UMC (presentation)	2022	0.5
- 'Samen beslissen over de behandeling van mensen met ongeneeslijke kanker: blended learnings voor oncologen en huisartsen/verpleegkundigen' – NVPO conference (poster)	2022	0.5
- 'Ondersteunen van samen beslissen - blended learning voor verpleegkundigen in de palliatieve oncologische zorg' – V&VN Oncologiedagen 2022 (poster and presentation)	2022	0.5
- Pecha Kucha travel grant – APH Personalized Medicine programme (Pecha Kucha presentation)	2022	0.5
- 'Equipping oncologists for shared decision-making about palliative cancer treatment' – ICCH 2022 (presentation)	2022	0.5
- 'Supporting shared decision-making: online blended learning for general practitioners and nurses' – ICCH 2022 (presentation)	2022	0.5

**(Inter)national conferences**

- Congres Beslist Samen! 'Je beslist samen of je beslist niet, een schot voor open doel?', Nederlandse Vereniging van Ziekenhuizen (NVZ), Utrecht, The Netherlands	2018	0.25
- Symposium Besluitvorming in de oncologie; en nu samen met de patiënt!, Oncologisch Netwerk Zuidoost-Nederland, Utrecht, The Netherlands	2019	0.25
- Conference of the Association for Researchers in Psychology and Health (ARPH), Egmond aan Zee, The Netherlands; online	2019; 2021	1.0
- Conference of the Dutch Society for Psychosocial Oncology (NVPO), Utrecht, The Netherlands; online (2x)	2019; 2020; 2022	1.0
- International Conference for Communication in Healthcare (ICCH), online; Glasgow, Scotland	2020; 2022	3.0
- Forum of the International Conference for Communication in Healthcare (ICCH), Leiden, The Netherlands	2019	1.0
- Autumn meeting Amsterdam Public Health (APH) research institute, online	2020	0.1
- Spring meeting Amsterdam Public Health (APH) research institute, online (2x)	2021; 2022	0.4
- 38 <sup>th</sup> V&VN Oncologiedagen, Ede, The Netherlands	2022	0.25

**Other**

- Peer review for Progress in Palliative Care	2018	0.1
- Peer review for Psycho-Oncology	2020	0.1
- Peer review for BMC Palliative Care	2021	0.1
- Peer review for BMC Medical Informatics and Decision Making	2021	0.1
- Peer review for Patient Education and Counseling	2022	0.1

**2. Teaching****Year ECTS****Tutoring, Mentoring**

- Rozemarijn Huisman, 'The role and needs of general practitioners in shared decision making in the treatment of incurable cancer in the early palliative phase', Master of Medicine, University of Amsterdam (supervising master's thesis)	2018	1.0
- Assessment bachelor thesis as independent assessor	2021	0.1

**3. Parameters of Esteem****Year**

- Co-applicant grant Amsterdam Public Health research institute Personalised Medicine	2020
- Clinical Impact Award Cancer Centre Amsterdam	2021
- Nomination Societal Impact Award Amsterdam UMC	2021
- Honourable mention travel award APH PM	2022

## 4. Publications

### Peer reviewed

- Bos-van den Hoek DW, Visser LNC, Brown RF, Smets EMA, Henselmans I. Communication skills training for healthcare professionals in oncology over the past decade: A systematic review of reviews. *Current Opinion in Supportive and Palliative Care*. 2019;13(1):33-45.
- Bos-van den Hoek DW, Thode M, Jongerden IP, Van Laarhoven HWM, Smets EMA, Tange D, Henselmans I, Pasman HR. The role of hospital nurses in shared decision-making about life-prolonging treatment: A qualitative interview study. *Journal of Advanced Nursing*. 2021;77(1):296-307.
- Bos-van den Hoek DW, van der Velden NCA, Huisman R, van Laarhoven HWM, Tange D, Wind J, Smets EMA, Henselmans I. Role of GPs in shared decision making with patients about palliative cancer treatment: A qualitative study in the Netherlands. *British Journal of General Practice*. 2022;72(717):e276-84.

### Other

- Henselmans I, Bos-van den Hoek DW, Van Laarhoven HWM. Met de huisarts in gesprek over het oncologische behandelbesluit. Een goede investering? *Nederlands Tijdschrift voor Geneeskunde*. 2021;165(D5973):1-3.

### Submitted

- Bos-van den Hoek DW, van Laarhoven HWM, Ali R, Bakker S, Goosens A, Hendriks MP, Pepels MJAE, Tange D, de Vos FYF, van de Wouw AJ, Smets EMA, Henselmans I. Online blended learning for oncologists to improve skills in shared decision making about palliative chemotherapy: A pre-posttest evaluation. *Submitted*.
- Bos-van den Hoek DW, Smets EMA, Ali R, Baas-Thijssen MCM, Bomhof-Roordink H, Helsper CW, Stacey D, Tange D, van Laarhoven HWM, Henselmans I. The effects of a blended learning for general practitioners and nurses on skills to support shared decision making with patients about palliative cancer treatment: A one-group pre-posttest study. *Submitted*.
- Bos-van den Hoek DW, Smets EMA, Ali R, Tange D, van Laarhoven HWM, Henselmans I. Through the eyes of patients: The effect of training general practitioners and nurses on perceived shared decision making support. *Submitted*.

### In preparation

- van de Water LF, Bos-van den Hoek DW, Creemers G-J, Dijkgraaf MGW, Dohmen S, Fiebrich H-B, de Haes HCJM, Kuijper SC, van Maarschalkerweerd PEA, Ottevanger PB, Sommeijer DW, Smets EMA, de Vos FYF, van Laarhoven HWM, Henselmans I. Potential adverse effects of shared decision making about palliative cancer treatment: A secondary analysis of a randomised trial. *In preparation*.
- van de Water LF, Bos-van den Hoek DW, Hoedjes M, Roodbeen R, Vos P, van Laarhoven HWM, Henselmans I. Oncologists' communication about substance use during treatment for oesophagogastric cancer: A qualitative observational study. *In preparation*.
- Bos-van den Hoek DW, Tuinman MA, Hillen MA, Huijgens FL, Kurpershoek E, Hagedoorn M, Calaminus G, Kaatsch P, Lehmann V. Disclosing a history of childhood cancer to romantic partners. *In preparation*.



