THE POWER OF HELPFUL AND HARMFUL COMMUNICATION IN HEALTHCARE

JANINE WESTENDORP

The power of helpful and harmful communication in healthcare

Janine Westendorp

The power of helpful and harmful communication in healthcare

Author: Janine Westendorp
Cover: Erwin Timmerman, Optima Grafische Communicatie (www.ogc.nl)
Layout: Dennis Hendriks, Optima Grafische Communicatie (www.ogc.nl)
Printing: Optima Grafische Communicatie (www.ogc.nl)

ISBN: 978-94-6510-235-1

The research presented in this dissertation was carried out at NIVEL (Netherlands institute for health services research), and the Health, Medical and Neuropsychology Unit of Leiden University. This research was supported by grants of the Dutch Cancer Society (YIG 10392) and Leids University Funds/Schild-de Groen Funds (W19312-5-38) awarded to dr. Liesbeth M. van Vliet, the European Research Council (ERC proof of concept grant; 966785-COMMUNICATE-HEAL-TH) and NWO Stevin Award awarded to prof. dr. Andrea W.M. Evers, and the Leids University Funds (W222159-5-1) awarded to Janine Westendorp.

The power of helpful and harmful communication in healthcare

Proefschrift
ter verkrijging van
de graad doctor aan de Universiteit Leiden,
op gezag van rector magnificus prof.dr.ir. H. Bijl,
volgens besluit van het college van promoties
ter verdediging op woensdag 13 november 2024
klokke 16.00 uur

door

Janine Westendorp
geboren te Doetinchem in 1997

Promotores
prof.dr. A.W.M. Evers
prof.dr. M.L. van der Lee (Universiteit van Tilburg)

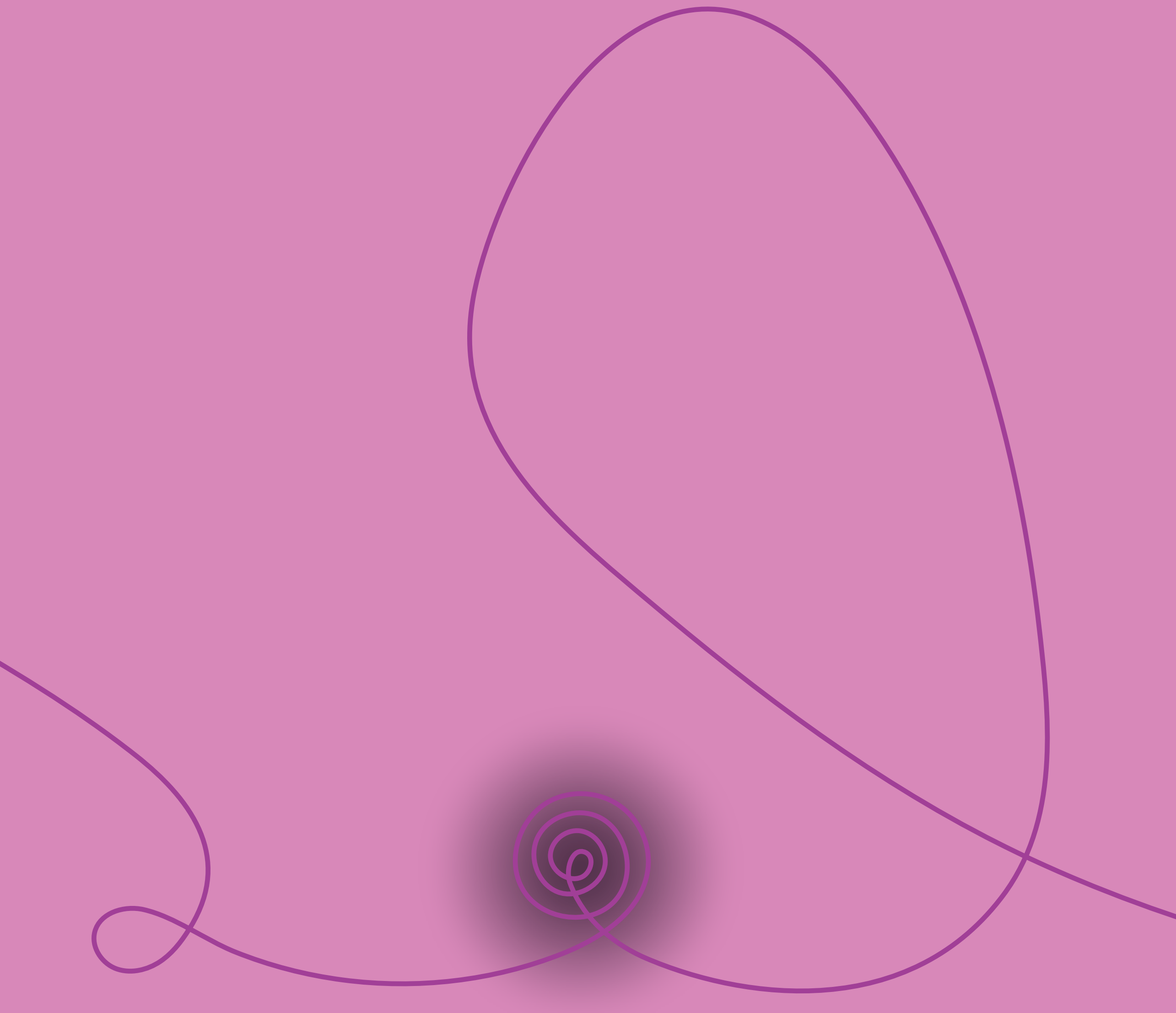
Co-promotor
dr. L.M. van Vliet

Promotiecommissie
Prof.dr. H.E. Hulst (voorzitter)
prof.dr. I.J.M. van der Ham
prof.dr. Y.M. van der Linden
prof.dr. E.M.A. Smets (Amsterdam UMC)
prof.dr. K.M. Lombarts (Amsterdam UMC)
prof.dr. W.J. Kop (Universiteit van Tilburg)

“It is more important to know what sort of person has a disease
than to know what sort of disease a person has.” - Hippocrates

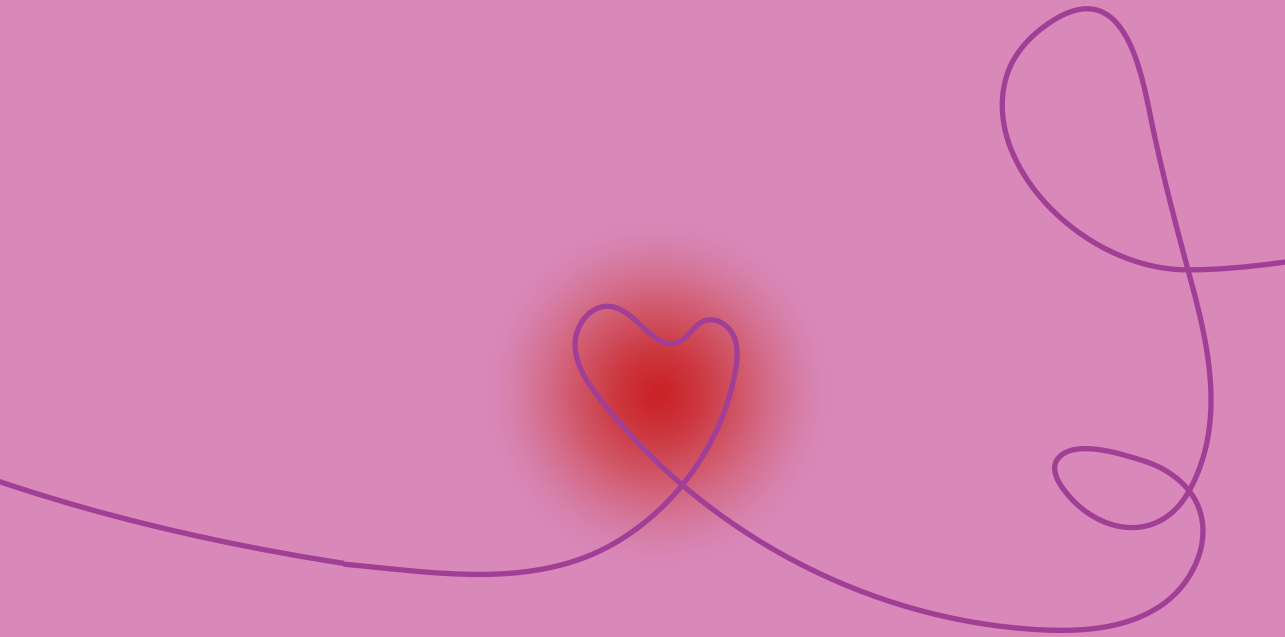
CONTENTS OF THIS DISSERTATION

Appendices



1

General introduction



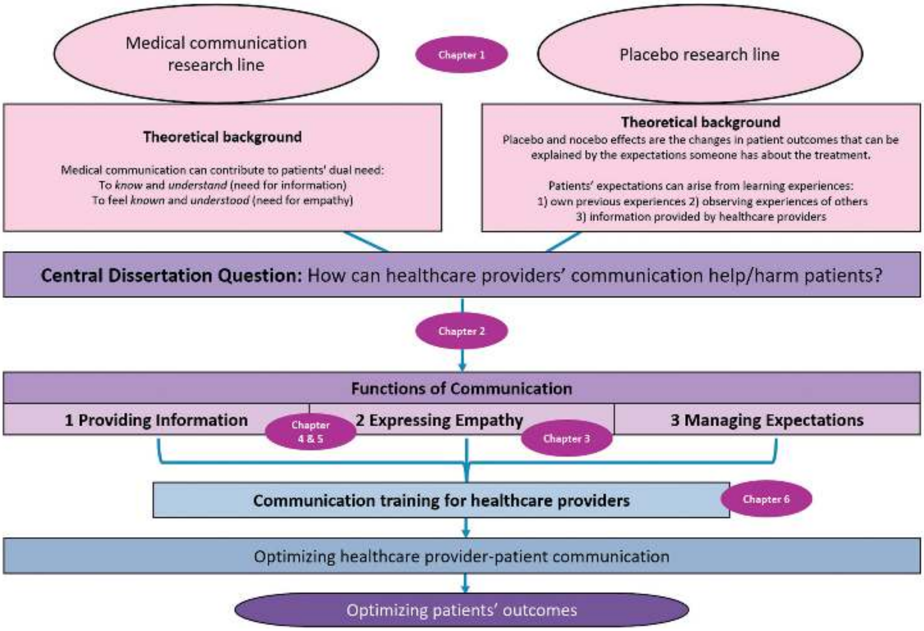
"It was not only the medicine in the bottle, or the pills in the box, that mattered, but the way the doctor gave them to his patient... by far the most frequently used drug in general practice was the doctor himself..." (Balint, 1955).[1]

In recent decades, research has increasingly emphasized that the context in which medical treatment is administered, plays a major role in treatment effectiveness and patient outcomes.[2-4] Healthcare providers' communication is seen as an important part of this context.[4 5] The way healthcare providers provide information, express empathy, and manage patients' expectations can significantly impact patient outcomes. Provided medical information can contribute to patients understanding and decision making.[6] Expressed empathy can help patients alleviating the emotional impact of an illness and can contribute to a reduction in patients' anxiety and uncertainty.[7-10] Patients expectations of a treatment, such as a painkiller, can notably contribute the effectiveness of the treatment. Through communication (e.g. exploring existing expectations and providing new information), healthcare providers can manage patients' expectations and optimize them wherever possible.[11-14] Healthcare providers' communication can thus make a significant contribution to optimizing patient care. It can enhance patients' ability to cope with the illness[6] and improve their perceived quality of life[15], especially in patients with serious illnesses, such as cancer.[16 17]

It is acknowledged that communication has also the power to harm patients.[18-20] Which specific communication patients perceive as harmful is not well understood yet. This is primarily a result of ethical constraints since, in research settings, patients cannot be intentionally harmed. What we do know so far, is that patients are regularly dissatisfied with communication. This dissatisfaction is evident in the number of healthcare complaints related to communication.[21] Many of those complaints are related to a lack of tailored information and a lack of empathy.[21 22] Furthermore, patients' negative expectations can also negatively impact the effectiveness of medication and may potentially contribute to the occurrence of unnecessary side effects.[23-26] Healthcare providers thus have an important role in preventing potential harm through their communication.

This dissertation aims to shed light on how healthcare providers' communication could help and harm patients. In this first chapter, we provide a historical overview of two distinct research lines (the medical communication research line and the placebo research line) that have studied the communication between healthcare providers and patients. Secondly, based on these research lines, we will delineate three functions of communication (providing information, expressing empathy and managing expectations), through which healthcare providers' communication can either help or harm patients. Then we will explicitly outline the research questions for each of the following chapters. See Figure 1 for the dissertation outline.

Figure 1. Dissertation outline



TWO PERSPECTIVES

The interaction between healthcare providers and patients has been studied extensively by two distinct research lines: the medical communication research line and the placebo research line. Both of these research lines have explored healthcare provider-patient communication from different perspectives, which we will elaborate on.

MEDICAL COMMUNICATION RESEARCH LINE

Historically, medical communication has been more commonly regarded as an art rather than a science.[27] Due to a lack of operationalization capacity and evidence base, medical communication was perceived as a soft skill (i.e. a skill someone inherently possesses or not) rather than a hard skill (i.e. a skill that can be learned). As a result, for a long time communication was not integrated into medical education.[27] Student doctors were advised to develop their own communication style by practicing and observing their mentors. From the second half of the 20th century onward, research into medical communication increased. Two research methodologies, specifically the Roter Interactional Analysis System (RIAS)[28 29] and Randomized Controlled Trials (RCTs)[30], played a role in fostering this expansion of medical communication research. With the RIAS method, healthcare provider-patient conversations were recorded (either in video or audio format), and each utterance was coded and categorized, resulting in communication becoming measurable. This method increased the reliability and validity of communication research and illustrated how healthcare provider-patient communication took place in clinical practice and what functions communication could have. RCTs are experimental research designs in which participants are randomly allocated to different groups (groups with a specific intervention or a control group). RCTs constitute a robust design for investigating causal relationships and assessing the effectiveness of an intervention. This method allowed for the examination of whether specific communication interventions could contribute to better care for patients.[6]

In the subsequent years, research into medical communication increased,[31] and various new models were developed to describe the aims and functions of medical communication.[8 32-35] In 2009, de Haes and Bensing[6] compared the four most utilized models and integrated those into a 'six-function model of medical communication' (see Figure 2 – part A).

Figure 2. Models explaining the functions of medical communication

part A*					**part B**
(1) Three function model Bird & Cohen-Cole[32]	**(2) Three function model** Lazare et. al.[33]	**(3) Model of medical communication functions** de Haes & Teunissen[34] Smets, et. al.[35]	**(4) Framework for patient centered communication** Epstein & Street[8]	**Six function model of medical communication**** De Haes & Bensing[6]	**This dissertation:** Three functions of communication through which communication can help/harm.
Data gathering	Determine and monitor the nature of the problem	Information exchange: gathering and giving information	Information exchange	**Gathering information**	**1 Providing Information**
				Providing information	
		Decision making	Making decisions	**Decision making**	
Educating patients	Carry out education and implementation of treatment plans			**Enabling disease & treatment related behavior**	
	Develop, maintain & conclude the relationship	Relationship building	Fostering relationships	**Fostering the relationship(s)**	**2 Expressing Empathy**
Responding to emotions				**Responding to emotions**	
			Managing uncertainty		From placebo research: **3 Managing Expectations**

* This figure is derived and adapted from de Haes and Bensing 2009: *De Haes, H., & Bensing, J. (2009). Endpoints in medical communication research, proposing a framework of functions and outcomes. Patient education and counseling, 74(3), 287-294.*

De Haes and Bensing described six functions of medical communication. As the first two functions, they distinguish between *gathering* and *providing information.* From the healthcare providers' perspective, it is crucial to obtain information from patients regarding symptoms, experiences, and expectations to formulate a precise diagnosis and treatment plan.[32] The third function is *decision making.* The healthcare provider must present the available treatment options, after which a choice will need to be made. The fourth function of medical communication is described as *enabling disease and treatment related behavior.* This indicates that patients can be encouraged to actively contribute to the enhancement of their recovery or the prevention of decline in health through their own behaviors.[6] The last two functions de Haes and Bensing described were *fostering the relationship(s)* and *responding to emotions*. From the moment a patient receives a diagnosis and comes into contact with a healthcare provider, they enter into a relationship together. This relationship is important because there must be a mutual trust between the healthcare provider and the patient to provide and receive optimal care.[36] Having a disease can evoke emotions in patients, such as sadness, anxiety, and anger. Healthcare providers have to deal with these emotions in the conversation with a patient. In this dissertation, we examine the six functions described by de Haes and Bensing[6] from a broader perspective, distilling them into two main functions of medical communication, based on patients' dual need.

PATIENTS DUAL NEED

We can align the six function model of medical communication with the theoretical framework of Engel[37], who divided the needs of patients into two distinct categories: the *need to know and understand*, and the *need to feel known and understood.*[37-39] The *need to know and understand* is a cognitive need for medical information, for example about the disease and available treatment options. Examining the six functions of medical communication, the functions *gathering/providing information, decision making* and *enabling disease and treatment related behavior* align with this patient' cognitive need for information. Patients require accurate and tailored information to make well-informed decisions about their treatment and to optimize the treatment process. The *need to feel known and understood* is described as a more emotional need for empathy, emotional support and being seen as a person instead of an disease. The functions *fostering the relationship(s)* and *responding to emotions* contribute to satisfying this patient emotional need. These dual needs can be distinguished but are also interconnected. For instance, acquiring information can influence emotions, and the intensity of emotions can, in turn, impact the assimilation of information. So, taking a broader perspective, literature from the medical communication research line has acknowledged that the communication of healthcare providers serves crucial functions in (1) *providing* patients with *information* and (2) offering acknowledgment for the emotional impact of the illness (in this dissertation referred to as *expressing empathy*). The placebo research line approached medical communication from a different perspective and identified another valuable function of communication: *managing* patients' *expectations* (see Figure 2 – part B).

PLACEBO RESEARCH LINE

While the research line of medical communication started by studying the functions of communication and the impact of communication on patient outcomes, the research line on placebo effects explained health effects that did not arise from prescribed treatments, described as *placebo effects* (Latin: "I shall please").[40] This research line also has its origins in the development of the RCTs. Through this research method, the effectiveness of treatments, such as medication, could be systematically investigated.[41] In RCTs, the intervention group received the 'real' medication, while the control group received a 'fake pill,' also called a placebo pill.[42] The primary objective of these studies was to demonstrate the effectiveness of the 'real' medication. Researchers initially aimed to observe a decrease in symptoms within the intervention group, contrasting with no change in the control group. The researchers were less satisfied when symptoms in the control group also decreased, indicating a *placebo effect*.[41] Initially, placebo effects were regarded as undesirable effects. However, there were also researchers who sought to illuminate it from a different perspective: if the effects cannot be attributed to an active substance in medication, which mechanisms can then explain these effects? Extensive research into the mechanisms behind placebo effects followed.[43-47] The patient's expectations of the treatment (conscious or unconscious) were identified as a critical mechanism in elucidating placebo effects: expecting that a treatment will be effective can indeed produce a positive effect.[42 48 49] The opposite effect, known as the *nocebo effect* (Latin: "I shall harm"), can also occur. Nocebo effects can arise when negative expectations significantly worsen treatment outcomes and are often associated with increased side effects.[26 50] The impact of patients' expectations on treatment outcomes were demonstrated not only in placebo/nocebo research (with a fake pill), but it was also shown that expectations have an extra add on effects of 'real treatments,' such as painkillers.[51 52] In this dissertation we define placebo and nocebo effects as *the changes in patient outcomes that can be explained by the expectations someone has about the treatment.*

EXPECTANCY LEARNING MECHANISMS

Patients' expectations about a treatment, conscious or unconscious, can arise from learning experiences, shaped by: personal experiences from the past (conditioning), observing experiences of others (observational learning), and information provided by doctors, nurses, or other medical staff (instructional learning).

Patients all have personal previous experiences that can influence their expectations of treatment.[53-56] A previous positive experience with, for example, a particular context (e.g. shape, scent, color, or taste) of a treatment, can contribute to creating the expectation that a new treatment will be effective.[57-60] When conditioning-based learning occurs, an association is established between a neutral stimulus (e.g. color) and a treatment (e.g. painkiller). This conditioning mechanism has been shown to be potentially very powerful, for instance, in dosage reduction.[61 62] The opposite can also occur, such as when an association is established between a neutral stimulus and side effects.[63] For example, in patients undergoing chemotherapy, they may experience nausea as soon as they enter the hospital (neutral stimulus), even before the chemotherapy is administered.[64] Observing or hearing about medical experiences of others can also influence the expectations of the patient.[65 66] Studies found that the observation of individuals perceiving a specific stimulus as non-painful, created an expectation that subsequently led to the perceived reduction of the stimulus's painfulness, regardless of the actual intensity of pain associated with it.[67] The patient thus brings their own unique expectations (formed through personal experiences or experiences of others) to the consultation with the healthcare provider. However, new expectations can also arise during the interaction with the healthcare provider, for instance, through information provided by the healthcare provider, commonly referred to as *verbal suggestions*.[26 68] Studies demonstrated that healthcare providers' verbally expressed expectations can contribute to patients' expectations about a treatment, and subsequently, to the effectiveness of the intervention.[11 69] In conclusion, literature from the placebo research line acknowledged that healthcare providers play a crucial role in managing patients' expectations through their communication, thereby improving patient outcomes.[26 68] In this dissertation, we therefore incorporate *managing* patients' *expectations* as an essential function of optimal medical communication (see Figure 2 – part B).

THREE FUNCTIONS OF MEDICAL COMMUNICATION

Considering the literature from both research lines, we posit that healthcare providers' communication has three overarching functions that can contribute to enhancing patient care: 1) providing information, 2) expressing empathy and 3) managing expectations. We will delineate the current understanding of how healthcare providers, through these functions, can either help or unintentionally harm patients, as well as identify existing research gaps.

1 PROVIDING INFORMATION

The cognitive need of patients for medical information is also described as their *need to know and understand*.[37 39] Patients require accurate information to comprehend their disease, cope with the consequences, understand the treatment options, and make well-informed decisions.[6] However, the information needs vary among patients. Some patients seek more control and want all available information.[20] Others become overwhelmed with too much information and prefer the healthcare provider to make a preselection.[70 71] In the decision-making process, informing patients is also crucial. While in the past, it was implicit that the physician made the medical decisions, there is currently a strive for a more shared decision-making process, involving both the physician and the patient.[72] Shared decision-making can positively contribute to patient trust in the medical decision, treatment adherence, satisfaction, perceived quality of life, and the reduction of anxiety symptoms.[73 74] When patients become seriously ill, information may become even more crucial, treatment choices more impactful, and questions may arise, such as "*what is my life-expectancy?*".[75] Most research has been conducted on patients' preferences in helpful information provision and decision-making, however less is known about which communication patients specifically perceive as harmful. We might expect that the opposite of helpful communication (e.g. lack of shared decision making) could be perceived as harmful. However, we do not have conclusive literature on this yet, so we aim to explore this aspect in this dissertation.

2 EXPRESSING EMPATHY

A healthcare provider is often the messenger of news that can have a significant impact on patients, with emotions as anxiety, sadness, and anger as result.[76] Especially when patients receive a diagnosis of a serious illness, such as cancer, we know that the emotional impact is enormous, affecting the patients loved ones as well.[77 78] Healthcare providers play a crucial role here in acknowledging this emotional impact, as patients need to *feel known and understood*.[37 39] Neglecting these emotions can potentially intensify them and might also impede other conversational goals, such as information exchange and decision-making.[32] Intense emotions, for example, can lead to difficulties in recalling information.[79-81] The existing literature lacks uniformity in terminology regarding the communication behaviors for fulfilling patients need to feel known. Communication behaviors that are mentioned in literature are a warm and friendly attitude, sympathy, compassion and empathy. [82] To enhance clarity, we will use the term *empathy* and proceed to elaborate on its intended meaning. For defining empathy, we align with the definition provided by Mercer and Reynolds[83], who have extensively elaborated on the construct of empathy in medical conversations: "*Empathy involves an ability to; (a) understand the patient's situation, perspective and feelings (and their attached meanings); (b) to communicate that understanding and check its accuracy;*

and, (c) to act on that understanding with the patient in a helpful (therapeutic) way."[83] Researchers generally agree that in medical encounters, empathy is deemed ineffective without the 'action component' (i.e. actually acting upon the understanding for the patient).[83 84] This action component can be fulfilled via communication of the healthcare provider. Both nonverbal and verbal empathic communication behaviors can positively impact patient outcomes: reduced negative emotions, increase satisfaction, less side-effects and a better provider-patient relationship.[85-87] While empathy is often used as an umbrella term, specific empathic behaviors that can contribute to improved patient outcomes include: actively listening to concerns, focusing on the whole person, taking time, being available, maintaining eye contact, sitting instead of standing, and responding to emotions.[88-91] The majority of studies investigating the impact of empathy have focused on how empathy can improve patients' emotional need. Experimental studies have recently indicated that empathy may also affect cognitive needs, such as the recall of information.[7 92 93] Nevertheless, this effect has not yet been demonstrated in a clinical setting. Therefore, an objective of this dissertation is to explore the effect of empathy on information recall in clinical practice. Furthermore this dissertation explores the extent to which a lack of empathy is considered harmful.

3 MANAGING EXPECTATIONS

The potential effectiveness of a treatment is significantly influenced by patients' expectations, and healthcare providers play a crucial role in managing these expectations.[11 12 69] Hence, it is essential for healthcare providers to thoroughly understand and explore the expectations of their patients, and to choose their words carefully when conveying new expectations.[94 95] Different strategies to optimize placebo effects and minimize nocebo effects through communication can be distinguished: 1) explore about existing expectations and respond accordingly; 2) optimize treatment information to optimize positive expectations; 3) choose words carefully when discussing side effects; and 4) provide patients with explanations about the mechanisms behind placebo and nocebo effects.[12 94-97] A first step to optimize patient expectations is to explore about patients' existing expectations.[12] This exploration may reveal, for example, that the patient is very anxious about experiencing side effects. In response, the healthcare provider can adjust their communication to address these expectations—redirecting them where possible or reassuring the patient.[96 97] Secondly, a straightforward strategy to improve the patient new expectations via healthcare providers communication involves optimizing treatment information through clear verbal instructions: explaining the mechanism of treatment, and specifying the intended effect. This strategy has already been effectively demonstrated in various experimental and clinical studies (e.g. reduced pain after surgery).[98-100] Thirdly, it may be important to carefully address the discussion of potential side effects to diminish the occurrence of nocebo effects in medication or medical procedures.[23 24] For instance, providing comforting communication (e.g. *"I will numb this place on your arm, ensuring your comfort during the procedure"*[101]) during the administration of a local anesthetic injection, rather than emphasizing the painful aspects of the procedure, can result in a decrease in reported pain.[101] The fourth strategy is explaining patients about placebo and nocebo mechanisms.[94-96] From studies on open-label placebos (where individuals are aware that they were prescribed a placebo), we know that providing explanations about the mechanisms of placebo effects can contribute to positive expectations and, consequently, positive health effects.[102 103] Researchers reached a consensus that we should also apply this mechanism in regular treatments.[94 95 104] On the other side, explaining the mechanisms of nocebo effects can be employed as a way to reduce nocebo effects.[105] For example, a study with patients who had discontinued their Statin treatment due to side effects showed that half of the patients successfully resume treatment when it became clear that these side effects were partly attributable to nocebo effects.[106] There is ample evidence that managing and optimizing expectations through these strategies can contribute to better care for patients. However, researchers agree that these communication strategies are currently underutilized, and that healthcare providers should preferably be trained to address placebo and nocebo effects via their communication.[95] Additionally, it is still unclear if and how healthcare providers manage patients' expectations when discussing prognosis, treatment outcomes, and side effects with patients facing advanced cancer. This dissertation aims to address these questions by developing a communication training for healthcare providers and exploring the use of expectations in the clinical setting of advanced cancer.

AIMS OF THIS DISSERTATION

This dissertation aims to shed light on how healthcare providers' communication could help and harm patients. We will illuminate the critical role of healthcare providers' communication in providing information, expressing empathy, and managing expectations. In the initial chapters of this dissertation, we specifically focus on communication with patients with a serious illness, specifically cancer. This emphasis stems from the heightened impact of emotions, such as anxiety and uncertainty, in the context of serious illness, where information and decisions bear even greater significance. Optimal communication therefore is of even greater importance in cancer care. Therefore we aim to delve deeper into understanding how communication in oncological settings can be both helpful and harmful for patients. First we will examine how empathy and expectations are currently used in clinical setting (chapter 2). Then we will focus more specifically on exploring the effect of empathic communication behavior on cancer patients' recall in clinical practice (chapter 3). We will investigate whether this effect could be mediated by a decrease in patients' anxiety. In the next two chapters, we will navigate into the realm of the yet-to-be-explored 'harmful communication' part. Through both an survey study on the perspectives of cancer patients (chapter 4) and a systematic literature review (chapter 5), we will investigate what is perceived as harmful communication in cancer care. Subsequently, it is crucial to connect these findings to clinical practice because healthcare providers need to learn which communication is best to use and which to avoid. Researchers agree that, right now, not enough of these communication strategies are being utilized in clinical practice.[94 95] The goal of this dissertation, therefore, is not only to explore communication strategies but also to develop and evaluate a training that can help healthcare providers communicate optimally with their patients. In chapter 6 we will describe the development and evaluation of a communication training (using an e-learning and virtual reality) for healthcare providers in regular care. In chapter 7, we present a summary of the main findings in this dissertation. Chapter 8 contains a general discussion in which we elucidate the theoretical contribution of this dissertation, discuss the limitations and strengths, offer suggestions for future directions, provide implications for clinical practice, and end with an overall conclusion.

REFERENCES

1. Balint M. The doctor, his patient, and the illness. *The lancet* 1955;265(6866):683-88.
2. Kaptchuk TJ, Miller FG. Placebo effects in medicine. *N Engl J Med* 2015;373(1):8-9.
3. Finniss DG, Kaptchuk TJ, Miller F, Benedetti F. Biological, clinical, and ethical advances of placebo effects. *The Lancet* 2010;375(9715):686-95.
4. Benedetti F. Placebo and the new physiology of the doctor-patient relationship. *Physiological reviews* 2013;93(3):1207-46.
5. Van Dulmen A, Bensing J. Health promoting effects of the physician-patient encounter. *Psychology, Health & Medicine* 2002;7(3):289-300.
6. De Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. *Patient education and counseling* 2009;74(3):287-94.
7. van Osch M, Sep M, van Vliet LM, et al. Reducing patients' anxiety and uncertainty, and improving recall in bad news consultations. *Health Psychology* 2014;33(11):1382.
8. Epstein RM, Street Jr RL. Patient-centered communication in cancer care: promoting healing and reducing suffering. 2007
9. Fogarty LA, Curbow BA, Wingard JR, et al. Can 40 seconds of compassion reduce patient anxiety? *Journal of clinical oncology* 1999;17(1):371-79.
10. Derksen F, Bensing J, Lagro-Janssen A. Effectiveness of empathy in general practice: a systematic review. *British journal of general practice* 2013;63(606):e76-e84.
11. Peerdeman KJ, van Laarhoven AI, Keij SM, et al. Relieving patients' pain with expectation interventions: a meta-analysis. *Pain* 2016;157(6):1179-91.
12. Bingel U. Placebo 2.0: the impact of expectations on analgesic treatment outcome. *Pain* 2020;161:S48-S56.
13. Bingel U, Wanigasekera V, Wiech K, et al. The effect of treatment expectation on drug efficacy: imaging the analgesic benefit of the opioid remifentanil. *Science translational medicine* 2011;3(70):70ra14-70ra14.
14. Kam-Hansen S, Jakubowski M, Kelley JM, et al. Altered placebo and drug labeling changes the outcome of episodic migraine attacks. *Science translational medicine* 2014;6(218):218ra5-18ra5.
15. Stewart MA. Effective physician-patient communication and health outcomes: a review. *CMAJ: Canadian medical association journal* 1995;152(9):1423.
16. Street Jr RL, Voigt B. Patient participation in deciding breast cancer treatment and subsequent quality of life. *Medical Decision Making* 1997;17(3):298-306.
17. Rosenberg HJ, Rosenberg SD, Ernstoff MS, et al. Expressive disclosure and health outcomes in a prostate cancer population. *The International Journal of Psychiatry in Medicine* 2002;32(1):37-53.
18. Bedell SE, Graboys TB, Bedell E, Lown B. Words that harm, words that heal. *Archives of internal medicine* 2004;164(13):1365-68.
19. Thorne S, Oliffe JL, Stajduhar KI, et al. Poor communication in cancer care: patient perspectives on what it is and what to do about it. *Cancer Nurs* 2013;36(6):445-53. doi: 10.1097/NCC.0b013e31827eeda410.1097/NCC.0b013e31827eeda4. [published Online First: 2013/01/26]
20. Thorne SE, Hislop TG, Armstrong E-A, Oglov V. Cancer care communication: the power to harm and the power to heal? *Patient education and counseling* 2008;71(1):34-40.
21. Cohen-Mansfield J, Skornick-Bouchbinder M, Cohen R, Brill S. Treatment and communication–that is what matters: An analysis of complaints regarding end-of-life care. *Journal of Palliative Medicine* 2017;20(12):1359-65.

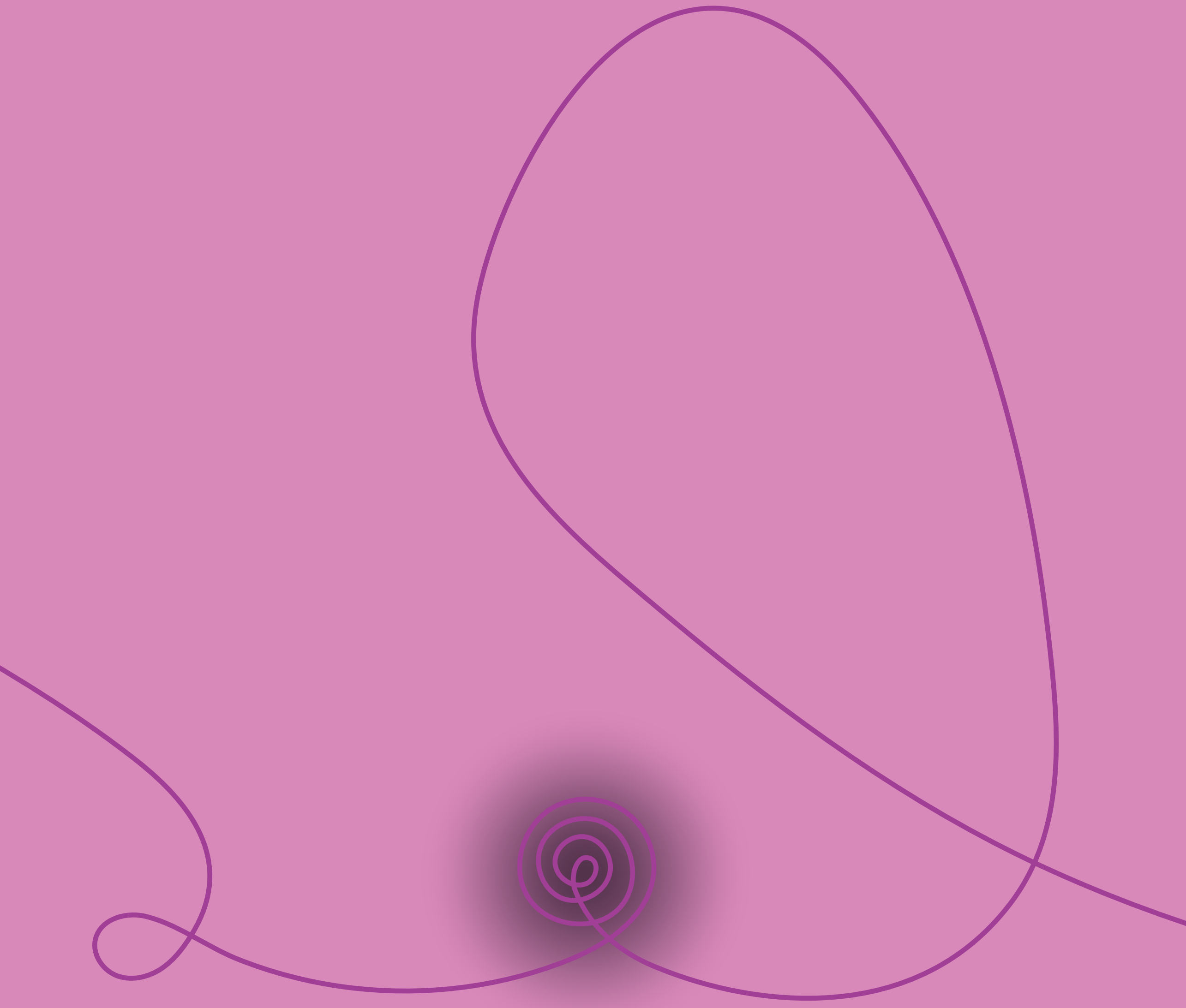
22. Abdelrahman W, Abdelmageed A. Understanding patient complaints. *BMJ: British Medical Journal* 2017;356
23. Colagiuri B, McGuinness K, Boakes RA, Butow PN. Warning about side effects can increase their occurrence: an experimental model using placebo treatment for sleep difficulty. *Journal of psychopharmacology* 2012;26(12):1540-47.
24. Krauss BS. “This may hurt”: predictions in procedural disclosure may do harm. *BMJ* 2015;350
25. Planès S, Villier C, Mallaret M. The nocebo effect of drugs. *Pharmacology research & perspectives* 2016;4(2):e00208.
26. Benedetti F, Lanotte M, Lopiano L, Colloca L. When words are painful: unraveling the mechanisms of the nocebo effect. *Neuroscience* 2007;147(2):260-71.
27. Lipkin M, Kissane D, Butow P, et al. The history of communications skills knowledge and training. *Oxford Textbook of Communication in Oncology and Palliative Care* 2017:3.
28. Bales RF. A set of categories for the analysis of small group interaction. *American Sociological Review* 1950;15(2):257-63.
29. Roter D, Larson S. The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. *Patient education and counseling* 2002;46(4):243-51.
30. Bothwell LE, Podolsky SH. The emergence of the randomized, controlled trial. *N Engl J Med* 2016;375(6):501-04.
31. Roter DL, Hall JA, Katz NR. Patient-physician communication: a descriptive summary of the literature. *Patient Education and Counseling* 1988;12(2):99-119.
32. Bird J, Cohen-Cole SA. The three-function model of the medical interview. Methods in teaching consultation-liaison psychiatry: Karger Publishers 1990:65-88.
33. Lazare A, Putnam SM, Lipkin Jr M. Three functions of the medical interview. The medical interview: Clinical care, education, and research: Springer 1995:3-19.
34. de Haes H, Teunissen S. Communication in palliative care: a review of recent literature. *Current opinion in oncology* 2005;17(4):345-50.
35. Smets E, van Zwieten M, Michie S. Comparing genetic counseling with non-genetic health care interactions: two of a kind? *Patient Education and Counseling* 2007;68(3):225-34.
36. Brennan N, Barnes R, Calnan M, et al. Trust in the health-care provider–patient relationship: a systematic mapping review of the evidence base. *International Journal for Quality in Health Care* 2013;25(6):682-88.
37. Engel GL. How much longer must medicine’s science be bound by a seventeenth century world view? *Psychotherapy and psychosomatics* 1992;57(1-2):3-16.
38. Bensing JM, Dronkers J. Instrumental and affective aspects of physician behavior. *Medical care* 1992:283-98.
39. van Vliet LM, Epstein AS. Current state of the art and science of patient-clinician communication in progressive disease: patients’ need to know and need to feel known. *Journal of Clinical Oncology* 2014;32(31):3474.
40. De Craen AJ, Kaptchuk TJ, Tijssen JG, Kleijnen J. Placebos and placebo effects in medicine: historical overview. *Journal of the Royal Society of Medicine* 1999;92(10):511-15.
41. Kaptchuk TJ. The double-blind, randomized, placebo-controlled trial: gold standard or golden calf? *Journal of clinical epidemiology* 2001;54(6):541-49.
42. Price DD, Finniss DG, Benedetti F. A comprehensive review of the placebo effect: recent advances and current thought. *Annu Rev Psychol* 2008;59:565-90.
43. Meissner K, Kohls N, Colloca L. Introduction to placebo effects in medicine: mechanisms and clinical implications: The Royal Society, 2011:1783-89.

44. Benedetti F, Mayberg HS, Wager TD, et al. Neurobiological mechanisms of the placebo effect. *Journal of Neuroscience* 2005;25(45):10390-402.
45. Kirsch I. Specifying nonspecifics: Psychological mechanisms of placebo effects. *The placebo effect: An interdisciplinary exploration* 1997:166-86.
46. Benedetti F. Mechanisms of placebo and placebo-related effects across diseases and treatments. *Annu Rev Pharmacol Toxicol* 2008;48:33-60.
47. Petrie KJ, Rief W. Psychobiological mechanisms of placebo and nocebo effects: pathways to improve treatments and reduce side effects. *Annual review of psychology* 2019;70:599-625.
48. Kirsch I. Response expectancy as a determinant of experience and behavior. *American Psychologist* 1985;40(11):1189.
49. Kirsch I. Response expectancy theory and application: A decennial review. *Applied and preventive Psychology* 1997;6(2):69-79.
50. Colloca L, Finniss D. Nocebo effects, patient-clinician communication, and therapeutic outcomes. *Jama* 2012;307(6):567-68.
51. Cormier S, Lavigne GL, Choinière M, Rainville P. Expectations predict chronic pain treatment outcomes. *Pain* 2016;157(2):329-38.
52. Sohl SJ, Schnur JB, Montgomery GH. A meta-analysis of the relationship between response expectancies and cancer treatment-related side effects. *Journal of pain and symptom management* 2009;38(5):775-84.
53. Klosterhalfen S, Enck P. Psychobiology of the placebo response. *Autonomic Neuroscience* 2006;125(1-2):94-99.
54. Colloca L, Miller FG. Harnessing the placebo effect: the need for translational research. *Philosophical Transactions of the Royal Society B: Biological Sciences* 2011;366(1572):1922-30.
55. Ader R. The role of conditioning in pharmacotherapy. *The placebo effect: An interdisciplinary exploration* 1997:138-65.
56. Colloca L, Benedetti F. How prior experience shapes placebo analgesia. *Pain* 2006;124(1-2):126-33.
57. Ader R. Conditioned responses in pharmacotherapy research. *Psychol Med* 1993;23(2):297-99.
58. Goebel MU, Trebst AE, Steiner J, et al. Behavioral conditioning of immunosuppression is possible in humans. *The FASEB journal* 2002;16(14):1869-73.
59. Hadamitzky M, Bösche K, Engler A, et al. Extinction of conditioned taste aversion is related to the aversion strength and associated with c-fos expression in the insular cortex. *Neuroscience* 2015;303:34-41.
60. Kessner S, Wiech K, Forkmann K, et al. The effect of treatment history on therapeutic outcome: an experimental approach. *JAMA Intern Med* 2013;173(15):1468-69.
61. Sandler AD, Glesne CE, Bodfish JW. Conditioned placebo dose reduction: a new treatment in ADHD? *Journal of developmental and behavioral pediatrics: JDBP* 2010;31(5):369.
62. Doering BK, Rief W. Utilizing placebo mechanisms for dose reduction in pharmacotherapy. *Trends in pharmacological sciences* 2012;33(3):165-72.
63. Colloca L, Sigaudo M, Benedetti F. The role of learning in nocebo and placebo effects. *PAIN®* 2008;136(1-2):211-18.
64. Stockhorst U, Steingrueber H-J, Enck P, Klosterhalfen S. Pavlovian conditioning of nausea and vomiting. *Autonomic Neuroscience* 2006;129(1-2):50-57.
65. Faasse K, Petrie KJ. From me to you: The effect of social modeling on treatment outcomes. *Current Directions in Psychological Science* 2016;25(6):438-43.

66. Benedetti F. Responding to nocebos through observation: social contagion of negative emotions. *Pain* 2013;154(8):1165.
67. Bajcar EA, Bąbel P. How does observational learning produce placebo effects? A model integrating research findings. *Frontiers in psychology* 2018;9:2041.
68. van Laarhoven AI, Vogelaar ML, Wilder-Smith OH, et al. Induction of nocebo and placebo effects on itch and pain by verbal suggestions. *PAIN®* 2011;152(7):1486-94.
69. Suarez-Almazor ME, Looney C, Liu Y, et al. A randomized controlled trial of acupuncture for osteoarthritis of the knee: effects of patient-provider communication. *Arthritis Care Res (Hoboken)* 2010;62(9):1229-36. doi: 10.1002/acr.2022510.1002/acr.20225. [published Online First: 2010/05/28]
70. Back AL, Arnold RM, Baile WF, et al. Approaching difficult communication tasks in oncology. *CA Cancer J Clin* 2005;55(3):164-77. doi: 10.3322/canjclin.55.3.164 [published Online First: 2005/05/14]
71. Bergqvist J, Strang P. Breast Cancer Patients' Preferences for Truth Versus Hope Are Dynamic and Change During Late Lines of Palliative Chemotherapy. *J Pain Symptom Manage* 2019;57(4):746-52. doi: 10.1016/j.jpainsymman.2018.12.33610.1016/j.jpainsymman.2018.12.336. Epub 2019 Jan 11. [published Online First: 2019/01/15]
72. Stiggelbout AM, Pieterse AH, De Haes JC. Shared decision making: concepts, evidence, and practice. *Patient education and counseling* 2015;98(10):1172-79.
73. Joosten EA, DeFuentes-Merillas L, De Weert G, et al. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychotherapy and psychosomatics* 2008;77(4):219-26.
74. Loh A, Simon D, Kriston L, Härter M. Shared decision making in medicine. *Dtsch Arztebl* 2007;104(21):1483-8.
75. van der Velden NC, Meijers MC, Han PK, et al. The effect of prognostic communication on patient outcomes in palliative cancer care: a systematic review. *Current Treatment Options in Oncology* 2020;21:1-38.
76. Buckman RA. Breaking bad news: the SPIKES strategy. *Community oncology* 2005;2(2):138-42.
77. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *The lancet oncology* 2011;12(2):160-74.
78. Götze H, Brähler E, Gansera L, et al. Anxiety, depression and quality of life in family caregivers of palliative cancer patients during home care and after the patient's death. *European journal of cancer care* 2018;27(2):e12606.
79. Sharot T, Delgado MR, Phelps EA. How emotion enhances the feeling of remembering. *Nature neuroscience* 2004;7(12):1376-80.
80. Kessels RP. Patients' memory for medical information. *Journal of the Royal Society of Medicine* 2003;96(5):219-22.
81. Schwabe L, Wolf OT. Learning under stress impairs memory formation. *Neurobiology of learning and memory* 2010;93(2):183-88.
82. Di Blasi Z, Harkness E, Ernst E, et al. Influence of context effects on health outcomes: a systematic review. *The Lancet* 2001;357(9258):757-62.
83. Mercer SW, Reynolds WJ. Empathy and quality of care. *British Journal of General Practice* 2002;52(Suppl):S9-12.

84. Jani BD, Blane DN, Mercer SW. The role of empathy in therapy and the physician-patient relationship. *Forschende Komplementärmedizin/Research in Complementary Medicine* 2012;19(5):252-57.
85. Lelorain S, Brédart A, Dolbeault S, Sultan S. A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psychooncology* 2012;21(12):1255-64. doi: 10.1002/pon.211510.1002/pon.2115. Epub 2012 Jan 11. [published Online First: 2012/01/13]
86. Decety J. Empathy in medicine: what it is, and how much we really need it. *The American journal of medicine* 2020;133(5):561-66.
87. Decety J, Fotopoulou A. Why empathy has a beneficial impact on others in medicine: unifying theories. *Frontiers in behavioral neuroscience* 2015;8:457.
88. Sanders JJ, Dubey M, Hall JA, et al. What is empathy? Oncology patient perspectives on empathic clinician behaviors. *Cancer* 2021;127(22):4258-65.
89. Swayden KJ, Anderson KK, Connelly LM, et al. Effect of sitting vs. standing on perception of provider time at bedside: a pilot study. *Patient education and counseling* 2012;86(2):166-71.
90. Hillen MA, de Haes HC, van Tienhoven G, et al. All eyes on the patient: the influence of oncologists' nonverbal communication on breast cancer patients' trust. *Breast cancer research and treatment* 2015;153:161-71.
91. Uitterhoeve R, Bensing J, Dilven E, et al. Nurse–patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication. *Psycho-oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 2009;18(10):1060-68.
92. Visser LN, Tollenaar MS, van Doornen LJ, et al. Does silence speak louder than words? The impact of oncologists' emotion-oriented communication on analogue patients' information recall and emotional stress. *Patient Education and Counseling* 2019;102(1):43-52.
93. Visser LNC, Tollenaar MS, de Haes HCJM, Smets EMA. The value of physicians' affect-oriented communication for patients' recall of information. *Patient Education and Counseling* 2017;100(11):2116-20. doi: http://dx.doi.org/10.1016/j.pec.2017.06.005
94. Evers AW, Colloca L, Blease C, et al. Implications of placebo and nocebo effects for clinical practice: expert consensus. *Psychotherapy and psychosomatics* 2018;87(4):204-10.
95. Evers AW, Colloca L, Blease C, et al. What should clinicians tell patients about placebo and nocebo effects? Practical considerations based on expert consensus. *Psychotherapy and psychosomatics* 2021;90(1):49-56.
96. Klinger R, Colloca L, Bingel U, Flor H. Placebo analgesia: clinical applications. *PAIN®* 2014;155(6):1055-58.
97. Bystad M, Bystad C, Wynn R. How can placebo effects best be applied in clinical practice? A narrative review. *Psychology Research and Behavior Management* 2015:41-45.
98. Benson S, Hagen S, Hoffmann O, et al. Can a brief psychological expectancy intervention improve postoperative pain? A randomized, controlled trial in patients with breast cancer. *Pain* 2019;160(7):1562-71.
99. Klinger R, Stuhlreyer J, Schmitz J, et al. Psychological factors in the context of perioperative knee and joint pain: the role of treatment expectations in pain evolvement. *Der Schmerz* 2019;33:13-21.
100. Rief W, Shedden-Mora MC, Laferton JA, et al. Preoperative optimization of patient expectations improves long-term outcome in heart surgery patients: results of the randomized controlled PSY-HEART trial. *BMC medicine* 2017;15(1):1-13.
101. Varelmann D, Pancaro C, Cappiello EC, Camann WR. Nocebo-induced hyperalgesia during local anesthetic injection. *Anesthesia & Analgesia* 2010;110(3):868-70.

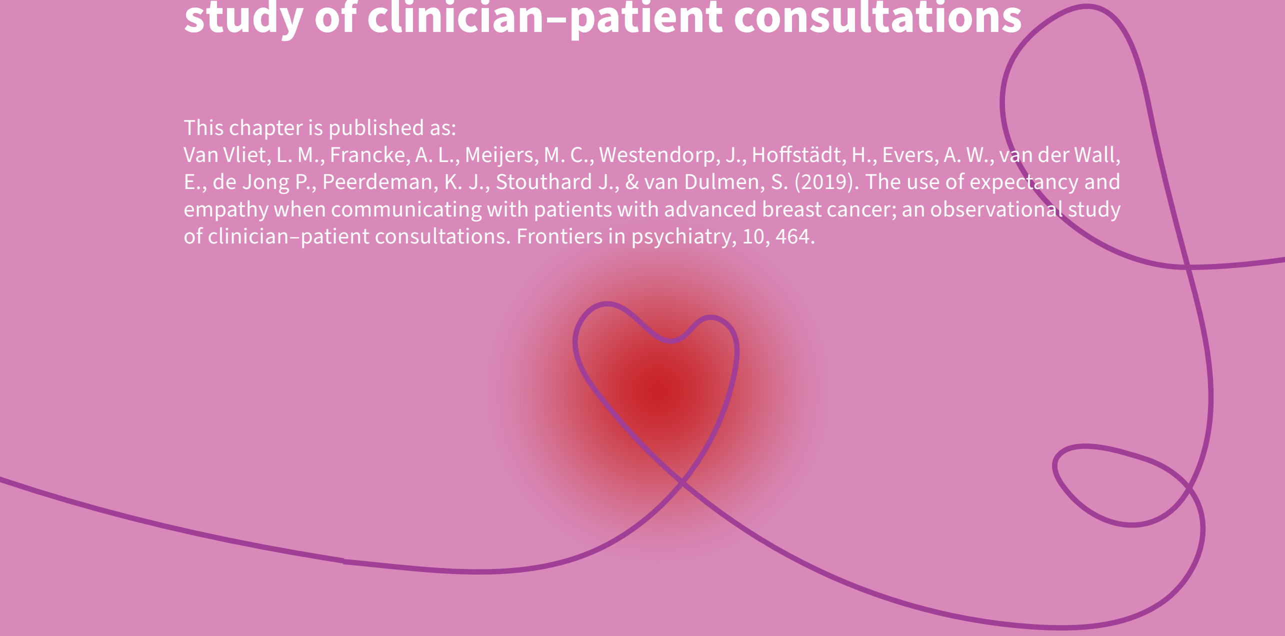
102. Colloca L, Howick J. Placebos without deception: outcomes, mechanisms, and ethics. *International review of neurobiology* 2018;138:219-40.
103. Locher C, Nascimento AF, Kirsch I, et al. Is the rationale more important than deception? A randomized controlled trial of open-label placebo analgesia. *Pain* 2017;158(12):2320-28.
104. Crum A, Zuckerman B. Changing mindsets to enhance treatment effectiveness. *Jama* 2017;317(20):2063-64.
105. Crichton F, Petrie KJ. Health complaints and wind turbines: The efficacy of explaining the nocebo response to reduce symptom reporting. *Environmental Research* 2015;140:449-55.
106. Wood FA, Howard JP, Finegold JA, et al. N-of-1 trial of a statin, placebo, or no treatment to assess side effects. *New England Journal of Medicine* 2020;383(22):2182-84.



2

The use of expectancy and empathy when communicating with patients with advanced breast cancer; an observational study of clinician–patient consultations

This chapter is published as:
Van Vliet, L. M., Francke, A. L., Meijers, M. C., Westendorp, J., Hoffstädt, H., Evers, A. W., van der Wall, E., de Jong P., Peerdeman, K. J., Stouthard J., & van Dulmen, S. (2019). The use of expectancy and empathy when communicating with patients with advanced breast cancer; an observational study of clinician–patient consultations. Frontiers in psychiatry, 10, 464.



ABSTRACT

Background: Information-provision about prognosis, treatments and side-effects is important in advanced cancer, yet also associated with impaired patient well-being. To counter potential detrimental effects, communication strategies based on placebo and nocebo effect mechanisms might be promising to apply in daily practice. This study aimed to provide more insight into how often and how oncologists use expectancy- and empathy-expressions in consultations with patients with advanced breast cancer.

Methods: 45 consultations between oncologists and patients were audiotaped. To determine how often expectancy- and empathy-expressions were used, a coding scheme was created. Most consultations (n=33) were coded and discussed by two coders, the remaining 13 by one coder. To determine how expectancy- and empathy-expressions were used, principles of inductive content analysis were followed.

Results: Discussed evaluation (i.e. scan) results were good (n=26,58%) or uncertain (n=12,27%) and less often bad (n=7,15%). Uncertain expectations about prognosis, treatment outcomes and side-effects occurred in 13,38, and 27 consultations (29%,85%,56%); followed by negative expectations in 8,26, and 28 consultations (18%,58%, 62%); and positive expectations in 6,34, and 17 consultations (13%,76%, 38%). When oncologists provided expectancy-expressions, they tapped into three different dimensions; relational, personal, explicit. Positive expectations emphasized the doctor-patient relationship, while negative expectations focused on the severity of the illness, and uncertainty was characterized by a balance between (potential) negative outcomes and hope. Observed generic or specific empathy-expressions were regularly provided, most frequently understanding (n=29,64% of consultations), respecting (n=17,38%), supporting (n=16,36%), and exploring (n=16,36%). A lack of empathy occurred less often and contained among others not responding to patients' emotional concerns (n=13,27% of consultations), interrupting (n=7,16%), and an absence of understanding (n=4,9%).

Conclusion: In consultations with mainly positive or uncertain medical outcomes, oncologists predominantly made use of uncertain expectations (hope for the best, prepare for the worst) and used several empathic behaviors. Replication studies, e.g. in these and other medical situations, are needed. Follow-up studies should test the effect of specific communication strategies on patient outcomes, to counter potential negative effects of information-provision. Studies should focus on uncertain situations. Ultimately, specific placebo and nocebo effect inspired communication strategies can be harnessed in clinical care to improve patient outcomes.

INTRODUCTION

When faced with a serious disease such as advanced breast cancer, patients need information to understand what is going on and to plan for their future.[1] Information about prognosis, treatment outcomes and plans, and benefits and risks of treatments are essential to provide optimal patient-centered care. Earlier data showed that patients having experienced adequate information about treatment benefits and risks, experienced better person-centered care.[2]

Despite its importance, information-provision is by no means a ‘magic bullet’ and also entails risks. There are several possible negative effects of information-provision in advanced cancer. Explicit information about the incurability of a disease seems appreciated by most, but not all patients.[3-5] Patients who are fully aware of their poor prognosis, are also the ones with the lowest reported quality of life and highest anxiety.[6] It is known that providing information about side-effects can increase their occurrence.[7] A large study showed, for example, that breast cancer patients with relatively higher expectations of side-effects are the ones experiencing the most side-effects.[8] While information-provision is thus one of the cornerstones of communication[9], it can also lead to negative effects on patients’ well-being.

To counter any of these potential negative effects, communication-strategies derived from placebo and nocebo mechanisms might be promising to apply in daily practice. Integrating the research worlds of communication and placebo effects is still in its infancy.[10] Placebo effects can be seen as ‘all real biopsychological effects on patient outcomes that are not attributable to a medical-technical explanation’.[11 12] The most well-known mechanism via which placebo effects occur is the expectancy-mechanism. There is ample evidence (mainly from experimental studies) that the use of positive expectations can influence clinical patients’ outcomes for the better.[13 14] For example, post-operative patients are known to experience less pain when pain medication is delivered in full view while verbally raising positive expectations about its effectiveness.[15 16] A second possible placebo effect mechanism affecting patient outcomes is the empathy-mechanism, which is only mentioned by few scholars so far.[10 17 18] From communication studies, we know that empathy is highly appreciated by patients.[3 19] From experimental studies in advanced breast cancer we know that physician empathy is capable of reducing patients’ emotional distress, while increasing information recall.[4 20 21]

It is, however, unclear if and how expectancy- and empathy-strategies are currently employed by clinicians when discussing prognosis, treatment outcomes and side-effects with patients with advanced cancer. The aim of this study is to provide more insight into *how often* and *how* oncologists use expectancy- and empathy-expressions in consultations with patients with advanced breast cancer. This study serves as a starting point for a research area aimed at creating more insight into possible beneficial placebo and nocebo effect inspired communication strategies. Future studies should test the effect of specific communication strategies on patient outcomes, before the most beneficial strategies can be harnessed in clinical care.

METHODS

Design

We conducted a multi-center observational study of consultations between 12 oncologists and 45 patients with advanced breast cancer. Consultations were audiotaped, as audio-observations provide more objective insights into communication behavior than self-reports. Data were collected between August-December 2018 at two Dutch city-based hospitals (one cancer-specific hospital and one general hospital).

Ethical approval

The study was evaluated by the Medical Ethical committee of the Netherlands Cancer Institute (NKI-AVL), which exempted the study from formal ethical approval. Both participating hospitals approved the conduct of the study in their representative hospitals. All subjects gave written informed consent in accordance with the Declaration of Helsinki.

Sample

Initial consultations for patients with advanced breast cancer (i.e. the first time that patients would be informed that their disease is incurable), or follow-up visits in which evaluation results (i.e. scan results) would be discussed were included. It is likely that in these consultations a detailed discussion of prognosis, treatment outcomes and side-effects would occur. The consultations had to include patients who were female, were ≥18 years of age, had advanced cancer in the sense that cure was no option anymore (according to the medical team), were not in the terminal phase of their disease, were cognitively able to provide consent and to complete a questionnaire, and who had command of the Dutch language.

Recruitment

The medical team of the participating hospitals screened (mostly) weekly for eligible consultations and eligible patients. If there was too little time between identification of the consultation and the opportunity to recruit patients, eligible patients were not contacted. Remaining eligible patients were contacted by a member of the hospital team with a brief introduction of the study. The contact details of interested patients were transferred to the research team who explained the study in more detail via telephone contact with the eligible patient. More specifically, patients were informed that the study focused on communication between oncologists and patients, that one consultation would be audiotaped and that participants would have to complete both a pre-consultation question and a post-consultation questionnaire (only the post-consultation questionnaire assessing patient characteristics is included in this article, as this was a descriptive study). The research team did not mention the advanced stage of the disease. Preliminary oral consent was provided via telephone, after which patients were sent a written information letter via post or e-mail, and written consent was gathered by the research team immediately pre-consultation in the waiting area of the hospital. It was stressed that participation was voluntary and that patients could always withdraw their participation. Participating oncologists also provided consent for the consultations to be audiotaped.

Sample size

Being an audio-observation study of medical consultations (i.e. medical interviews) in which communication is explored in detail, data-saturation was aimed for. Taken into account the variability in patients, oncologists and consultations we aimed for a somewhat larger sample of consultations then normally recommended[22], and aimed to include 35-40 consultations between patients and oncologists.

Outcomes

Background characteristics: Participants and consultations

Patients' sociodemographic characteristics (e.g. age, ethnicity, education) and disease characteristics (i.e. treatments currently receiving) were assessed post-consultation using a self-created questionnaire.

Characteristics of the consultation were assessed by the coding team. This included consultation time and whether the provided evaluation results (i.e. scan results) in the consultations were 'good' (e.g. regression or stable disease) 'uncertain' (e.g. clinical data from scan results and blood results are contradictory) or 'bad' (e.g. disease progression). These criteria were determined in collaboration with the practicing oncologists who were part of the research and authorship team (EvdW, PdJ, JS). The core coding team (LV, MM, JW, HH) determined together the category of each result.

Coding

To determine the occurrence of expectancy- and empathy-expressions, we created a coding scheme. This coding scheme was based on previous studies in the field of communication, and placebo and nocebo effect research (expectancy references[23-28], empathy references[4 19-21 29-35]), observations of other recorded consultations, and clinical and research expertise. See Table 1 for a more detailed overview and explanation of the coding scheme.

For the expectancy-expressions, the coding scheme addressed the number and content of oncologist-expressed positive, negative, or uncertain expectations regarding i) prognosis, ii) treatment outcomes, iii) side effects, iv) others. This latter category was created to ensure we would not miss any expectancy-expressions that could not be captured in our predefined categories. We did, however, not encounter any ‘other expectancy-expressions’, hence this is not further discussed in the Results-section.

For the empathy-expressions, the coding scheme addressed the number and content of the following oncologist-expressed empathic behaviors (irrespective of patients’ expressed emotional expression, called ‘cue’ or ‘concern’[36]; i) NURSE (Naming, Understanding, Respecting, Supporting, Exploring)[30 31]; ii) showing interest in the patient and her feelings, not just the disease[19] ; iii) not interrupting the patient (only ‘negative’ was coded); iv) other. We coded both the occurrence of an empathic behavior as well as a non-empathic behavior. We created a third response category in case patients provided an emotional expression , which was not picked up by oncologists; labeling this a ‘missed opportunity for empathy’.[37]

Table 1. Coding scheme

Codes and examples of expectancy-expressions

Code for each behavior how often it occurred and give the content (sentences) from which this became apparent.

It is possible that an oncologist provided several remarks which e.g. illustrate that he/she is positive about the treatment outcomes. If that is the case, code each unique occurrence and provide the content for each occurrence.

If there are two occurrences in one sentence, both are coded.

Positive expectancy-expressions include expressions in which an oncologist expresses positive expectations about prognosis/treatment outcomes/side effects, negative expectancy-expressions include expressions in which an oncologists expresses negative expectations about prognosis/treatment outcomes/side effects, and neutral expectancy-expressions include expressions in which an oncologist expressed neither positive nor negative but neutral expectations about prognosis/treatment outcomes/side effects.

	Positive (number + content)	**Negative (number + content)**	**Neutral (number + content)**
Prognosis ***(referring to life expectancy/incurability)***	*‘ You are an active person, that will have a positive effect (on your life-expectancy, red)’ (other taped consultation)*	*‘You are not very fit anymore (talking about prognosis)’ (other taped consultation)*	*‘Your prognosis will also depend on your physical condition, how that will develop’(expert-opinion)*
Treatment outcomes ***(referring to whether or not a treatment will work, and the possiblity of (dis) continuation of treatment)***	*‘I think this will work for you’ 24*	*‘The problem is that there is little medication that is our go-to, there is not much better I can offer you’*[25,26]	*‘It is like a lottery; for some patients the treatment will work, for others it won’t. That’s all I can say unfortunately’(expert-opinion)*
Side effects ***(mentioned with reassurance à positive might or might not happen à neutral mentioning side effect à negative)***	*‘You should not believe all information on the internet. In my experience I have seen that around 80% of women respond very well with very little side effects’ (expert-opinion)*	*‘You can also become much sicker because of the treatment’ (other taped consultation)*	*‘Fatigue can arise, but it might also not occur’ (expert-opinion)*
Other			

Codes and examples of empathy-expressions

Code for each behavior how often it occurred and give the content (sentences) from which this became apparent.

It is possible that an oncologist provided several remarks which e.g. showed an interest in a person. If that is the case, code each unique occurrence and provide the content for each occurrence.

If there are two occurrences in one sentence, both are coded.

For coding of the behaviors, it is not necessary that a patient expressed an explicit cue/concern. If a cue or concern was expressed, which was not responded upon by the oncologist, this is coded as 'missed opportunity'.

Empathic behaviour	**Yes + number/content**	**No + number/content**	**Missed opportunities**
NURSE			
a. Naming ***(mentioning the occurring emotions explicitly)***	*'It sounds like you are worried'* [30]	*'I can see you are sad, but let's talk about your medical situation' (expert-opinion)*	
b. Understanding ***(showing understanding towards the emotions)***	*'I can't imagine how difficult this news must be for you'* [31]	*'My experience is that most patients do not react to this news the way you do' (expert-opinion)*	
c. Respecting ***(giving a compliment about emotion/ response patient)***	*'I am very impressed with how well you've continued to care for your children during this long illness'* [30]	*'I think your response is a bit exaggerated' (expert-opinion)*	
d. Supporting ***(stressing that a patient will be continuously cared for by oncologist/ hospital)***	*'But whatever action we do take, and however that develops, we will continue to take good care of you. We will be with you all the way'* [4]	*'I will now refer you to the community care nurse. I will see you after the operation' (expert-opinion)*	
e. Exploring ***(exploring of further emotions)***	*'We've just discussed a lot. Tell me more about what you are feeling right now'* [31]	*'I don't have any time left unfortunately. There are more patients waiting. I will ask a nurse to contact you' (expert-opinion)*	
Showing interest in the patient and her feelings, not just the disease	*'Would you appreciate it if I would speak to your children? With or without you, whatever you prefer' (expert-opinion, based on[19])*		
Not interrupting the patient ***(only code in case of 'no)***			

Analyzing process

The actual analyzing process consisted of several steps. We followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement [38] and the Standards for Reporting Qualitative Research (SRQR) guideline[39], for the quantitative and qualitative part of the study, respectively.

Step 1: Patients' background characteristics and consultations characteristics were analyzed using descriptive statistics.

Step 2: The consultations were coded to determine how often expectancy- and empathy-expressions were used by clinicians. All consultations were transcribed verbatim and personal identifiers were removed. First, the audiotapes of the consultations were listened to and the transcripts were read several times. Next, the abovementioned coding scheme (see Table 1) was applied and all specific positive/negative/uncertain expectancy-expressions, and empathic/non-empathic behaviors including the missed opportunities for empathy were copy-pasted from Word to a dedicated Excel template in which the specific behaviors were grouped together. In addition, how often all behaviors occurred per consultation was noted. Two investigators (MM and JW) independently coded 33 out of the 45 (73%) transcripts. All transcripts and coded segments were discussed and any discrepancies were resolved through discussion until a consensus was reached. The remaining 27% (n=12) was coded by one investigator (JW). A third investigator (LV) coded all segments of a random 10% of the consultations (n=4). Agreement between the investigators for all coded segments was 96.45% (136 out of 141 segments). Descriptive statistics were used to describe how often all expectancy- and empathy-expressions occurred per consultation. To facilitate analyses, Stata 14.0 was used.

Step 3: The expectancy- and empathy-coded text segments were used to determine how oncologists use these behaviors in consultations. To do so, all the coded segments that were grouped together were explored following the principles of inductive content analysis [40]. First, in the preparation phase, the text was read several times, and two researchers (LV and JW or HH) independently wrote a memo for each subset of coded behavior, with most remarkable outcomes and sub-division of behaviors. These were discussed among the core researchers (LV, JW, MH, MM). Next, in the organizing phase, text fragment belonging together were highlighted and codes given. Emerging codes were grouped together under headings and compared to the entire dataset. In the final, reporting, phase, the final categories representing sub-forms of specific behaviors were determined. One researcher systematically coded all text (LV, communication/psychology background), while interim results were discussed among the research team (with a psychology, nursing, sociology, medicine, and communication background) to prevent one-sided interpretation of the data [41].

RESULTS

Participants

All approached oncologists participated (n=12). A total of 84 patients gave permission to be contacted by the research team. Of these, 19 gave no oral consent (they were not interested or found it too burdensome for the consultation to be audiotaped and/or to complete the questionnaires), 4 did not fulfill the inclusion criteria (e.g. they were scheduled for a check-up visit), 2 could not be reached by telephone, for 10 there were logistical problems preventing participation (e.g. there were 2 patients at the same time, the oncologist was too busy, or the consultation was cancelled), and 4 gave preliminary oral consent but withdrew their consent later. Lastly, for 2 patients who provided written consent the audio-recordings failed. Background characteristics of the remaining 45 consenting participants are displayed in Table 2.

Consultations

The consultation lasted on average 18.96 minutes (SD=8.00 range 4.43-34.83). All consultations were evaluative follow-up consultation in which evaluation results (i.e. scan results) were discussed. In 26 consultations (58%) good evaluation results were discussed, in 12 consultations (27%) uncertain evaluation results were discussed, and in 7 (15%) bad evaluation results were discussed. There were no disagreements within the coding theme when determining to which category a consultation belonged.

Table 2. Background characteristics participants

	Total (n=41*)
	M (SD)
Age	57.18 (12.20) Range 31-84
	N (%)
Marital status	
Married	27 (66)
Single (incl divorced, widowed)	14 (34
Highest Education**	
Low	-
Intermediate-1	9 (22)
Intermediate-2	18 (44)
High	14 (34)
Occupation	
Paid job	10 (24)
Disabled / Sick leave	14 (34)
Housewife	4 (10)
Retired	13 (32)
Ethnicity	
Dutch	35 (86)
Western Immigrants	5 (12)
Non-Western Immigrant	1 (2)
Treatments currently receiving***	
Chemotherapy	18 (44)
Radiotherapy	2 (5)
Hormone therapy	16 (39)
Immunotherapy	9 (22)
Operation	-
Targeted therapy	4 (9)
Symptom-oriented treatment	10 (24)
Tumor-oriented treatment possible, but refrained from	-
Tumor-oriented treatment impossible	1 (2)

**Out of the 45 participating women, 41 completed all questionnaires, data of the remaining 4 could not be retrieved. .*

***low = primary education or less*
Intermediate-1 = lower secondary
Intermediate-2 = upper secondary
High = tertiary

****Women can receive several treatments, so this does not add up to 100%*

Use of expectancy-expressions

How often are expectancy-expressions used

Positive expectations

Positive expectations about prognosis were provided in 6 (13% of) consultations, followed by positive expectations about side-effects which occurred in 17 (38% of) consultations, while in most consultations (n=34, 76%) positive expectations about treatment outcomes were provided. On average, positive expectations about prognosis and side effects occurred less than once per consultation while positive expectations about treatment outcomes occurred more than twice per consultation (see Table 3).

Negative expectations

Negative expectations about prognosis were provided in 8 (18% of) consultations, followed by negative expectations about treatment outcomes which occurred in 26 (58% of) consultations, while in 28 (62% of) consultations negative expectations about side-effects were provided. On average, negative expectations about prognosis occurred less than once while negative expectations about treatment outcomes and side effects occurred almost twice per consultation (see Table 3).

Uncertain expectations

Uncertain expectations about prognosis were provided in 13 (29% of) the consultations, followed by uncertain expectations about side effects which occurred in 27 (56% of) consultations, while in 38 (84% of) the consultations uncertain expectations about treatment outcomes were provided. On average, uncertain expectations about prognosis occurred less than once, while uncertain outcomes about treatment outcomes occurred more than four times per consultation (see Table 3).

Table 3. The occurrence of expectancy-expressions throughout the consultations

	Positive expectations			Negative expectations			Uncertain expectations		
	N (%)	**M (SD) Range**	**Examples content**	**N (%)**	**M (SD) range**	**Examples content**	**N (%)**	**M(SD) range**	**Examples content**
Prognosis	6 (13)	0.40 (1.25) 0-7	*'Yes, but wait. For the time being, you're still around'*	8 (18)	0.40 (1.03) 0-4	*'Um, well that makes that I don't think your prospect is very positive'*	13 (29)	0.8 (1.84) 0-8	*'For how long this is going to go well? I hope for a terribly long time. Can I predict it fully? No I don't know. Every time it's for me also a bit hoping that it's OK.'*
Treatment outcomes	34 (76)	2.58 (2.30) 0-10	*'No, these numbers are not disturbing at all, those tumor markers. I sometimes see numbers of 5.000 or 10.000'*	26 (58)	1.78 (2.39) 0-11	*'Um, well yes, that test result does scare me a bit, because… well, what you see on the scan is, well, that is not going well'*	38 (84)	4.29 (4.27) 0-23	*There's always a possibility that it'll work or a possibility that it won't (….): 'And then you're back at the point of this uncertainty.'*
Side effects	17 (38)	0.80 (1.24) 0-4	*'And we're finding a better balance with the side-effects'*	28 (62)	1.91 (2.37) 0-8)	*'Because for tiredness I have no miracle cure.'*	27 (56)	2.05 (2.84) 0-12	*'And some people don't experience this (side effect, red) at all and others a bit or very much (…) but there is no way to test that beforehand.'*

N = number of consultation in which specific expectancy-expression occurred
(%) = percentage of consultations in which specific expectancy-expression occurred
M = mean number of specific expectancy-expression per consultation
SD = Standard Deviation of specific expectancy-expression per consultation
Range = Range of specific expectancy-expression per consultation

How are expectancy-expressions used

When oncologists employed expectancy-expressions, they tapped into three different dimensions; i) relational; ii) personal; iii) explicit. The relational dimension refers to the extent to which expectations enhance the oncologist-patient relationship. The personal dimension refers to the extent to which expectations incorporate a personal reflection from oncologists. The explicit dimension refers to the extent to which expectations are made explicit. The different dimensions occur to various degrees within positive, negative, and uncertain expectations.

Positive expectations

Positive expectations were characterized by a high degree of – explicit – reassurance and thereby an emphasis on the doctor-patient relationship, while oncologists regularly referred to their personal thoughts and feelings. In Figure 1A these different dimensions and their overlap are visually displayed. Patients were often reassured that there are still options available, that complaints are harmless or that side effects will not be (or are not) too serious/burdensome. Such reassurance was frequently focused on very specific situations. Oncologists also regularly stressed their own thoughts and visions, which seemed to strengthen expressed positive expectations. Lastly, the doctor-patient partnership was often emphasized by referring to ‘we’.

‘I am not, I’m not worried about this at all. That scan is fine.’

‘With that reduced dose that (irritated mucous membranes, ed.) will also get better’

‘And we’re finding a better balance with the side-effects’

Example of a quote were the personal, relational and explicit dimensions come together:

‘Precisely, but just um looking into the far distance, I say yes, just carry on with it. Do we still have hormonal therapy as an alternative? Yes, if necessary we’ll use that. And if at a certain moment in time we are done with hormonal therapy, do we then still have something else? (…) Like chemo therapy? Yes. Even then there are some choices to be made and we’ll first and foremost have to make a choice that is then acceptable to you. (…) Do I have something good? Yes, I do. Is it acceptable to you? That is what we will talk about.’

Negative expectations

Negative expectations were characterized by a high degree of personal reflections, which seemed to strengthen a more or less explicit negative future vision. In Figure 1B these different dimensions and their overlap are visually displayed. Oncologists expressed their own worries, about disease progression, a lack of treatment effects or side effects by which they seemed to emphasize the severity of the situation.

‘Do you want me to honestly tell you how um I think it’ll go? (…) Yes, I’m worried about you. Whether this will turn out well, because these blood counts, those blood platelets are suddenly so low.’

‘Because for tiredness I have no miracle cure.’

Such negative expressions varied in their level of explicitness, with treatment related expectations often being expressed more implicitly than side-effect related expectations, and with prognostic related expectations being expressed both explicitly and implicitly.

‘For well, to be totally cured you have to, for that the various spots are actually too numerous.’

When all is said and done, the options I have are not infinite. Then it’ll grow and then it’ll get into your system and still further.’

With negative expectations there was much less emphasis on relationship building. In the rare occasions the relationship dimension was tapped into, oncologists seemed to either emphasize or de-emphasize the clinician-patient relationship:

‘Yes, they are really nasty jabs. I have to admit that’

Uncertain expectations

Uncertain expectations were characterized by an emphasis on what an oncologist hopes for, but cannot guarantee. While expressing such hopes, oncologists both focused on their own perceptions, making it personal, and on the positive relationship with patients. In Figure 1C these different dimensions and their overlap are visually displayed.

‘For how long this is going to go well? I hope for a terribly long time. Can I predict it fully? No I don’t know. Every time it’s for me also a bit hoping that it’s OK’

Most importantly, uncertain expectations seemed to represent a balancing act. On the one hand, patients were being prepared for negative outcomes such as a future discontinuation of treatments or occurrence of problematic side effects. On the other hand, potential possibilities were mentioned, which were not presented as ‘magic bullets’ but as a quest for a balance between treatment (intensity) and side effects.

‘So the first step is reducing the dose a bit and at a certain moment we’ll be putting in weeks of rest, with you doing two weeks followed by a week of no treatment. Um and doing so you hope that at a given time you’ll find a sort of stable situation that is doable for you, that you can get on with, doesn’t bother you too much yeah you’ll experience some bother, but something that you can get on with. If we should see that this causes problems, yeah well, then we’ll have to find the right balance, for that’s of course always what it is; the balance between side effect and effect.’

Uncertain expectations about current and future treatment options and side effects were predominantly implicit in nature, but also sometimes more explicit (especially regarding treatment outcomes). They focused on (the source of) side effects and complaints that are currently present or might develop in the future, but also on the continuation of current and future treatments.

‘And some people don’t experience this (side effect, red) at all and others a bit or very much (…) but there is no way to test that beforehand.’

‘There’s always a possibility that it’ll work or a possibility that it won’t.’ Patient: ‘Umm mm.’ Oncologist: ‘And then you’re back at the point of this uncertainty’.

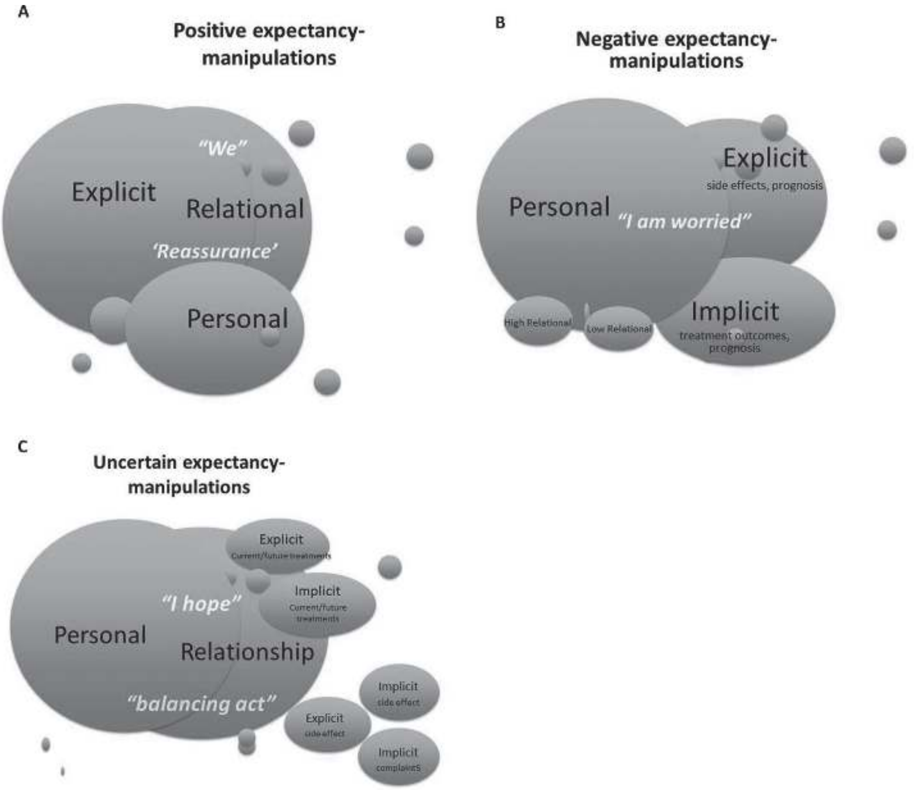


Figure 1A, 1B and 1C. Visual Representations
Figure 1A – Visual representation of the presence and overlap of the personal/relational/explicit dimensions of positive expectancy-expressions
Figure 1B – Visual representation of the presence and overlap of the personal/relational/explicit dimensions of negative expectancy-expressions
Figure 1C - Visual representation of the presence and overlap of the personal/relational/explicit dimensions of uncertain expectancy-expressions

Use of empathy-expressions

Number of expressions

Use of empathy

All studied empathy-expressions were displayed throughout the consultations, ranging from showing understanding of emotions in 29 (64% of) consultations, to the use of naming emotions in 4 (9% of) consultations. The other empathy-expressions occurred in around a third of consultations, e.g. respecting (n=17, 38%), supporting (n=16, 36%), exploring of patients' emotions (n=16, 36%), and showing interest in the patient (n=13, 29%). On average, understanding remarks occurred more than twice per consultation, while all other statements occurred generally less than once per consultation (see Table 4).

Table 4. The occurrence of empathy-expressions throughout the consultations

Empathic behaviour	**Yes + number/content**			**No + number/content**		
NURSE	N (%)	M (SD) range	Examples content	N (%)	M (SD) Range	Examples content
a. Naming *(mentioning the occuring emotions explicitly)*	4 (9)	0.09 (0.29) 0-1	*'I can hear a sigh'*	-	-	
b. Understanding *(showing understanding towards the emotions)*	29 (64)	2.27 (2.73) 0-13	*'Yes, I understand.'*	4 (9)	0.09 (0.29) 0-1	*Patient: 'Right. Um … is the therapy we're using now enough to extend my life?' Oncologist: 'Oh what a difficult question ha ha [loud laughter].'*
c. Respecting *(giving a compliment about emotion/response patient)*	17 (38)	0.69 (1.08) 0-4	*'Well I agree. I think you are handling this very very well'*	-	-	
d. Supporting *(stressing that a patient will be continuously cared for by oncologist/hospital)*	16 (36)	0.51 (1.01) 0-6	*Or you can always give me a ring.'*	1 (2)	0.02 (0.15) 0-1	*'I think that is really something for a psychologist'*
e. Exploring *(exploring of further emotions)*	16 (36)	0.47 (0.73) 0-3	*Exploring specific: And um … What do you find stressful about it? Is it such a result or is it the Nivolumab itself?*	-	-	
Showing interest in the patient and her feelings, not just the disease	13 (29)	0.62 (1.23) 0-6	*'And how many years have you been married for?'*	1 (2)	0.02 (0.15) 0-1	*Patient: 'I'll handle this again. Well, yes the oldest son has Pfeiffer disease, so… Oncologist: Yes, you mentioned that. Patient: So, yes that… Oncologist: Let's look at the blood pressure'*
Not Interrupting the patient *(only code in case of 'no')*				7 (16)	0.2 (0.5) 0-2	*Patient: 'Right, so it's not as if you spinal column as one….. 'Oncologist: 'It's counted spot by spot.'*
Missed opportunity *(only code in the case of occurrence, which is thus negative)*	12 (27)	0.89 (2.36) 0-14	*Patient: 'Aaahhh liver biopsy really is hell. But OK you're right I'm not a wimp, but I really don't like that, but well.' Oncologist: 'No, well, right.'*			

N = number of consultations in which specific empathy-expression occurred
(%) = percentage of consultations in which specific empathy-expression occurred
M = mean number of specific empathy-expression per consultation
(SD) = standard deviation of specific empathy-expression per consultation
Range = Range of number of specific empathy-expression s per consultation

Lack of empathy

Non-empathic behaviors were infrequently displayed throughout the consultation; interrupting the patient occurred in 7 (16% of) consultations, followed by 4 (9% of) consultations in which a lack of understanding occurred, while showing non-supporting statements or a lack of interest in the patient occurred in 1 consultation (2%). On average, negative behaviors occurred less than once per consultation (ranging from an average of 0.2 interruptions per consultation, to an average of 0.09 lack of showing understanding towards patient emotions per consultation). However, in more than a quarter of consultations (n=12, 27%) oncologists failed to pick-up on an emotional expression from a patient, which occurred on average 0.89 times per consultation (see Table 4).

How empathy-expressions are used

Use of empathy

When oncologists used empathy-expressions, they used several manners to do so, which are closely aligned to the coding categories; NURSE (Naming, Understanding, Respecting, Supporting, Exploring) and showing interest in the person.

The most important distinction in empathy-expressions referred to the level of specificity. Across the different NURSE categories oncologists could either be generic in their level of expressed empathy, or, alternatively, could be specific. Specific empathic behaviors were characterized by referring to specific situations, emotions, or by referring to the individual.

Understanding generic: *'Yes, I understand.'*

Understanding specific: *'Yeah, so it's really stressful, isn't it.'*

Respecting generic: *'OK, that's very good'. (responding to a patient saying she will walk the dog on the beach)*

Respecting specific: *'What an extraordinary person you are, aren't you'.*

Exploring generic: *'For um, how um do you feel about it.'*

Exploring specific: *And um … What do you find stressful about it? Is it such a result or is it the Nivolumab itself?*

When providing support, both generic and more specific statements were made that either referred to the oncologist proactively offering support, or referred to the patient proactively needing to request support.

Proactive oncologist generic: *‘Is there anything else I can do for you?’*

Proactive oncologist specific: *‘You know what, I’ll give you a call tomorrow morning to see if things are getting a bit better.’*

Proactive patient generic: *‘Oh, right. Or you can always give me a ring.’*

Proactive patient specific: *‘Um … hey, so give me a ring next week if you haven’t recovered from that flue yet.’*

Lastly, there were several ways in which oncologists showed an interest in the patient as a person. These included enquiring about holidays, patients’ loved-ones, important days coming up, and non-cancer related health problems.

‘OK, nice where are you going?’

‘And how many years have you been married for?’

Lack of empathy

Although a lack of empathy did not frequently occur, there were a few occasions in which oncologists showed little understanding of patients’ emotions by talking or laughing over them.

Patient: ‘And um … well, that vocal chord, so you’re saying I’d better see the ENT doctor.’ Oncologist: ‘We could also wait for a bit.’

Patient: ‘Right. Um … is the therapy we’re using now enough to extend my life?’ Oncologist: ‘Oh what a difficult question ha ha [loud laughter].’

The one occasion in which there was little interest in the person, occurred when an oncologist failed to enquire about an ill loved one.

Patient: ‘I’ll handle this again. Well, yes the oldest son has Pfeiffer disease, so… Oncologist: Yes, you mentioned that. Patient: So, yes that… Oncologist: Let’s look at the blood pressure’

If patients were interrupted this was mainly because oncologists seemed to complete their sentences.

Patient: 'Right, so it's not as if you spinal column as one….. 'Oncologist: 'It's counted spot by spot.'

Lastly, oncologists sometimes did not respond to patients' emotional expressions.

Patient: 'Aaahhh liver biopsy really is hell. But OK you're right I'm not a wimp, but I really don't like that, but well.' Oncologist: 'No, well, right.'

DISCUSSION

In this observational study of consultations between oncologists and patients with advanced breast cancer, we aimed to get an insight and create a better understanding into *how often* and *how* oncologists make use of expectancy- and empathy-expressions in clinical care. While there has been a recent interest in the placebo and nocebo effects of communication, and clinicians' empathic responses to patients' expressed cues and concerns have extensively been studied (see e.g. Zimmermann et al., 2007)[42], to the best of our knowledge, this is the first study to objectively determine how clinicians use expectancy- and empathy-expressions in advanced clinical breast cancer care. We found that in our sample, consisting of consultations in which mainly positive or uncertain medical outcomes were discussed, oncologists predominantly expressed uncertain expectations. Provided expectations differed in the extent to which they had a relational, personal, and explicit dimension. When expressing positive expectations, the doctor-patient relationship was emphasized, negative expectations focused on the severity of the illness, and uncertain expectations were characterized by a balance between (potential) negative outcomes and hope. Moreover, oncologists displayed several generic and specific empathic behaviors, most frequently showing an understanding towards patients' emotions. A lack of empathy was not common, but mainly included oncologists not responding to patients' emotional expressions. In sum, although various placebo- and nocebo effect inspired communication strategies were observed, their generalizability and their effects on patient outcomes remains to be determined, especially in uncertain situations with inherent uncertain expectations.

Focusing on expectancy-expressions, several of our results are noteworthy. First, most (n=26, 58%) consultations contained a 'good' medical outcome (i.e. scan results), but positive expectancy-expressions did not occur more often than negative or uncertain expectations. It might be that oncologists in our sample were reluctant to express –

overtly – positive expectations in the context of advanced cancer, as patients are known to already often hold unrealistic expectations about their disease and treatment aims.[43-45] This contrasts results from a study among heart disease patients, in which clinicians were often overly positive.[46] Indeed, oncologists place great importance on not offering false hopes.[47] Although very understandable, by refraining from positive expectations, oncologists might miss out on the potential helpful effects of this communication strategy. Patients appreciate it when clinicians are optimistic[48] and stress what can be done when facing an incurable cancer diagnosis.[3 49] Moreover, outside of the area of (advanced) cancer, positive expectations have shown to influence patient outcomes such as pain (evaluations) ([14 50], van Vliet et al., submitted) and symptom burden.[48] While it is a prerequisite that such expectations are realistic in nature, our insights suggest that there might be an – underused – potential for stressing positive aspects when communicating with patients with advanced cancer.

A second important observation was that expectation-expressions did not only differ in content (positive, uncertain, negative), but also in the dimensions of being relational, personal and explicit. By reassuring patients of the positive nature of outcomes, or by stressing that they hope for positive outcomes, oncologists in our sample did not only provide information but also seem to build a relationship, two distinct core functions of medical consultations.[9] The stressful nature of discussing bad news [51], such as a lack of further treatment options, might for some oncologists limit the ability for relationship-building when providing negative expectations. In these situations, the severity of the situation is emphasized by making use of the negative impact of self-referring (e.g. *'I am worried'*) in contrast to its optimistic impact when raising positive expectations (e.g. *'I am not worried at all'*). Interestingly, in a series of experimental studies aimed at helpful communication styles, all communication elements that led to positive effects made use of a personal account (e.g. *'I understand you're worried. We will look together at the options'*)[4 20 21 33] stressing the potential power of this dimension, also in the context of bad news. Lastly, the explicitness in which expectations were expressed varied widely, with more explicit expectations emphasizing an anticipation and implicit expectations characterizing uncertainty.

Uncertain situations seemed to be of critical importance and difficulty when raising expectations. In uncertain expectations, oncologists in our study made use of a balancing act in which they prepare patients for potential or certain negative outcomes, while simultaneously trying to offer some forms of perspective. In the literature, such an approach is called *'Hope for the best, prepare for the worst'*[52], illustrating a dual pathway followed in serious and uncertain illnesses. Previous studies have shown that patients differ in their preferences for how to handle the uncertainty of their advanced illness, with some wanting more explicit information than others.[53] Clinicians, meanwhile, are reluctant towards and have difficulty in discussing clinician uncertainty.[54 55] We indeed found that especially the level of explicitness varied widely when providing uncertain expectations, illustrating a lack of clear guidance on how to do so best. With treatment and care options in advanced cancer becoming increasingly complex, and targeted and personalized medicine options rapidly growing, there is a pressing need to develop more insight into how oncologists should best deal with uncertainty and provide expectations with an uncertain nature.

Focusing on empathy-expressions, a more straightforward picture seemed to emerge compared to expectancy-expressions. Oncologists made use of various forms of empathy, most frequently of showing understanding for patients' emotions and complimenting patients on how they handle their disease. The importance of acknowledging the emotions of patients with advanced cancer has been stressed before.[49] Noteworthy, empathic remarks varied widely in their level of specificity, e.g. *'That's good'* compared to *'You have handled situation X very well'*. As patients value to be seen and treated as an individual person[19], also when faced with an incurable cancer diagnoses[49], one could expect that more specific expressions of empathy are most appreciated and beneficial. Although intuitively logical, there is a lack of empirical evidence on the effect of more generic or specific empathic remarks.

Interestingly, while most patient complaints in medical care are about clinician communication, also in advanced illnesses (e.g.[56-58]) in our study we found that a lack of empathic communication did not often occur. There were, however, occasions in which patients' cues and concerns were not picked up by clinicians. Previous studies have shown this is not uncommon in clinical practice.[42 59] If clinicians, however, do respond to emotional expressions this can lead to positive outcomes, such as a decrease in consultation time [42], and an increase in the amount of information patients recall.[59] So, based on our results there seems to be room for improving the extent to which clinicians respond to patients' emotional expressions, leading to potentially positive effects.

Limitations

Our study has limitations. Firstly, our participants might not be representative for the entire population of people with advanced breast cancer, as they were female, highly educated, almost completely with a Dutch or other Western European background, and mainly recruited in a specialized research-focused cancer hospital. Secondly, our analyses were based on transcripts and thus verbal communication, while non-verbal elements such as eye-contact remained masked. Intonation was used in the first but not latter phases of the qualitative analyzing process, as we used the transcripts for the coding. Thirdly, as we focused on the communication within the 45 audiotaped consultations, we did not take into account the nested design of our study (expectancy- and empathy- expressions were clustered within consultations, which were clustered within oncologists, which were clustered within hospitals). The number of audiotaped consultations per oncologist ranged from 1 to 8, while 8 of the 12 participating oncologists were from the specialized hospital, implying that the communication from the oncologists with more audiotaped consultations and from the specialized hospital influenced our results more strongly. Fourthly, given our limited sample size, we did not explore differences in used manipulations between consultations with a good, bad or uncertain medical outcome. Fifthly, we only included consultations in which test results were discussed as these were the only ones identified, which potentially limits the generalizability of our results to initial consultations. Sixthly, as the research area of the placebo effects of communication is still in development, we welcomed the comment of one of the reviewers who wondered whether a comment as 'that scan is fine' is a positive expectation and hope future discussions will help to clarify the criteria under study. Seventhly, although we did not observe other categories of expectancy-expressions apart from our predefined categories, we cannot rule out that this is due to an implicit bias of the coding team, who all had a background in communication research. Our conceptualization was further hampered by a lack of a universally agreed conceptualization of expectancies (see e.g. Laferton et al.)[60] for a detailed overview). Eighthly, we did not assess what patients' information and communication preferences were. Lastly, although all approached oncologists participated, they might form a subgroup of clinicians particularly interested and competent in communication.

Future research

This study serves as a starting point for a research area aimed at creating more insight into possible beneficial placebo and nocebo effect inspired communication strategies. The most pressing question our study does not answer is which specific forms of expectancy- and empathy-expressions are most promising in countering any negative effects of information-provision, and improving advanced cancer patients' outcomes. Moreover, there is a need for a better understanding into why oncologists use specific placebo and nocebo effect inspired communication strategies, and which strategies are most appreciated by patients. These questions need to be answered in follow-up studies. Ultimately, evidence-based expectancy- and empathy-expressions should be recommended for clinical use in advanced cancer. This specifically applies to expectancy-expressions in uncertain situations, which seems to be most complex, and the effect of more generic or specific empathic behaviors. Additionally, replication studies within our and other medical and cultural contexts are needed, e.g. in other diseases of a chronic and often ultimately fatal nature, in non-Western countries, and with other participants such as men or patients with low health literacy. Furthermore, future observational studies should focus in more detail on the expressed manipulations, e.g. focus on differences between dyads, oncologists and (specialized) hospitals, differences between consultations discussing varying medical outcomes, and on sequential analyses of expressed manipulations. Such studies could also include other potential forms of expectations, such as regarding procedures, or expectations regarding patient behavior (e.g. self-efficacy).. Lastly, larger replication studies could also focus on the relation between consultation time and the use of positive expectancy- and empathy-expressions. In our sample, given the limited sample size, we explored this association, which did not seem to be present (except for the expression of positive expectations about side effects, and for showing understanding towards emotions ($p<0.01$)).

Conclusions

To conclude, our study illustrated that when discussing positive or uncertain medical outcomes in advanced breast cancer, oncologists predominantly made use of uncertain expectancy-manipulations. When providing positive expectations oncologists emphasized the doctor-patient relationship, while negative expectations focused on the severity of the illness, and the area of uncertainty was characterized by a ‘hope for the best, prepare for the worst’ approach. Moreover, empathy-manipulations were generic or specific in nature, and were dominated by oncologists showing an understanding towards patients’ emotions. A lack of empathy was uncommon, and mainly included oncologists not picking up on patients’ emotions. Follow-up studies should expand observational studies in this field, and focus on which communication strategies are most useful and influence patients’ outcomes for the better, to counter any potential negative effects of information provision. Such studies should focus especially on uncertain and complex medical situations, in which oncologists have to discuss uncertain expectations. Ultimately, specific placebo and nocebo effect inspired communication strategies can be harnessed in clinical care to improve patient outcomes.

Acknowledgements

We would like to thank all the women and the oncologists for participating. We thank Dr Annemiek van Ommen-Nijhof, Youssra Gokalp- El Benhaji and Nanine van den Ing for their help in recruitment. We thank Drs Janneke Budding for her help with translating the quotes. We thank our patient experts for their help with setting up the studies, and especially the questionnaire and patient information letters. We would like to thank Tessie October for sharing her NURSE codebook.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Funding

This study was funded by a Young Investigator Grant of the Dutch Cancer Society (number 10392) awarded to Liesbeth van Vliet.

Author contributions

LvV: conceptualization, methodology, data collection, data analyses, writing – original draft
AF: conceptualization, methodology, data analyses, writing – review and editing
MM: methodology, data collection, data analyses, writing – review and editing
JW: methodology, data collection, data analyses, writing – review and editing
HH: methodology, data collection, data analyses, writing – review and editing
AE: data analyses, writing – review and editing
EvdW: data analyses, writing – review and editing
PJ: methodology, data collection, data analyses, writing – review and editing
KP: methodology, data analyses, writing – review and editing
JS: methodology, data collection, data analyses, writing – review and editing
SvD: conceptualization, methodology, data analyses, writing – review and editing

Contribution to the field

To counter potential detrimental effects of information-provision in advanced breast cancer, communication strategies based on placebo and nocebo effect mechanisms might be promising. While there has been a recent interest in the placebo and nocebo effects of communication, we conducted the first study to provide insight into how *often* and *how* oncologists use expectancy- and empathy-expressions in consultations with patients with advanced cancer. Our study illustrated that when discussing positive or uncertain medical outcomes in advanced breast cancer, oncologists predominantly made use of uncertain expectancy-manipulations, characterized by *'hope for the best, prepare for the worst'*. Moreover, empathy-manipulations were generic or specific in nature, and dominated by oncologists' showing an understanding towards patients' emotions. A lack of empathy was uncommon, and mainly included oncologists not responding to patients' emotional expressions. This study serves as a starting point for a research area aimed at creating more insight into possible beneficial placebo and nocebo effect inspired communication strategies. Follow-up studies should focus on which communication strategies are most useful and improve patients' outcomes. Studies should focus especially on uncertain and complex medical situations, in which oncologists have to discuss uncertain expectations. Ultimately, specific placebo and nocebo effect inspired communication strategies can be harnessed in clinical care.

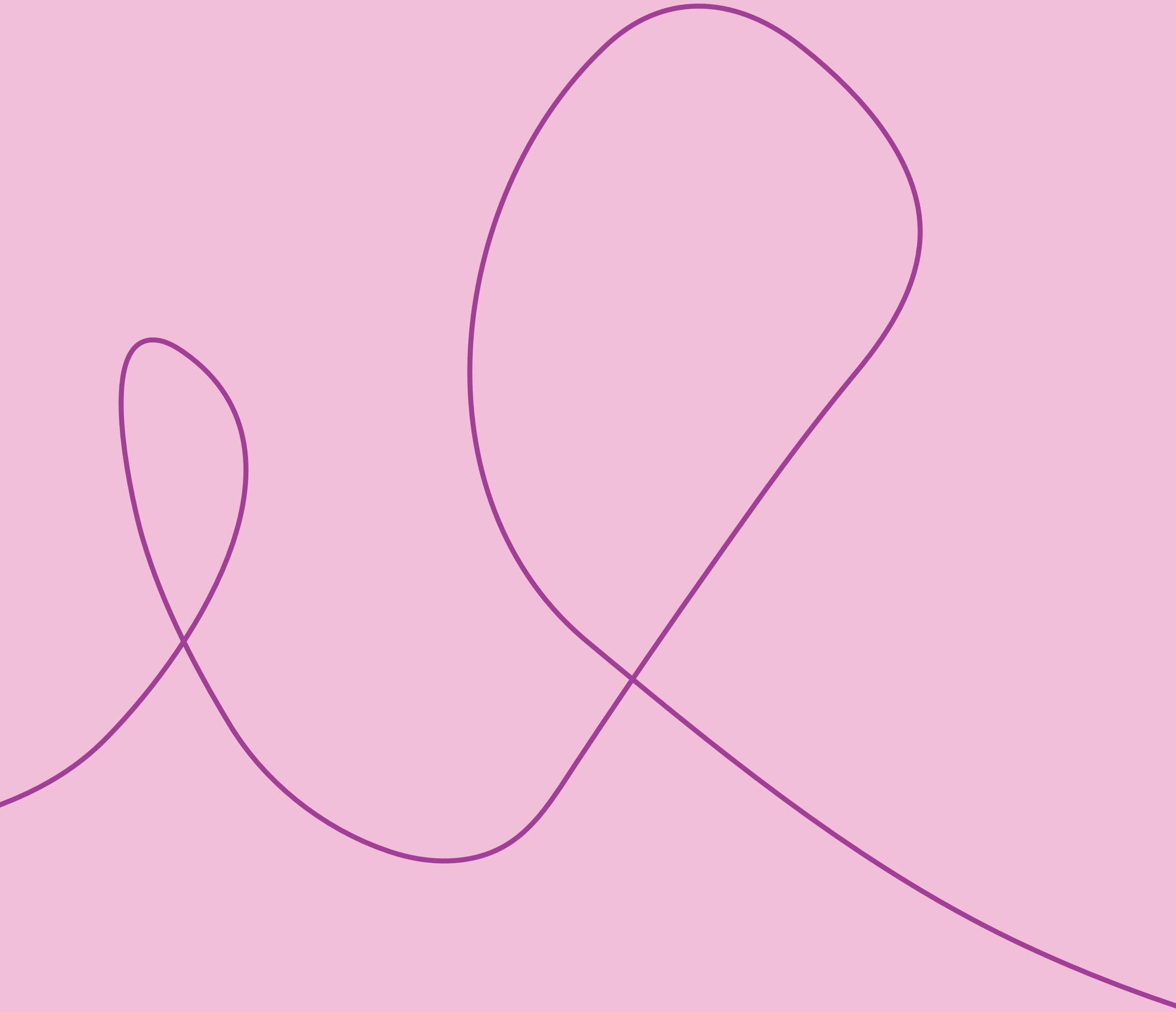
REFERENCES

1. Parker SM, Clayton JM, Hancock K, et al. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management* 2007;34(1):81-93.
2. van Vliet LMdV, A; Raijmakers, NJH; Francke, AF. Is information-provision about benefits and risks of treatment options associated with receiving person-centered care: A survey among incurably ill cancer patients. *Journal of palliative medicine* in press
3. van Vliet L, Francke A, Tomson S, et al. When cure is no option: how explicit and hopeful can information be given? A qualitative study in breast cancer. *Patient education and counseling* 2013;90(3):315-22.
4. Van Vliet LM, Van Der Wall E, Plum NM, Bensing JM. Explicit prognostic information and reassurance about nonabandonment when entering palliative breast cancer care: findings from a scripted video-vignette study. *Journal of Clinical Oncology* 2013;31(26):3242-49.
5. Leydon GM, Boulton M, Moynihan C, et al. Cancer patients' information needs and information seeking behaviour: in depth interview study. *Bmj* 2000;320(7239):909-13.
6. El-Jawahri A, Traeger L, Park ER, et al. Associations among prognostic understanding, quality of life, and mood in patients with advanced cancer. *Cancer* 2014;120(2):278-85. doi: 10.1002/cncr.28369 [published Online First: 2013/10/15]
7. Amanzio M, Corazzini LL, Vase L, Benedetti F. A systematic review of adverse events in placebo groups of anti-migraine clinical trials. *Pain* 2009;146(3):261-9. doi: 10.1016/j.pain.2009.07.010 [published Online First: 2009/09/29]
8. Nestoriuc Y, von Blanckenburg P, Schuricht F, et al. Is it best to expect the worst? Influence of patients' side-effect expectations on endocrine treatment outcome in a 2-year prospective clinical cohort study. *Annals of oncology : official journal of the European Society for Medical Oncology* 2016;27(10):1909-15. doi: 10.1093/annonc/mdw266 [published Online First: 2016/08/24]
9. de Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. *Patient education and counseling* 2009;74(3):287-94.
10. Bensing JM, Verheul W. The silent healer: the role of communication in placebo effects. *Patient education and counseling* 2010;80(3):293-99.
11. Brody H, Miller FG. Lessons from recent research about the placebo effect—from art to science. *Jama* 2011;306(23):2612-13.
12. Finniss DG, Kaptchuk TJ, Miller F, Benedetti F. Biological, clinical, and ethical advances of placebo effects. *The Lancet* 2010;375(9715):686-95.
13. Peerdeman KJ, van Laarhoven AI, Keij SM, et al. Relieving patients' pain with expectation interventions: a meta-analysis. *Pain* 2016;157(6):1179-91. doi: 10.1097/j.pain.0000000000000540 [published Online First: 2016/03/06]
14. Mistiaen P, van Osch M, van Vliet L, et al. The effect of patient-practitioner communication on pain: a systematic review. *European journal of pain (London, England)* 2015 doi: 10.1002/ejp.797 [published Online First: 2015/10/23]
15. Benedetti F, Maggi G, Lopiano L, et al. Open versus hidden medical treatments: The patient's knowledge about a therapy affects the therapy outcome. *Prevention & Treatment* 2003;6(1):1a.
16. Colloca L, Lopiano L, Lanotte M, Benedetti F. Overt versus covert treatment for pain, anxiety, and Parkinson's disease. *The Lancet Neurology* 2004;3(11):679-84.

17. Jubb J, Bensing JM. The sweetest pill to swallow: How patient neurobiology can be harnessed to maximise placebo effects. *Neuroscience & Biobehavioral Reviews* 2013;37(10):2709-20.
18. Kaptchuk TJ, Kelley JM, Conboy LA, et al. Components of placebo effect: randomised controlled trial in patients with irritable bowel syndrome. *Bmj* 2008;336(7651):999-1003.
19. Bensing JM, Deveugele M, Moretti F, et al. How to make the medical consultation more successful from a patient's perspective? Tips for doctors and patients from lay people in the United Kingdom, Italy, Belgium and the Netherlands. *Patient Educ Couns* 2011;84(3):287-93. doi: 10.1016/j.pec.2011.06.008 [published Online First: 2011/07/29]
20. Sep MS, van Osch M, van Vliet LM, et al. The power of clinicians' affective communication: How reassurance about non-abandonment can reduce patients' physiological arousal and increase information recall in bad news consultations. An experimental study using analogue patients. *Patient Education and Counseling* 2014
21. van Osch M, Sep M, van Vliet LM, et al. Reducing patients' anxiety and uncertainty, and improving recall in bad news consultations. *Health Psychology* 2014;33(11):1382.
22. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field methods* 2006;18(1):59-82.
23. Petersen GL, Finnerup NB, Grosen K, et al. Expectations and positive emotional feelings accompany reductions in ongoing and evoked neuropathic pain following placebo interventions. *PAIN®* 2014;155(12):2687-98.
24. Suarez-Almazor ME, Looney C, Liu Y, et al. A randomized controlled trial of acupuncture for osteoarthritis of the knee: Effects of patient-provider communication. *Arthritis care & research* 2010;62(9):1229-36.
25. Verheul W, Sanders A, Bensing J. The effects of physicians' affect-oriented communication style and raising expectations on analogue patients' anxiety, affect and expectancies. *Patient education and counseling* 2010;80(3):300-06.
26. van Osch M, van Dulmen S, van Vliet L, Bensing J. Specifying the effects of physician's communication on patients' outcomes: A randomised controlled trial. *Patient Education and Counseling* 2017
27. Gryll SL, Katahn M. Situational factors contributing to the placebos effect. *Psychopharmacology* 1978;57(3):253-61. [published Online First: 1978/05/31]
28. Colagiuri B, McGuinness K, Boakes RA, Butow PN. Warning about side effects can increase their occurrence: an experimental model using placebo treatment for sleep difficulty. *Journal of psychopharmacology (Oxford, England)* 2012;26(12):1540-7. doi: 10.1177/0269881112458730 [published Online First: 2012/09/21]
29. Visser LNC, Tollenaar MS, van Doornen LJP, et al. Does silence speak louder than words? The impact of oncologists' emotion-oriented communication on analogue patients' information recall and emotional stress. *Patient Educ Couns* 2018 doi: 10.1016/j.pec.2018.08.032 [published Online First: 2018/09/19]
30. Back AL, Arnold RM, Baile WF, et al. Approaching difficult communication tasks in oncology. *CA Cancer J Clin* 2005;55(3):164-77. doi: 10.3322/canjclin.55.3.164 [published Online First: 2005/05/14]
31. van Vliet LM, Epstein AS. Current state of the art and science of patient-clinician communication in progressive disease: patients' need to know and need to feel known. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology* 2014;32(31):3474-8. doi: 10.1200/jco.2014.56.0425 [published Online First: 2014/10/01]

32. October TW, Dizon ZB, Arnold RM, Rosenberg AR. Characteristics of physician empathetic statements during pediatric intensive care conferences with family members: A qualitative study. *JAMA Network Open* 2018;1(3):e180351. doi: 10.1001/jamanetworkopen.2018.0351
33. Hillen M, de Haes H, Stalpers L, et al. How can communication by oncologists enhance patients' trust? An experimental study. *Annals of oncology* 2014;25(4):896-901.
34. Mazzi MA, Bensing J, Rimondini M, et al. How do lay people assess the quality of physicians' communicative responses to patients' emotional cues and concerns? An international multicentre study based on videotaped medical consultations. *Patient education and counseling* 2013;90(3):347-53.
35. Marvel MK, Epstein RM, Flowers K, Beckman HB. Soliciting the patient's agenda: have we improved? *Jama* 1999;281(3):283-87.
36. Zimmermann C, Del Piccolo L, Bensing J, et al. Coding patient emotional cues and concerns in medical consultations: the Verona coding definitions of emotional sequences (VR-CoDES). *Patient Educ Couns* 2011;82(2):141-8. doi: 10.1016/j.pec.2010.03.017 [published Online First: 2010/05/01]
37. Curtis JR, Engelberg RA, Wenrich MD, et al. Missed opportunities during family conferences about end-of-life care in the intensive care unit. *American journal of respiratory and critical care medicine* 2005;171(8):844-9. doi: 10.1164/rccm.200409-1267OC [published Online First: 2005/01/11]
38. Von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Annals of internal medicine* 2007;147(8):573-77.
39. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for reporting qualitative research: a synthesis of recommendations. *Academic medicine : journal of the Association of American Medical Colleges* 2014;89(9):1245-51. doi: 10.1097/acm.0000000000000388 [published Online First: 2014/07/01]
40. Elo S, Kyngäs H. The qualitative content analysis process. *Journal of advanced nursing* 2008;62(1):107-15.
41. Strauss A, Corbin J. Basics of qualitative research: Sage publications 1990.
42. Zimmermann C, Del Piccolo L, Finset A. Cues and concerns by patients in medical consultations: a literature review. *Psychological bulletin* 2007;133(3):438.
43. Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *New England Journal of Medicine* 2012;367(17):1616-25.
44. Yennurajalingam S, Rodrigues LF, Shamieh O, et al. Perception of curability among advanced cancer patients: An international collaborative study. *The oncologist* 2018;23(4):501-06.
45. Chen AB, Cronin A, Weeks JC, et al. Expectations about the effectiveness of radiation therapy among patients with incurable lung cancer. *Journal of Clinical Oncology* 2013;31(21):2730.
46. Hauptman PJ, Chibnall JT, Guild C, Armbrecht ES. Patient perceptions, physician communication, and the implantable cardioverter-defibrillator. *JAMA internal medicine* 2013;173(7):571-77.
47. Clayton JM, Butow PN, Arnold RM, Tattersall MH. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer* 2005;103(9):1965-75. doi: 10.1002/cncr.21011 [published Online First: 2005/03/25]
48. Little P, Everitt H, Williamson I, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *Bmj* 2001;323(7318):908-11.
49. Hagerty RG, Butow PN, Ellis PM, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *Journal of clinical oncology* 2005;23(6):1278-88.

50. Peerdeman KJ, van Laarhoven AI, Keij SM, et al. Relieving patients' pain with expectation interventions: a meta-analysis. *Pain* 2016;157(6):1179-91.
51. Baile WF, Lenzi R, Parker PA, et al. Oncologists' attitudes toward and practices in giving bad news: an exploratory study. *Journal of Clinical Oncology* 2002;20(8):2189-96.
52. Back AL, Arnold RM, Quill TE. Hope for the best, and prepare for the worst. *Annals of internal medicine* 2003;138(5):439-43.
53. Etkind SN, Bristowe K, Bailey K, et al. How does uncertainty shape patient experience in advanced illness? A secondary analysis of qualitative data. *Palliative medicine* 2017;31(2):171-80.
54. Tai-Seale M, Stults C, Zhang W, Shumway M. Expressing uncertainty in clinical interactions between physicians and older patients: what matters? *Patient education and counseling* 2012;86(3):322-28.
55. Barclay S, Momen N, Case-Upton S, et al. End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. *Br J Gen Pract* 2011;61(582):e49-e62.
56. Pincock S. Poor communication lies at heart of NHS complaints, says ombudsman. *BMJ: British Medical Journal* 2004;328(7430):10.
57. Abdelrahman W, Abdelmageed A. Understanding patient complaints. *BMJ* 2017;356:j452.
58. Cohen-Mansfield J, Skornick-Bouchbinder M, Cohen R, Brill S. Treatment and communication– that is what matters: An analysis of complaints regarding end-of-life care. *Journal of Palliative Medicine* 2017;20(12):1359-65.
59. Jansen J, van Weert JC, de Groot J, et al. Emotional and informational patient cues: the impact of nurses' responses on recall. *Patient education and counseling* 2010;79(2):218-24.
60. Laferton JA, Kube T, Salzmann S, et al. Patients' expectations regarding medical treatment: a critical review of concepts and their assessment. *Frontiers in psychology* 2017;8:233.



3

The power of clinician-expressed empathy to increase information recall in advanced breast cancer care: an observational study in clinical care, exploring the mediating role of anxiety

This chapter is published as:
Westendorp, J., Stouthard, J., Meijers, M. C., Neyrinck, B. A., de Jong, P., van Dulmen, S. & van Vliet, L. M. (2021). The power of clinician-expressed empathy to increase information recall in advanced breast cancer care: an observational study in clinical care, exploring the mediating role of anxiety. Patient education and counseling, 104(5), 1109-1115.

ABSTRACT

Objective: Experimental studies have found that clinician-expressed empathy improves patients' information recall in (advanced) cancer consultations. Whether these results are generalizable to clinical care and, if so, what the underlying mechanism is, remains unclear. We aimed to: i) determine the relationship between clinician-expressed empathy and patients' information recall in clinical advanced cancer consultations; and ii) test whether the relationship between clinician-expressed empathy and recall is mediated by a decrease in patients' anxiety.

Methods: Forty-one consultations between oncologists and female patients with advanced breast cancer were audio recorded. Patients' post-consultation information recall and pre- and post-consultation anxiety (0-100) were assessed. Objective information recall (self-created coding scheme) and clinician-expressed empathy (0-100) were coded. Structural Equation Modelling was used for all analyses.

Results: Participants remembered 61% of the discussed information Clinician-expressed empathy significantly increased patients' total information recall (p=.041) and recall of treatment aims/positive effects (p=.028). The mediating role of anxiety could not be established.

Conclusion: Although the underlying mechanism remains unclear, clinicians have a powerful tool to improve seriously ill cancer patients' recall of provided information: empathy.

Practice implications: Clinicians can be encouraged to express empathy in consultations with patients with advanced cancer, which can improve recall and consequently well-informed decision-making.

INTRODUCTION

In advanced cancer care consultations, patients have to remember information about treatment aims, options and side effects in order to make treatment-decisions and cope with being incurably ill.[1-3] Information recall might, however, be poor with 40-80 percent of information provided during cancer consultations being forgotten.[4-6] This seems to apply especially to information about treatment options, treatment aims, positive and side effects of treatments but less so to information about the diagnosis.[5 7] A reason for patients' impaired recall of medical information may be found in high emotional stress during consultations[8], impairing the processing of information.[9 10] According to *attentional narrowing,* the dual task of dealing with stress while processing information leads to deteriorated storage of information.[6 8] Reducing patients' emotional distress during consultations may therefore enhance patients´ recall of medical information.

One of the most powerful ways to reduce emotional stress in consultations is the use of empathy.[11-14] Recent experimental video-vignette studies have indeed found that when oncologists use more empathic communication, such as providing reassurance and attentive silence, information recall increases in the setting of advanced cancer[15-18]). At the same time, an older systematic review in clinical care failed to find an association between empathy and recall, although this review focused on the entire cancer trajectory.[19] So, the question remains whether clinician-expressed empathy in clinical – opposed to experimental - advanced cancer consultations has the power to influence patients' recall for the better.

Moreover, the possible mechanism behind a potential positive effect of clinician-expressed empathy on recall needs to be established. The aforementioned experimental studies indeed found that empathy decreased participants' emotional distress.[15 16 20] However, there was no conclusive evidence for a mediating effect of decreased emotional distress on the relationship between clinician-expressed empathy and information recall.[16 18] Whether this mechanism is present in clinical consultations with naturally higher emotions, needs to be explored.

Against this background, the aim of this study in clinical care is twofold: i) determine the relationship between clinician-expressed empathy and patients' information recall in clinical advanced cancer consultations; and ii) test whether the relationship between clinician-expressed empathy and recall is mediated by a decrease in patients' anxiety. Providing insight into these aims is important, as it can help shed light on whether – and how - empathy might lead to patients better understanding their illness and treatment options, which in turn could lead to more informed care decisions.

MATERIALS AND METHODS

Design and ethics

This study has an observational design using audio-recorded consultations between clinicians (oncologists) and patients with advanced breast cancer. Audio-observations were used because they provide a more objective view of communication behaviour than self-reports. Between August 2018 and December 2018 the data were collected at two Dutch hospitals (one cancer-specific hospital and one general hospital). The method has also been described in detail elsewhere.[21] [22] The study was submitted to the Ethical Committee of the Dutch Cancer Hospital, who redeemed the study from formal ethical approval [P18LVW]. Both participating hospitals approved the conduct of the study in their hospitals.

Female patients (>18 years) with incurable breast cancer (as determined by the clinical team), who had sufficient Dutch language skills and were cognitively able to give consent and fill in a questionnaire were eligible for participation. Moreover, only first consultations in which the incurable diagnosis was discussed, or evaluative follow-up consultations which included test-results, were included as it is likely that in these consultations treatment aims, options and side effects are discussed (which were the topics of the recall questionnaire). Short check-up consultations and consultations with patients in the terminal phase of their disease were excluded from this study.

Procedure

Patients were approached by the medical teams from the participating hospitals. Eligible patients were called by the medical team who briefly introduced the study. If patients were interested in participating, their contact details were transferred to the research team who called the patient and explained the details of the study. Patients were told that (1) the study was about communication between oncologists and breast cancer patients, and (2) the next consultation with their oncologist would be audio recorded. Information about the incurable nature of their disease was omitted. Patients were informed that they had to complete two questionnaires; one short questionnaire (including one question) pre-consultation and one more extensive (<20 min) questionnaire post-consultation. If patients gave preliminary oral informed consent through the telephone, they were sent an information letter (via post or e-mail). The medical team was informed of (preliminary) participation and written informed consent was gathered immediately pre-consultation in the hospital's waiting room. Patients were ensured that participation was anonymous and voluntary; they could always withdraw their participation.

Measurements

Questionnaires were developed in collaboration with patient representatives.

Background characteristics

In the post-consultation questionnaire, participants reported their sociodemographic characteristics (age, education, marital status, ethnicity and occupation) and medical information (currently received treatments).

Clinician-expressed empathy

Clinician-expressed empathy was assessed by the research team using a 0-100 Visual Analogue Scale (VAS; 'not at all'-'very much'). To determine an empathy score, several behaviours were taken into account[19 23]: showing interest in the patient beyond their disease, not interrupting the patient, oncologists' tone of voice and empathic responses to patient-expressed emotions. For this latter element, the NURSE model was used: Naming, Understanding, Respecting, Supporting and Exploring.[24 25] Examples of the NURSE model are displayed in Box 1. Clinician-expressed empathy was coded in 33/45 (73%) of the consultations by two researchers (MM, JW) and their scores were averaged (correlation between the two coders was high; r=.69, p<.001). The remaining 12 (27%) consultations were rated by one researcher (JW).

Box 1. Examples of the NURSE model

NURSE components*	Examples†
Naming (mentioning the occurring emotions explicitly)	"You seem very upset by the news."
Understanding (showing understanding towards the emotions)	"I can't imagine how difficult this news must be for you."
Respecting (giving a compliment about emotion/ response of the patient)	"You've done such a good job in coping thus far with the situation."
Supporting (stressing that a patient will be continuously cared for by oncologist/hospital)	"No matter what happens, we are going to be here to support you and your family through this."
Exploring (exploring of further emotions)	"What are your most pressing concerns?"

*Adapted from: [21 24]
† Adapted from: [24-26]

Patients' information recall

Post-consultation, patients' recall of provided information was assessed using a combination of closed and open-ended self-created questions. There were four recall categories: *i) treatment options, ii) treatment aims, iii) positive effects of the treatment, iv) side effects of the treatment*. Using transcribed consultations, the research team coded the provided information of oncologists about treatment options, aims/positive effects and side effects. 73% of the consultations were double coded and discussed by two researchers (JW, MM). The remaining 27% of the consultations were coded by one researcher (JW). The used coding scheme was based on previous recall studies.[5 15-18] Every coded information category from the transcripts was compared with the patient questionnaire assessing recall. The categories *treatment aims* (e.g. disease stabilisation) and *positive effects* (e.g. better quality of life) were grouped together (into *recall aims/positive effects)* as the coding process revealed patients had difficulty to distinguish the two. Item scores of the *treatment options* (multiple-choice question) could be recalled correctly (1 point) or not (0 points). Item scores of the *treatment aims/positive effects* and *side effects* (open-ended questions) ranged from not (0 points), partially (1 point), to completely (2 points) recalled. Two coders (JW and ML) coded all responses and discrepancies were discussed with another researcher (LV) until consensus was reached.

Patients' anxiety

To measure patients' anxiety pre- and post-consultation, participants completed a 1-item Visual Analogue Scale (VAS), i.e. "Can you indicate how anxious you are at the moment?" (0-100 range 'not at all'-'very much').[27] Pre-consultation anxiety was assessed in the waiting room, post-consultation anxiety was assessed at home. The pre-post-consultation difference score was used in all analyses.

Data analysis

Data preparation

84 patients in total gave permission to be contacted by the research team. 19 of them gave no oral consent, 4 did not fulfil the inclusion criteria (e.g. they were scheduled for a check-up visit), 2 could not be contacted, 10 dropped out due to logistical problems preventing participation (e.g. there were 2 patients at the same time or the consultation was cancelled), 4 withdrew their consent later and 4 patients did not complete all questionnaires.[21] Data of the remaining 41 participants were used in the analysis. The correct percentage recall was calculated using the following formula (individual score/maximum possible score) x 100.[16] Participants' pre- and post-anxiety levels and their post-pre difference score were determined.

Statistical analysis

First, patients' socio-demographics, and the levels of clinician-expressed empathy, patients' recall and anxiety were determined. To compare pre- and post-consultation anxiety levels a paired sample *t* test was used. Second, the association between clinician-expressed empathy and recall was tested with linear regression analyses. Third, the total and direct effects of empathy (via patients' anxiety) on recall were tested using multiple regression analyses, where empathy was added in the first step as a predictor, and patients' anxiety was added in the second step. Structural Equation Modelling (SEM) was used to investigate the total, direct and indirect effects.[28] The total effect refers to the specific relationship between clinician-expressed empathy and patients' information recall without accounting for patients' anxiety levels. The direct effect refers to predicting information recall based on empathy while controlling for anxiety levels. The indirect effect refers to the effect of empathy on information recall via patients' anxiety.[29] For performing all data analyses STATA 14.0 was used, with two-sided significance testing at p<0.05.

RESULTS

Participants

All approached clinicians (oncologists) participated (n=12). Background characteristics of the included 41 patients are summarized Table 1 (n=41, re-used from:[21]). Mean age of the participants was 57 years old (SD=12.20, range:31-84).

Table 1. Participants' background characteristics

	N (%)
Highest Education	
Low (primary education or less)	-
Intermediate-1 (lower education)	9 (22)
Intermediate-2 (upper secondary)	18 (44)
High	14 (34)
Occupation	
Paid job	10 (24)
Disabled / Sick leave	14 (34)
Housewife	4 (10)
Retired	13 (32)
Marital status	
Married	27 (66)
Single	14 (34)
Ethnicity	
Dutch	35 (86)
Western Immigrant	5 (12)
Non-Western Immigrant	1 (2)
Treatments currently receiving*	
Chemotherapy	18 (44)
Radiotherapy	2 (5)
Hormone therapy	16 (39)
Immunotherapy	9 (22)
Operation	-
Targeted therapy	4 (9)
Symptom-oriented treatment	10 (24)
Tumor-oriented treatment possible, but refrained from	-
Tumor-oriented treatment impossible	1 (2)

* Women can receive several treatments, so this does not add up to 100%
This table is re-used from: van Vliet et al., 2019 [21]

Clinician-expressed empathy

Clinicians' mean empathy score was 59.44 (SD=17.98, range: 19-83).

Patients' information recall

In total, participants remembered 61% of the discussed information about treatment options, aims/positive effects and side effects. Recall was best for information about treatment options (77%) followed by treatment aims/positive effects information (63%) and least for information about side effects (40%) (see Table 2).

Table 2. Participants' information recall

	N	Mean % (*SD*)
Recall Total (possible range: 0-100)*	40	61 (38.52)
Recall Treatment options (possible range: 0-100)	40	77 (32.94)
Recall aims/positive effects (possible range: 0-100)	28	63 (42.12)
Recall side effects (possible range: 0-100)	30	40 (45.58)

* in all recall categories minimum was 0 and maximum was 100

Patients' anxiety

Patients' anxiety decreased with 27.48 points from before to after the consultation (pre-consultation: *M*=57.41, *SD*=28.88, 0-100 range; post-consultation: *M*= 29.37, *SD*=25.80, 0-83 range). This decrease was significant: t(40)=-5.77, *p*<.001, 95% CI [-37.11, -17.86].

Recall of provided information

Effect of clinician-expressed empathy on recall

As displayed in Table 3 (see total effects), the use of more empathy led to increased information recall (*p*=.040). Focussing on the different categories of information, empathy significantly influenced recall of treatment aims/positive effects (*p*=.030), but not recall of treatment options (*p*=.120) and side effects (*p*=.130). Also shown in Table 3, the direct effects of empathy (controlled for anxiety) on total recall and recall of treatment aims/positive effects remained a trend towards significance (p<.10). Figure 1 schematically displays the results of the SEM analyses of total recall (total, direct and indirect effects).

Mediating effect of anxiety on recall

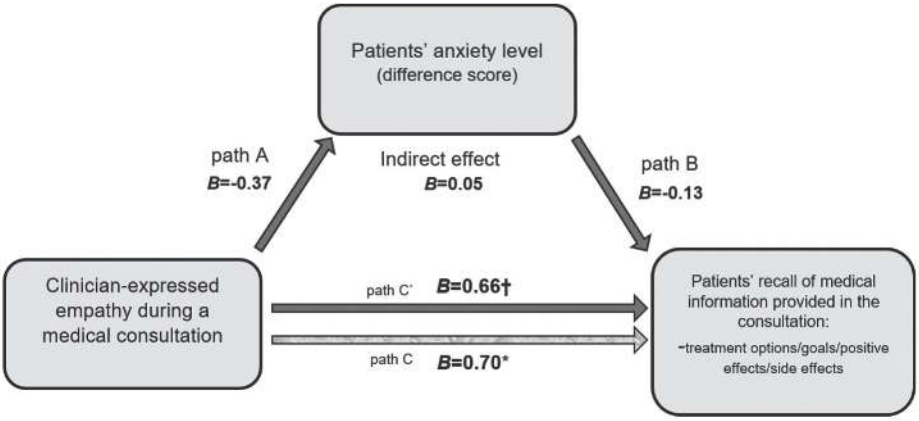
As shown in Table 3 (see indirect effects) and Figure 1, anxiety did not mediate the relationship between clinician-expressed empathy and recall as the indirect effects of all individual parts and total recall were close to zero and non-significant.

Table 3. Direct effect, indirect effect and total effects of empathy on recall

	Direct[1]			Indirect[2]			Total[3]		
	B	*p*	[95% CI]	*B*	*p*	[95% CI]	*B*	*p*	[95% CI]
Recall treatment options	0.38	.206	[-0.21, 0.97]	0.08	.342	[-0.09, 0.26]	0.46	.123	[-0.13, 1.05]
Recall aims/ positive effects	0.69	.061†	[-0.03, 1.41]	0.19	.315	[-0.18, 0.56]	**0.88**	**.028 ***	**[0.10, 1.66]**
Recall side effects	0.80	.084†	[-0.11, 1.70]	-0.10	.434	[-0.37, 0.16]	0.69	.129	[-0.20, 1.59]
Recall total	0.66	.061†	[-0.03, 1.34]	0.05	.564	[-0.11, 0.21]	**0.70**	**.041***	**[0.03, 1.38]**

* *p* <.05
† *p* <.10
[1] Directs effects are the effects of empathy on recall controlled for anxiety
[2] Indirect effects are the effects of empathy on recall via patients’ anxiety
[3] Total effects are the effects of empathy on recall uncontrolled for anxiety

Figure 1. SEM analysis results of hypothesized relationship between empathy and total recall via anxiety



* *p* <.05
† *p* <.10

DISCUSSION AND CONCLUSION

Discussion and limitations

This observational study of consultations between oncologists and patients with advanced breast cancer aimed to i) determine the relationship between clinician-expressed empathy and patients’ information recall in clinical advanced cancer consultations; and ii) test whether the relationship between clinician-expressed empathy and recall is mediated by a decrease in patients’ anxiety. Our results revealed that clinician-expressed empathy positively influenced patients´ recall in clinical practice; more specifically, both the total amount of information and more specifically the information about treatment aims/positive effects were better remembered after consultations in which more empathy was expressed. These effects, however, could not be explained by a decrease in patients´ anxiety level.

This clinical study mirrors what various experimental studies have shown previously [15 16 18], namely that empathic communication positively influences recall of information in the advanced cancer setting. They are also in line with the clinical study of Jansen et al. [30], demonstrating that nurses' empathic responses to patients' emotional cues increased cancer patients' information recall. Interestingly, they illustrate that empathy might be most important in the more advanced phase of cancer, as the aforementioned systematic review [19] failed to find a clear positive association between empathy and recall focused on the entire cancer journey spectrum.

Focussing on the different categories of recall, the total recall average of 61% is also in line with previous findings [6 31]. However, especially aims and positive effects of treatments were better remembered following empathy, in contrast to information about side effects and treatment options. This contradicts findings from a previous experimental study [16], which did found an effect of empathy on recall of treatment options. This opposite result might be explained by the fact that we also included follow-up consultations in comparison to the initial bad news consultations used by van Osch et al. [16] and conducted a study in clinical care. Patients might have received information in previous consultations already, leading to increased recall. Indeed, 77% of information about treatment options was correctly remembered in this study.

Although clinician-expressed empathy has an effect on patients' recall, the expected mediating effect of a decrease in patient anxiety could not be established. This is in line with two earlier experimental studies [16 18]. It might be that a decrease in anxiety is not the mechanism by which empathy increases recall. Alternatively, we might speculate that anxiety is just a small part of a bigger mechanism, such as a good overall therapeutic relationship (consisting of knowledge, trust, loyalty and regard) [32], which might have a positive effect on patients' information recall. This, however, remains open for further investigation.

Our study has limitations. Firstly, using a clinical design we could not control for all variables; e.g. levels of empathy and provided information varied per consultation, and patients' recall might have been influenced by information discussed in earlier consultations. That being said, being it a study in clinical care, our results have high ecological validity. Secondly, empathy was assessed by observers, whose perspective might differ from patients' perspectives. However, using an objective assessment does imply that all consultations were rated with the same outlook, making it possible to provide more specific recommendations on how to use empathy (e.g. by using NURSE statements) and overcomes possible halo-effects in patient evaluations [24 33]. Thirdly, our limited sample consisted of mainly high educated females recruited in a specialized cancer hospital, limiting generalizability of results. Fourthly, non-verbal empathic communication was omitted in our analyses as we used audio recorded consultations, while these elements are a crucial part of affective communication [34 35] and might improve patient recall [18]. Lastly as we used questionnaires to assess recall, it was sometimes difficult to establish whether patients really understood the information.

Future studies should overcome these limitations by including a larger population of more diverse patients, by making use of video recorded consultations to include non-verbal communication and by assessing recall with real-life or telephoned interviews for obtaining more in-depth data. Most importantly, more research is needed to discover the underlying mechanism of how empathy can improve patients' information recall. Anxiety may be a small part of a more comprehensive mechanism that can be influenced by empathy (such as the therapeutic relationship, which can be assessed by the Human Connection Scale [36]).

Conclusion

Although the underlying mechanism remains unclear, results from the current observational study illustrate the power of clinician-expressed empathy during consultations with seriously ill patients. With the use of empathy, clinicians can influence patients' recall of provided medical information.

Practice implications

Clinicians can be encouraged to display empathy in consultations with patients with advanced cancer. To do so, short and practical communication training might be promising [37 38]. Such training might integrate the NURSE model [24 25], also used to determine empathy levels in our study. Ultimately this might lead to improved recall of provided information, leading to more well-informed (shared) decision making.

Funding

This study was funded by a Young Investigator Grant of the Dutch Cancer Society (number 10392) awarded to Liesbeth van Vliet. LV is also supported by the Netherlands Institute for Advanced Study in the Humanities and Social Sciences (NIAS-KNAW).

CRediT authorship contribution statement

J. Westendorp: Methodology, Formal Analysis, Investigation, Data Curation, Writing – original draft, Writing – review & editing, Validation. **J. Stouthard**: Methodology, Resources, Writing – review & editing. **M. C. Meijers**: Methodology, Investigation, Project Administration, Data Curation, Writing – review & editing, Validation. **B. A. M. Neyrinck**: Supervision, Writing – review & editing. **P. de Jong:** Methodology, Resources, Writing –

Review & Editing. **S. van Dulmen**: Conceptualisation, Methodology, Writing – review & editing. **L. M. van Vliet**: Conceptualisation, Methodology, Investigation, Data Curating, Writing – review & editing, Supervision, Validation, Project Administration, Funding Acquisition.

Acknowledgements

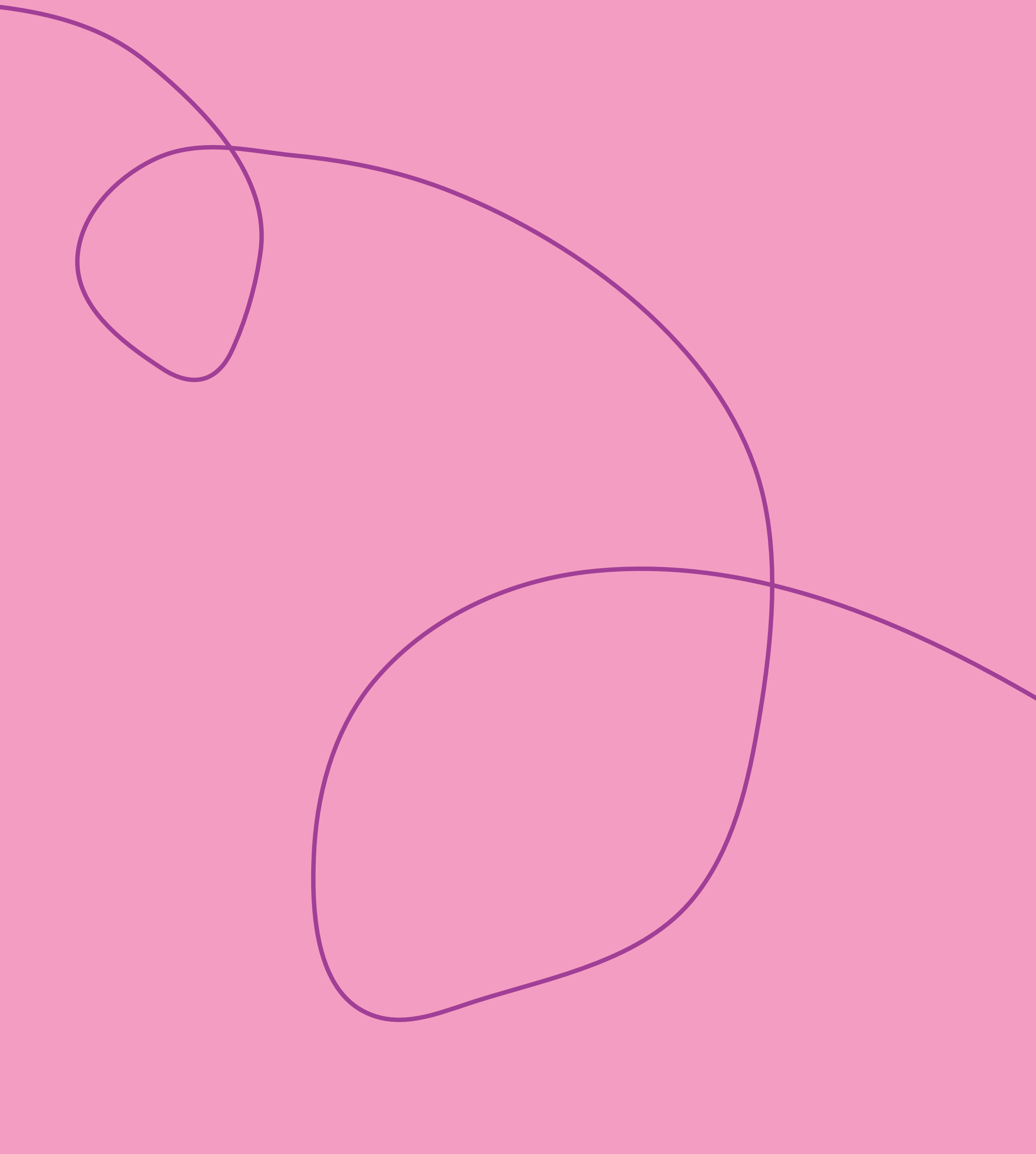
We would like to thank all the women and oncologists for participating. We would like to thank Peter Spreeuwenberg for his statistical advice. We are grateful for our patient experts for helping setting up the study. We would like to thank Margot Leeuwenburgh for her help with the recall coding. We would like to thank Dr. Annemiek van Ommen-Nijhof, Youssra Gokalp-El Benhaji and Nanine van den Ing for their help in recruiting patients.

REFERENCES

1. Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. *Soc Sci Med* 2005;61(10):2252-64.
2. Rutten LJF, Arora NK, Bakos AD, et al. Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient education and counseling* 2005;57(3):250-61.
3. Tariman JD, Doorenbos A, Schepp KG, et al. Information needs priorities in patients diagnosed with cancer: a systematic review. *Journal of the advanced practitioner in oncology* 2014;5(2):115.
4. Dunn SM, Butow PN, Tattersall MH, et al. General information tapes inhibit recall of the cancer consultation. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology* 1993;11(11):2279-85. doi: 10.1200/jco.1993.11.11.2279 [published Online First: 1993/11/01]
5. Jansen J, Butow PN, Van Weert J, et al. Does age really matter? Recall of information presented to newly referred patients with cancer. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology* 2008;26(33):5450-57.
6. Kessels RP. Patients' memory for medical information. *Journal of the Royal Society of Medicine* 2003;96(5):219-22.
7. Gabrijel S, Grize L, Helfenstein E, et al. Receiving the diagnosis of lung cancer: patient recall of information and satisfaction with physician communication. *Journal of clinical oncology* 2008;26(2):297-302.
8. Schwabe L, Wolf OT. Learning under stress impairs memory formation. *Neurobiology of learning and memory* 2010;93(2):183-88.
9. Burke A, Heuer F, Reisberg D. Remembering emotional events. *Memory & cognition* 1992;20(3):277-90.
10. Sharot T, Delgado MR, Phelps EA. How emotion enhances the feeling of remembering. *Nature neuroscience* 2004;7(12):1376-80.
11. De Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. *Patient education and counseling* 2009;74(3):287-94.
12. Horvath AO, Symonds BD. Relation between working alliance and outcome in psychotherapy: A meta-analysis. *Journal of counseling psychology* 1991;38(2):139.
13. Krupnick JL, Sotsky SM, Elkin I, et al. The role of the therapeutic alliance in psychotherapy and pharmacotherapy outcome: Findings in the National Institute of Mental Health Treatment of Depression Collaborative Research Program. *Focus* 2006;64(2):532-277.
14. Street Jr RL, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician–patient communication to health outcomes. *Patient education and counseling* 2009;74(3):295-301.
15. Sep MS, Van Osch M, Van Vliet LM, et al. The power of clinicians' affective communication: how reassurance about non-abandonment can reduce patients' physiological arousal and increase information recall in bad news consultations. An experimental study using analogue patients. *Patient education and counseling* 2014;95(1):45-52.
16. van Osch M, Sep M, van Vliet LM, et al. Reducing patients' anxiety and uncertainty, and improving recall in bad news consultations. *Health Psychology* 2014;33(11):1382.
17. Visser LN, Tollenaar MS, de Haes HC, Smets EM. The value of physicians' affect-oriented communication for patients' recall of information. *Patient Education and Counseling* 2017;100(11):2116-20.

18. Visser LN, Tollenaar MS, van Doornen LJ, et al. Does silence speak louder than words? The impact of oncologists' emotion-oriented communication on analogue patients' information recall and emotional stress. *Patient education and counseling* 2019;102(1):43-52.
19. Lelorain S, Brédart A, Dolbeault S, Sultan S. A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psycho-Oncology* 2012;21(12):1255-64.
20. Van Vliet LM, Van Der Wall E, Plum NM, Bensing JM. Explicit prognostic information and reassurance about nonabandonment when entering palliative breast cancer care: findings from a scripted video-vignette study. *Journal of Clinical Oncology* 2013;31(26):3242-49.
21. Van Vliet LM, Francke AL, Westendorp J, et al. The Use of Expectancy and Empathy When Communicating With Patients With Advanced Breast Cancer; an Observational Study of Clinician-Patient Consultations. *Frontiers in psychiatry* 2019;10:464.
22. Hoffstädt H, Stouthard J, Meijers MC, et al. Patients' and clinicians' perceptions of clinician-expressed empathy in advanced cancer consultations and associations with patient outcomes. *Palliative Medicine Reports* 2020;in press
23. Bensing JM, Deveugele M, Moretti F, et al. How to make the medical consultation more successful from a patient's perspective? Tips for doctors and patients from lay people in the United Kingdom, Italy, Belgium and the Netherlands. *Patient education and counseling* 2011;84(3):287-93.
24. Back AL, Arnold RM, Baile WF, et al. Approaching difficult communication tasks in oncology 1. *CA: a cancer journal for clinicians* 2005;55(3):164-77.
25. van Vliet LM, Epstein AS. Current state of the art and science of patient-clinician communication in progressive disease: patients' need to know and need to feel known. *Journal of Clinical Oncology* 2014;32(31):3474.
26. Pollak KI, Arnold RM, Jeffreys AS, et al. Oncologist communication about emotion during visits with patients with advanced cancer. *Journal of Clinical Oncology* 2007;25(36):5748-52.
27. Henselmans I, Smets E, de Haes J, et al. A randomized controlled trial of a skills training for oncologists and a communication aid for patients to stimulate shared decision making about palliative systemic treatment (CHOICE): study protocol. *BMC cancer* 2018;18(1):55.
28. Gunzler D, Chen T, Wu P, Zhang H. Introduction to mediation analysis with structural equation modeling. *Shanghai archives of psychiatry* 2013;25(6):390.
29. MacKinnon DP, Fairchild AJ, Fritz MS. Mediation analysis. *Annu Rev Psychol* 2007;58:593-614.
30. Jansen J, van Weert JC, de Groot J, et al. Emotional and informational patient cues: the impact of nurses' responses on recall. *Patient education and counseling* 2010;79(2):218-24.
31. Danzi OP, Perlini C, Tedeschi F, et al. Affective communication during bad news consultation. Effect on analogue patients' heart rate variability and recall. *Patient education and counseling* 2018;101(11):1892-99.
32. Ridd M, Shaw A, Lewis G, Salisbury C. The patient–doctor relationship: a synthesis of the qualitative literature on patients' perspectives. *Br J Gen Pract* 2009;59(561):e116-e33.
33. Mazzi MA, Bensing J, Rimondini M, et al. How do lay people assess the quality of physicians' communicative responses to patients' emotional cues and concerns? An international multicentre study based on videotaped medical consultations. *Patient Education and Counseling* 2013;90(3):347-53.
34. Fogarty LA, Curbow BA, Wingard JR, et al. Can 40 seconds of compassion reduce patient anxiety? *Journal of Clinical Oncology* 1999;17(1):371-71.
35. Hall JA, Harrigan JA, Rosenthal R. Nonverbal behavior in clinician—patient interaction. *Applied and preventive psychology* 1995;4(1):21-37.

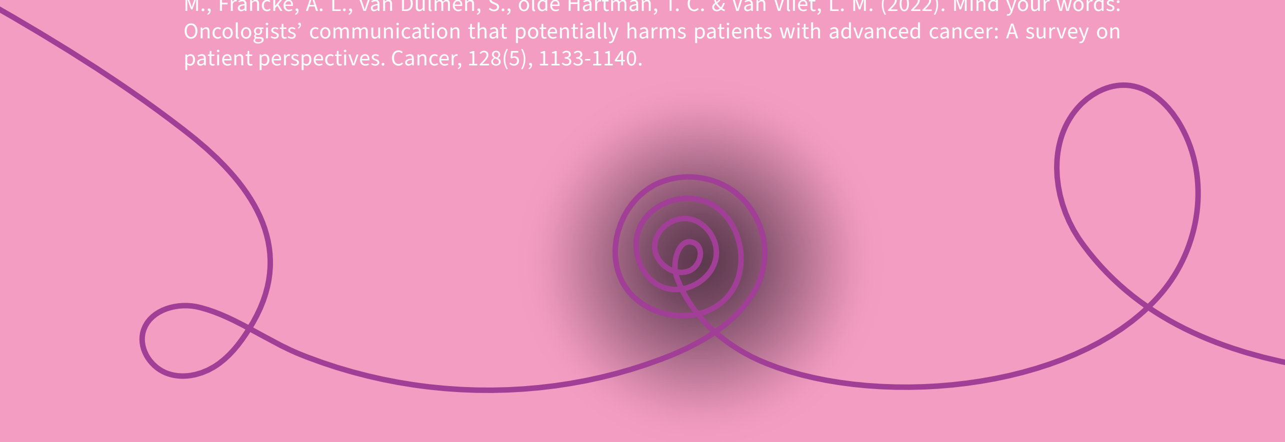
36. Eveleigh RM, Muskens E, van Ravesteijn H, et al. An overview of 19 instruments assessing the doctor-patient relationship: different models or concepts are used. *Journal of clinical epidemiology* 2012;65(1):10-15.
37. Baile WF, Lenzi R, Parker PA, et al. Oncologists' attitudes toward and practices in giving bad news: an exploratory study. *Journal of Clinical Oncology* 2002;20(8):2189-96.
38. Riess H, Kelley JM, Bailey RW, et al. Empathy training for resident physicians: a randomized controlled trial of a neuroscience-informed curriculum. *Journal of general internal medicine* 2012;27(10):1280-86.



4

Mind your words: Oncologists' communication that potentially harms patients with advanced cancer: A survey on patient perspectives

This chapter is published as:
Westendorp, J., Evers, A. W., Stouthard, J. M., Budding, J., van der Wall, E., Plum, N. M., Velting, M., Francke, A. L., van Dulmen, S., olde Hartman, T. C. & Van Vliet, L. M. (2022). Mind your words: Oncologists' communication that potentially harms patients with advanced cancer: A survey on patient perspectives. Cancer, 128(5), 1133-1140.



ABSTRACT

Background: Many complaints in medicine, also in advanced illnesses, are about communication. Little is known about which specific communication harms. This study explored the perspectives of patients with advanced cancer about potentially harmful communication behaviors by oncologists, and helpful alternatives.

Methods: An online survey-design was employed, based on literature scoping and patient/clinician/researcher input. Patients with advanced cancer (n=74) reflected on the potential harmfulness of 19 communication situations. They were asked if they perceived the situation as one in which communication could be harmful (yes/no). If “yes”, they were asked if they perceived the examples as harmful (yes/no) or helpful (yes/no) and to provide open comments. Results were analyzed quantitatively and qualitatively (content analysis).

Results: Communication may be unnecessarily potentially harmful regarding information provision, prognosis discussion, decision-making, and empathy, and occurs in various ways: e.g. by making vague instead of concrete promises (92%);being too directive in decision-making (qualitative);not listening to the patient (88%). Not all patients considered other situations potentially harmful: e.g. introducing the option of refraining from anti-cancer therapy (49%); giving too much (prognostic) information (60%). Exploring each individual patients’ needs/preferences seems a precondition for helpful communication.

Conclusions: We provide a patient perspective on oncologists’ unnecessarily potentially harmful communication behaviors and offer practical tools to improve communication in advanced cancer care. We describe both preventable pitfalls and delicate challenges requiring an individualized approach, where exploration might help. While providing difficult and unwelcome news is a clinicians’ core task, our study might help them doing so while preventing potential unnecessary harm.

INTRODUCTION

“Do no harm” lies at the heart of medicine. Harm can arise not only from medical-technical errors, but also what is historically perceived as the ‘soft’ side of medicine: communication. Many complaints about medical care, also in the area of advanced illness[1], can be traced back to communication deficits.[2]

However, surprisingly little is known about why many complaints in medical care are about communication. Until now, it is unclear which *specific* communication behaviors have the potential to unnecessarily harm patients. Multiple studies have found that communication behaviors such as empathy, listening, reassuring, and providing tailored information have positive effects on patient-reported outcomes in (advanced) cancer.[3-5] We might expect that opposite behaviors could be perceived as harmful. Complaints about communication in cancer care indeed include a lack of caring and respect, incorrect information, and breakdowns in communication.[6]

Recently, research has addressed the clinician’s – but not the patient’s – perspective on unnecessarily potentially harmful communication. A recent essay postulated which communication behavior might be improper and harmful and suggested more appropriate alternatives (e.g. referring to the patient as a disease instead of person;*“Ms X is our CHF-er”* instead of *“Ms X is a person with heart failure”*).[7] Although clinicians’ viewpoint are important, individual patients’ perspectives are ultimately even more important and may differ from expert opinion[8 9]; nevertheless, to date they are missing from the research.

The aim of this study is to explore the perspectives of patients with advanced cancer about potentially harmful communication behaviors by oncologists, and to suggest helpful alternatives. Fulfilling this aim will provide concrete tools to help oncologists prevent unnecessary potential harm to patients via their communication at a point in the patient’s care when this is most important.

METHODS

Design

An online survey design was used. Based on results of a scoping literature search and patient, clinician, and researcher input, an online questionnaire was created (for detailed information of the scoping process see Appendix 1). Themes and examples of potential harmful communication and helpful alternatives in cancer care were extracted from the included articles, collated and reviewed by the project team (consisting of experts in cancer, palliative care, and communication, supplemented by patient representation). The agreed upon themes/situations and examples (see Appendix 2; e.g.

not supporting shared decision-making, using medical jargon, and ignoring emotions) were transformed into questions for the online questionnaire. The questionnaire was piloted on clarity/format by two patient representatives (JB/NP). Various changes, e.g. the inclusion of an example-question and simplifications of questions, were made.

Ethics

The study was approved by the Ethical Committee of Psychology Research of Leiden University (2020-09-22-L.M.vanVliet-V1-2643).

Participants and Recruitment

Eligible patients were ≥18 years with advanced (incurable) cancer and sufficient Dutch language skills. Initially, we only included women with incurable breast cancer. To increase recruitment numbers, eligibility criteria were widened.

From June-November 2020, patients were recruited via channels of patient organizations (e.g. the Dutch Breast Cancer Association [BVN], the Dutch Federation of Cancer Patient Organizations [NFK], and cancer.nl [kanker.nl]). Social media advertisements could be freely shared. Participants from previous studies were also approached, if they had consented to being contacted again. The advertisement (which was either sent directly to patients with incurable cancer or clearly stated that this was the eligible group) included a link to the online study, and after interested patients read the information letter and provided electronic Informed Consent, they could access the questionnaire.

Background characteristics

Sociodemographic characteristics (e.g. age, education) and medical information (e.g. cancer type, prior/current treatments) were assessed.

Harmful and helpful communication

Patients were presented with 19 situations that could potentially entail unnecessarily harmful communication (grouped under decision-making, information provision; and empathy); see Box 1/ Appendix 2. These situations were accompanied by an example of potentially harmful communication and an alternative of potentially helpful communication. First, patients were asked whether they thought this was a situation in which communication could be harmful (yes/no). If they replied “yes”, they were asked whether they thought the examples provided were indeed i) harmful (yes/no) or ii) helpful (yes/no). In open-ended questions, they could then provide additional suggestions and/or experiences of harmful and helpful communication per situation and, lastly, in general. In order to assess participants’ views on the topics of ‘Discussing the option of refraining from anti-cancer therapy’ and ‘Giving information about life-expectancy' we included both a situation in which the discussion and a situation in which the non-discussion of these topics could be rated as potentially harmful - with mirrored harmful/helpful examples.

Data analysis

First, background characteristics were described. Second, the extent to which potentially harmful situations and their potentially harmful and helpful suggestions were perceived as such, were described. Quantitative analyses were performed using SPSS version-25. Third, open-ended questions were qualitatively analysed following principles of Content Analysis[10] , supported by Atlas.ti software. In the first step (deduction), researcher JW (supported by researcher LV) read through and coded all data for correspondence with the categories identified (displayed in Appendix 2). Two researchers (JW/LV) together created new coding unities for data that did not fit within the existing categories (step 2: induction). In the third step the lists of categories were grouped under higher order headings, and these were (step 4: abstraction) summarized qualitatively (see Results-section) as well as integrated with the quantitative results of the survey (see Box 1) in a final Table (see Box 2) Situations which <33% of patients assessed as potentially harmful were not included in the final table (based on the RAND-appropriateness method [11 12]). This table and interim analyses were reviewed and discussed with the co-authors (backgrounds in psychology, communication, medicine, and patient representation) to prevent one-sided interpretation of the data. PRISMA, STROBE and COREQ guidelines were followed for reporting.

RESULTS

Participants' characteristics

Of the 90 patients that started the questionnaire, 74 answered the communication questions and were included in our analyses. Background characteristics of these 74 patients are summarized in Table 1. The mean age of the patients was 57 years (SD=9.06).

Table 1. Background characteristics

Characteristics	**No.(%)**
Sex	
Female	68(92)
Male	6(8)
Marital status	
Married	52(70)
Single	22(30)
Education	
Lower	16(22)
Intermediate	20(27)
Tertiary	37(50)
Missing	1(1)
Occupation	
Paid job	19(26)
Disabled/Sick leave	32(43)
Houseman/Housewife	5(7)
Retired	15(20)
Other[a]	3(4)
Ethnicity	
Dutch	64(87)
Western-Immigrant	5(7)
Missing	5(7)
Type of cancer[b]	
Breast	58(78)
Colon	2(3)
Lung	5(7)
Kidney	2(3)
Prostate	2(3)
Other[c]	9(12)
Treatments currently receiving[b]	
Chemotherapy	19(26)
Radiotherapy	4(5)
Hormonetherapy	40(54)
Immunotherapy	13(18)
Operation	1(1)
Symptom-oriented treatment	24(32)
Tumor-oriented treatment possible, but refrained from	2 3)
Tumor-oriented treatment impossible	1(1)
Other[a]	13(18)

a Unspecified

b Multiple options possible

c Other i.e. ovarian/pancreatic/bladder/esophageal/unknown cancer, cholangiocarcinoma, eye-melanoma, leiomyocarcinoma (all,n=1)

Quantitative results

Box 1 shows the quantitative results of the survey; i.e. the extent to which various communication situations were perceived as potentially harmful communication. The situations *discussing the end of anti-cancer therapy without mentioning what is still possible* (85%), *not listening to the patient* (88%), and *making vague promises* (92%) were perceived as the most potentially harmful. *Focusing on side-effect occurrences* (31%) was perceived as the least potentially harmful. Views varied on the potential harmfulness of behaviors regarding *amount of information* (60% perceived too much as harmful; 65% perceived too little as harmful) and *the option of refraining from anti-cancer therapy* (49% perceived discussion as harmful; 44% perceived non-discussion as harmful). See Box 1 for patients' perceptions of potentially harmful and helpful examples.

Qualitative results

The qualitative results are based on the open-ended responses to the survey, i.e. patient-reported data about what patients perceived as potentially harmful communication behavior and helpful alternatives. Patients reported that communication might be potentially harmful in relation to i) information provision; ii) prognosis discussion; iii) decision-making; and iv) empathy. In terms of helpful communication, many patients commented about the importance of asking questions and exploring patients' needs and preferences.

Information provision

When providing information, communication can be potentially harmful in various ways. First, if information is provided without acknowledging the emotional impact, instead of giving the patient some time and exploration space. Second, harm might be experienced when oncologists may make vague, or even false, promises rather than specific promises, which leaves patients feeling unsettled and insecure. Third, when jargon instead of plain language is used, resulting in difficulties to understand the situation. Fourth, by providing either too much information (which is confusing and overwhelming), or too little (leaving the situation unclear). Helpful communication includes clear, honest, and concrete information, while at the same time exploring patients' preferences and tailoring information provision accordingly.

Harmful vague promise: *"Not responding to questions you pose via the electronic record. Not calling back at all. Or saying you'll be called on Friday and then not having time, so you end up spending the whole day waiting."*(ID-1021)

Helpful promise: *“They should always say when they’ll call back. If you don’t know when they’re going to call, that causes a lot of stress because you’re waiting.”*(ID-1049)

Approach to tailor information: *“Of course there are some people who want to discuss all the test results. A doctor should know or ask whether that’s what the patient wants.”*(ID-1051)

Prognosis

Patients’ perceptions about the potentially harmfulness of discussing prognostic information varied. Some found it harmful if (specific) prognostic information was provided, as this sort of information is inherently uncertain. Others found it harmful if no or vague prognostic information was provided. Asking patients about their preferences might be helpful. If a prognosis is discussed, it may be helpful to stress the uncertainty for an individual, as well as taking prognostic discussions step by step and mentioning (positive) outliers.

Harmful lack of prognostic information: *“Just saying nothing really isn’t on. Certainly when you’re just hearing it [for the first time].”*(ID-1032)

Harmful specific prognostic information: *“Mentioning time frames is tricky. You may get it wrong.”*(ID-1074)

Helpful exploration: “*To what extent is it important for that individual patient to have an indication about their life expectancy? Tailor the answer accordingly, without compromising the reality.”*(ID-1045)

Decision-making

Where decision-making was concerned, being too directive was perceived as potentially harmful (e.g. using words like “you must”). It might be helpful to provide a rationale, and to discuss alternative treatment options, including pros and cons. Patients differed as to whether oncologists should provide proactive advice and who should make the final decisions.

Harmful being directive: *“You must start your chemo within a certain time.”*(ID-1014)

Helpful rationale:*“[The doctor explaining] *why* they advise this, would make the communication less harmful.”*(ID-1045)

Patients varied in their perceptions about the potentially harmfulness of discussing the option of refraining from further aggressive anti-cancer therapy. Some found it harmful to discuss this, while there is still aggressive anti-cancer treatment available, as it takes away hope. Others found it harmful if it was not discussed, as they felt it should be presented as an option. If the matter was discussed, patients found it particularly harmful if the oncologist talked in terms of "nothing to be done". Approaches considered helpful were those that focused on what was still possible and stressed that the patient would be continuously supported, as well as discussing all available options with their pros and cons.

Harmful discussion: *"No treatment gives you no hope of living longer – yet hope is what you so badly want, only at the end of the trajectory I would not want any more treatment."*(ID-1040)

Harmful no discussion: *"All options should be discussed and explained, even if that is difficult."*(ID-1020)

Helpful: *"I will continue to help you."*(ID-1065)

Empathy

Various behaviors that revealed a lack of empathy were perceived by patients as potentially harmful. These behaviors included i) not responding to emotions (e.g. ignoring them); ii) not listening to the patient (e.g. ignoring or downplaying reported complaints); iii)providing premature reassurance; iv) not seeing the patient as a person (e.g. focusing only on medical facts) or an individual (e.g. not using their name); v) complimenting patients on looking good without checking if that matches how they feel. The overarching helpful approach was exploration: exploring patients' emotions, complaints, worries and feelings, psychological functioning, and (unmet) needs. A patient should be seen as a person behind the disease.

Harmful compliment: *"In daily life it's already pretty annoying that everyone is constantly saying you look great. A doctor should know that that's just on the outside."*(ID-1020)

Helpful compliment: *"It's fine to give compliments. But make sure to conclude with an open question."*(ID-1043)

Harmful not responding to emotions: *"Always harmful: ignoring the patient's reaction."*(ID-1051)

Helpful exploring of emotions: *"Are you worried about....? Would you perhaps find it helpful to talk about it with our department's psychological support counsellor?"*(ID-1045)

Exploration – ask the patient

In line with the abovementioned helpful exploration of patients' preferences regarding (prognostic) information provision and emotions and needs, exploration seemed an overall precondition for helpful communication. It was deemed helpful if oncologists ask questions and explore i) what patients already know, ii) what their main (treatment-related) aims and preferences are, iii) what symptoms and complaints they have, iv) whether they have understood the information provided and v) whether they have any additional questions.

Helpful:*"Asking what the patient themselves view as a possible solution and taking that as the starting point for advice or further discussion."*(ID-1060)

Helpful:*"Always probe further. Maybe the patient's complaints come from an underlying problem."*(ID-1074)

Table creation

Quantitative and qualitative results were integrated into a final Table depicting main and sub-themes of potentially harmful communication, including an explanation and concrete harmful/helpful examples (see Box 2).

DISCUSSION

While recognizing that providing difficult and unwelcome news is a core task of clinicians, this study aimed to explore the perspectives of patients with advanced cancer about potentially harmful communication behaviors by oncologists, and to suggest helpful alternatives. Our results provide a – mainly female breast cancer - patient-perspective overview of how communication can be unnecessarily potentially harmful in the areas of (prognostic) information provision, decision-making, and empathy. The results reveal preventable behaviors and delicate challenges on which patients' views varied, identifying the exploration of each individual patients' needs and preferences as a precondition for helpful communication. Potential harm can be prevented if patients' double communication needs are met: their need *to know and understand* (i.e. need for information and informed decision-making) and their need *to feel known and* understood (i.e. need for empathy and being seen as a person).[13-15]

Within oncologists' core tasks of honestly informing and supporting patients, our study highlighted several potentially harmful behaviors that would be relatively easy to prevent. These behaviors center around empathy (e.g. *informing without empathy, not listening)* and concreteness *(medical jargon, vague promises)* and largely overlap with a recent overview article of communication challenges in advanced cancer.[16] From previous studies we know that oncologists sometimes miss opportunities to show empathy[17 18], which might increase patients' anxiety.[3 19] If oncologists do not succeed in successfully displaying empathy in advanced cancer care consultations, this can negatively impact patients' feelings of satisfaction and their information recall.[4 17 20] These findings highlight the need for oncologist-expressed empathy, what can ensure to prevent unnecessary potential harm. Empathy can be demonstrated by behaviors such as NURSE-responses *(naming, understanding, respecting, supporting, and exploring emotions*[13 21]*)*; providing space after breaking bad news [22]; using questions to make patients feel heard[21], and listening[23] to establish patient-centered cancer care.[24] The other area in which patients perceived preventable harmful behavior was where communication lacked concreteness. It is known that (even well-educated) patients can misunderstand medical terminology[25] and information provided[26-28], while the uncertainty of vague promises (e.g. *"I will call you tomorrow")* can increase patients' anxiety.[29] These findings highlight the opportunity for oncologists to check if the patient has understood the information provided (*'teach-back'*[30]) and to provide a concrete call appointment, including a timeslot, to prevent unnecessary harm.

Other delicate challenges require an individualized approach in our era of ever-increasing precision medicine: e.g. *how much (prognostic) information to provide, how directive to be in the decision-making process,* and *how to introduce, or not to introduce, the topic of refraining from anti-cancer therapy.* Where the amount of information is concerned our findings overlap with previous results reporting that both too much information (being overwhelming and confusing[21 31]) and too little information (leaving the situation unclear, increasing anxiety[32]) may be perceived as potentially harmful. Prognostic preferences, particularly, vary.[33 34] Most, but not all, patients want to receive (some) information.[35 36] Checking patients (prognostic) information preferences – which can change over time[37 38] – seems essential[21 39], and tailoring can be achieved via questions as *"Would you like to talk about what this (scan) result means?".*[40] When it comes to the decision-making process, a 'paternalistic' decision-making style[21], especially, may be perceived as potentially harmful, although patients vary on how actively they want to be involved in decision-making.[41] What might be helpful here is to emphasize to patients that people vary, and again to ask about their preferences.[21] Lastly, it remains unclear whether patients perceive it as potentially harmful to discuss, or harmful *not* to discuss the option of refraining from anti-cancer therapy. In clinical care, oncologists do not always discuss it[42] - and quickly focus on additional treatment options[43]-, perhaps because they see it as an inferior option[44], at odds with their duty to discuss all possible treatment options.[45 46] While the option of no aggressive anti-cancer treatment needs to be carefully introduced at a certain point in time, patients in our and other studies[33 47] seemed to disagree on whether it should be discussed early-on (i.e. while there is still aggressive anti-cancer treatment available) or not. Moreover, most patients in our study agreed that it was harmful if oncologists mentioned that there was nothing to be done. This suggests that the harmful blow of raising the option of refraining from anti-cancer therapy could perhaps be softened by focusing on what is still possible (e.g. symptom-oriented treatments), and providing reassurance that the patient will not be abandoned.

A recurring suggestion for overcoming the above-mentioned delicate challenges seems to be to explore each individuals' patient needs and preferences. We found that exploration was helpful not only for addressing patients' varying information preferences, but also as a means to make communication more helpful in general: e.g. by exploring what patients know, want to know, and understand, and what they are aiming for. This reflects the essence of patient-centered care: receiving care and information that is tailored to each individual's needs and preferences.[48 49] Two key skills are noteworthy and valuable for making communication more helpful: *asking and listening.*[21 23] Although these recommendations are certainly not new (see[16]) in clinical care doctors sometime encounter difficulties exploring patients' preferences when discussing difficult topics, and patients sometimes do not dare to ask questions (*collusion* principle).[21 50]

Our study has limitations. Firstly, our sample was limited in terms of – quantitative – sample size and representativeness (mainly female breast cancer patients participated). This limits the generalizability of the results, although cancer type was not related to the perceived potential harmfulness of situations (data not shown). Secondly, while there were no comments about patients strongly disagreeing with specific situations/ examples, we could have asked for this specifically. Fourthly, a more nuanced answer scale trying to distinguish harm from preferences could have yielded different results. Fifthly, inclusion was based on self-assessment so, despite various safeguards, patients without incurable cancer could participate. Lastly, insight is lacking into how often potentially harmful behaviors occur, and what their effects are on patient-reported outcomes. Future studies should overcome these limitations and disentangle which specific behaviors can negatively influence which patient outcomes, and for which patients. These insights can be used to observe clinical interactions in a standardized way and, more importantly, to improve clinical care (e.g. via evidence-based trainings) to ultimately benefit patients. Existing training courses that offer a good starting point for these trainings include VitalTalk[51] and the Serious Illness Guide from Ariadne Labs.[52]

Conclusions

We provide a unique patient perspective on oncologists' unnecessarily potentially harmful communication behaviors and offer practical tools to overcome them in advanced cancer. We describe both preventable pitfalls (e.g. *patient* versus *Ms X*) and delicate challenges requiring an individualized approach (e.g. introducing the option of refraining from anti-cancer therapy), where exploration might help. While providing difficult and unwelcome news is a core task of clinicians, our study might help them doing so while preventing unnecessary potential harm.

REFERENCES

1. Cohen-Mansfield J, Skornick-Bouchbinder M, Cohen R, et al. Treatment and Communication-That Is What Matters: An Analysis of Complaints Regarding End-of-Life Care. *J Palliat Med.* 2017;20:1359-1365.
2. Abdelrahman W, Abdelmageed A. Understanding patient complaints. *BMJ.*2017;356:j452.
3. Schofield PE BP, Thompson JF, Tattersall MH, Beeney LJ, Dunn SM. Psychological responses of patients receiving a diagnosis of cancer. *Ann Oncol.*2003;14:48-56.
4. Westendorp J, Stouthard J, Meijers MC, et al. The power of clinician-expressed empathy to increase information recall in advanced breast cancer care: an observational study in clinical care, exploring the mediating role of anxiety. *Patient Educ. Couns.* 2020;104:1109-1115.
5. Van Vliet LM, Van Der Wall E, Plum NM, et al. Explicit prognostic information and reassurance about nonabandonment when entering palliative breast cancer care: findings from a scripted video-vignette study. *J. Clin. Oncol.* 2013;31:3242-3249.
6. Mack JW, Jacobson J, Frank D, et al. Evaluation of Patient and Family Outpatient Complaints as a Strategy to Prioritize Efforts to Improve Cancer Care Delivery. *Jt Comm J Qual Patient Saf.* 2017;43:498-507.
7. Luks AM, Goldberger ZD. Watch Your Language!—Misusage and Neologisms in Clinical Communication. *JAMA Intern Med.*2020;181:5-6.
8. Girgis A, Sanson-Fisher RW, Schofield MJ. Is there consensus between breast cancer patients and providers on guidelines for breaking bad news? *J. Behav. Med.* 1999;25:69-77.
9. Wright DN, Corner JL, Hopkinson JB, et al. The case for user involvement in research: the research priorities of cancer patients. *Breast Cancer Res.*2007;9:1-4.
10. Elo S, Kyngäs H. The qualitative content analysis process. *J. Adv. Nurs.* 2008;62:107-115.
11. Fitch K, Bernstein SJ, Aguilar MD, et al. The RAND/UCLA appropriateness method user’s manual: Rand Corp Santa Monica CA.2001.
12. Elwyn G, O’Connor A, Stacey D, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ.*2006;333:417.
13. van Vliet LM, Epstein AS. Current state of the art and science of patient-clinician communication in progressive disease: patients’ need to know and need to feel known. *J. Clin. Oncol.* 2014;32:3474.
14. Bensing JM, Dronkers J. Instrumental and affective aspects of physician behavior. *Medical care.* 1992:283-98.
15. Engel GL. How much longer must medicine’s science be bound by a seventeenth century world view? *Psychother Psychosom.* 1992;57:3-16.
16. Back AL. Patient-clinician communication issues in palliative care for patients with advanced cancer. *J. Clin. Oncol.*2020;38:866-876.
17. Van Vliet LM, Francke AL, Westendorp J, et al. The Use of Expectancy and Empathy When Communicating With Patients With Advanced Breast Cancer; an Observational Study of Clinician-Patient Consultations. *Front. Psychiatry.*2019;10:464.
18. Zimmermann C, Del Piccolo L, Finset A. Cues and concerns by patients in medical consultations: a literature review. *Psychol. Bull.*2007;133:438.
19. Fogarty LA, Curbow BA, Wingard JR, et al. Can 40 seconds of compassion reduce patient anxiety? *J. Clin. Oncol.* 1999;17:371.
20. Hoffstädt H, Stouthard J, Meijers MC, et al. Patients’ and Clinicians’ Perceptions of Clinician-Expressed Empathy in Advanced Cancer Consultations and Associations with Patient Outcomes. *Palliat Med. Reports.*2020;1:76-83.

21. Back AL, Arnold RM, Baile WF, et al. Approaching difficult communication tasks in oncology 1. *CA Cancer J. Clin.* 2005;55:164-177.
22. Van Vliet LM, Francke A, Tomson S, et al. When cure is no option: how explicit and hopeful can information be given? A qualitative study in breast cancer. *Patient Educ. Couns.* 2013;90:315-22.
23. Mack JW. On listening. *Cancer.*2020;126:1828-1831.
24. Mazor KM, Roblin DW, Greene SM, et al. Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response. *J. Clin. Oncol.* 2012;30:1784-1790.
25. von Itzstein MS, Railey E, Smith ML, et al. Patient familiarity with, understanding of, and preferences for clinical trial endpoints and terminology. *Cancer* 2020;126(8):1605-13.
26. Fallowfield LJ, Jenkins VA, Beveridge H. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat. Med.*2002;16:297-303.
27. Fenton JJ, Duberstein PR, Kravitz RL, et al. Impact of Prognostic Discussions on the Patient-Physician Relationship: Prospective Cohort Study. *J. Clin. Oncol.* 2018;36:225-230.
28. Schofield P, Carey M, Love A, et al. 'Would you like to talk about your future treatment options?'Discussing the transition from curative cancer treatment to palliative care. *Palliat. Med.* 2006;20:397-406.
29. Woolen S, Kazerooni EA, Wall A, et al. Waiting for radiology test results: patient expectations and emotional disutility. *J. Am. Coll. Radiol.* 2018;15:274-281.
30. Yen PH, Leasure AR. Use and effectiveness of the teach-back method in patient education and health outcomes. *Federal Practitioner.* 2019;36:284.
31. Bergqvist J, Strang P. Breast Cancer Patients' Preferences for Truth Versus Hope Are Dynamic and Change During Late Lines of Palliative Chemotherapy. *J. Pain Symptom Manag.* 2019;57:746-752.
32. Thorne SE, Hislop TG, Armstrong EA, et al. Cancer care communication: the power to harm and the power to heal? *Patient Educ. Couns.* 2008;71:34-40.
33. Hagerty R, Butow P, Ellis P, et al. Cancer patient preferences for communication of prognosis in the metastatic setting. *J. Clin. Oncol.*2004;22:1721-1730.
34. van der Velden NC, Meijers MC, Han PK, et al. The effect of prognostic communication on patient outcomes in palliative cancer care: a systematic review. *Curr Treat Options Oncol.* 2020;21:1-38.
35. Kirk P, Kirk I, Kristjanson LJ. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ.* 2004;328:1343.
36. Geerse OP, Lamas DJ, Sanders JJ, et al. A qualitative study of serious illness conversations in patients with advanced cancer. *J. Palliat. Med.* 2019;22:773-781.
37. Butow P, Maclean M, Dunn S, et al. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann. Oncol.* 1997;8:857-863.
38. Shim E-J, Park JE, Yi M, et al. Tailoring communications to the evolving needs of patients throughout the cancer care trajectory: a qualitative exploration with breast cancer patients. *BMC.* 2016;16:1-8.
39. Kreuter MW, Farrell DW, Olevitch LR, et al. *Tailoring health messages: Customizing communication with computer technology*: Routledge;2013.
40. Singh S, Cortez D, Maynard D, et al. Characterizing the nature of scan results discussions: insights into why patients misunderstand their prognosis. J. Oncol. Pract 2017;13:231-239.
41. Bélanger E, Rodríguez C, Groleau D. Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis. *Palliat. Med.*2011;25:242-261.
42. Gattellari M, Voigt KJ, Butow PN, et al. When the treatment goal is not cure: are cancer patients equipped to make informed decisions? *J. Clin. Oncol.* 2002;20:503-513.

43. Cortez D, Maynard DW, Campbell TC. Creating space to discuss end-of-life issues in cancer care. Patient Educ. Couns. 2019;102:216-222.
44. Brom L, De Snoo-Trimp JC, Onwuteaka-Philipsen BD, et al. Challenges in shared decision making in advanced cancer care: a qualitative longitudinal observational and interview study. *Health Expect.* 2017;20:69-84.
45. Dutch Government. https://www.rijksoverheid.nl/onderwerpen/rechten-van-patient-en-privacy/rechten-bij-een-medische-behandeling/informatie-arts--voor-medische-behandeling. Accessed January 26, 2021.
46. Chan SW, Tulloch E, Cooper ES, et al. Montgomery and informed consent: where are we now? *BMJ.* 2017;357.
47. Van Vliet LM, Meijers MC, van Dulmen S, et al. Addressing challenges in information-provision: a qualitative study among oncologists and women with advanced breast cancer. *BMC Palliat. Care*. 2021;20:1-12.
48. Venetis MK, Robinson JD, Turkiewicz KL, et al. An evidence base for patient-centered cancer care: a meta-analysis of studies of observed communication between cancer specialists and their patients. *Patient Educ. Couns.*2009;77:379-383.
49. Bensing J. Bridging the gap: The separate worlds of evidence-based medicine and patient-centered medicine. *Patient Educ. Couns.* 2000;39:17-25.
50. Hak T, Koëter G, van der Wal G. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ.* 2000;321:1376-1381.
51. VitalTalk. https://www.vitaltalk.org. Accessed January 26, 2021.
52. AriadneLabs. https://www.ariadnelabs.org/?s=training. Accessed January 26, 2021.

Box 1. Quantitative Results

Participants were asked whether they thought the situations presented were situations that might involve harmful communication (yes/no). Only if answered “yes”, they were asked whether they thought the examples given were indeed i) harmful (yes/no) and ii) helpful (yes/no). So please take this into account when interpreting the numbers/percentages.

Theme/Situation	No (%)**	Example of harmful communication	No (%)	Potentially helpful alternative	No (%)
DECISION-MAKING					
Not respecting that patients can make their own decisions[1]	33 (45)	Oncologist: “You really must rest.”	25 (83)	Oncologist: “You might want to consider getting sufficient rest.”	23 (77)
Not involving the patient in treatment decision-making[2 3]	46 (66)	Oncologist: “I really want to get started with chemotherapy.”	37 (80)	Oncologist: “It is possible to start chemotherapy, but I really want to know what your thoughts are about this.”	34 (74)
Discussing the option of refraining from anti-cancer therapy[2]	34 (49)	Oncologist: “We can also choose not to do any more chemotherapy. Chemotherapy can prolong life, but it can also cause side effects. So choosing not to proceed with chemotherapy is also very much an option.”	28 (85)	Oncologist: “We still have the option of using a new type of chemotherapy. It can prolong life, but it can also cause side effects.”	26 (79)
NOT discussing the option of refraining from anti-cancer therapy[2]	28 (44)	Oncologist: “We also have the option of using a new type of chemotherapy. It can prolong life, but it can also cause side effects.”	21 (81)	Oncologist: “We can also choose not to do a new type of chemotherapy. Chemotherapy can prolong life, but it can also cause side effects. So not doing that is also an option.”	19 (73)
Discussing the end of anti-cancer therapy without stressing what is still possible*	50 (85)	Oncologist: “There’s nothing more we can do for you.”	46 (92)	Oncologist: “We cannot cure the cancer, but there is still plenty we can do to help, and to help and support you if you develop complaints, for instance.”	45 (90)
INFORMATION PROVISION					
Giving information about life expectancy (prognosis)[3-5]	38 (68)	Oncologist: “I can say something about your life expectancy, although that is different for everyone. We know that half the women with your diagnosis are still alive after 2 years. So half the women live less than those 2 years, and the other half live longer.”	30 (79)	Oncologist: “ I can’t say much about your life expectancy; it’s different for everyone. There are women who live a long time with the type of breast cancer you have, and there are women who do not live very long. We don’t know how it will go for you.”	30 (81)

Theme/Situation	No (%)**	Example of harmful communication	No (%)	Potentially helpful alternative	No (%)
NOT giving information about life expectancy (prognosis)[3-5]	27 (50)	Oncologist: “I can’t say much about your life expectancy; it’s different for everyone. There are women who live a long time with the type of breast cancer you have, and there are women who live less long . We don’t know how it will go for you.”	16 (62)	Oncologist: “I can say something about your life expectancy, although that is different for everyone. We know that half the women with your diagnosis are still alive after 2 years. So half the women live less than those 2 years, and the other half live longer.”	12 (46)
Providing information without empathy[3 5-7]	39 (74)	Oncologist: “That was the result of the scan. So I will now discuss which treatment follows.”	37 (97)	Oncologist: “I’ve just discussed the results of the scan. I can imagine you will need to take a moment for it to sink in. Can you tell me how you feel after receiving this information?”	33 (87)
Providing too much information[5 6 8]	31 (60)	Oncologist: “So I will now take you through all the test results.”	23 (77)	Oncologist: “I can take you through all the test results, but alternatively we can just discuss the most important ones. What would you prefer at this point?”	25 (83)
Providing too little information[2 3 9]	33 (65)	Oncologist: “The results of the blood test are unfortunately not as we had hoped.”	32 (97)	Oncologist: “The results of the blood test are unfortunately not as we had hoped. The tumor marker is rising; in your case this means the cancer is becoming more active and growing again.”	30 (91)
Use of medical jargon[9 10]	33 (65)	Oncologist: “I have looked at your test results and the result is positive; there are signs that the cancer is progressive.”	30 (91)	Oncologist: “I have looked at the test results and they are not good: the tumor is growing.”	33 (100)
Negative framing of side effects[11]	16 (31)	Oncologist: “Just over half of patients feel more tired as a result of treatment, but it is impossible to predict how you will respond.”	12 (75)	Oncologist: “Just under half of patients are not troubled by fatigue as a result of treatment, but it is impossible to predict how you will respond.”	11 (69)
Making vague promises*	47 (92)	Oncologist: “I will call you” (giving no indication of when).	46 (98)	Oncologist: “I will call you as soon as I have discussed this with the team tomorrow afternoon. So I expect to be able to call you between 4-5pm.”	45 (96)

Theme/Situation	No (%)**	Example of harmful communication	No (%)	Potentially helpful alternative	No (%)
EMPATHY					
Not responding to emotions[6 10 12]	42 (82)	Patient: “I will manage to deal with this too. It’s just that my husband is sick too.” Oncologist: “Yes, you told me.” Patient: “Yes ... so, well ... (falls silent)” Oncologist: “Let’s measure your blood pressure.”	41 (98)	Patient: “I will manage to deal with this too. It’s just that my husband is sick too.” Oncologist: “Yes, you told me.” Patient: “Yes ... so, well ... (falls silent)” Oncologist: “Are you very worried about him?”	40 (95)
Not listening to the patient [8]	45 (88)	Patient: “I’ve also been experiencing pain when walking.” Not too bad, but it is uncomfortable.” Oncologist: “OK, and what about swallowing? Has that been going better?”	45 (100)	Patient: “I’ve also been experiencing pain when walking.” Not too bad, but it is uncomfortable.” Oncologist: “Is that worrying you?”	41 (91)
Providing reassurance before exploring whether the patient needs it[6]	38 (76)	Patient: “And I’ve been having headaches again.” Oncologist: “You don’t have to worry about that. I can really reassure you that has nothing to do with your cancer.”	34 (90)	Patient: “And I’ve been having headaches again.” Oncologist: “That’s too bad for you. Are you worried about it? Patient: “Not really. I just wondered if you could prescribe that medication again - that helped the last time.”	34 (90)
Not seeing the patient as a person[6-8 13]	32 (64)	Oncologist: “The tumor doesn’t seem to be growing, so that’s going well - great!”	31 (97)	Oncologist: “The tumor doesn’t seem to be growing, but how have you been feeling?”	28 (88)
Not respecting the patient as an individual[1]	22 (44)	The oncologist calls a fellow oncologist in the patient’s presence: The oncologist says: “**The patient** has been experiencing increasing pain in her back.”	17 (77)	The oncologist calls a fellow oncologist in the patient’s presence: The oncologist says: “**Ms. de Vries** has been experiencing increasing pain in her back”.	21 (96)
Giving a compliment without room to disagree*	39 (80)	The oncologist says: “You’re looking good” (which makes it hard to say you’re not feeling good)	35 (90)	The oncologist says: “How are you feeling? You look great, but I know that doesn’t always mean you’re feeling that way.”	33 (85)

*Patient perspective

**If less than 33.3% of patients believed this situation might have been harmful, it was eliminated from further qualitative analysis.

REFERENCES BOX 1

1. Mobbs N, Williams C, Weeks AD. Humanising birth: does the language we use matter? 2018
2. Brom L, De Snoo-Trimp JC, Onwuteaka-Philipsen BD, et al. Challenges in shared decision making in advanced cancer care: a qualitative longitudinal observational and interview study. *Health Expect.* 2017;20:69-84.
3. Thorne SE, Hislop TG, Armstrong EA, et al. Cancer care communication: the power to harm and the power to heal? *Patient Educ. Couns.* 2008;71:34-40
4. van Vliet LM. Balancing explicit with general information and realism with hope. Communication at the transition to palliative breast cancer care: *Utrecht University.* 2013.
5. Bergqvist J, Strang P. Breast Cancer Patients' Preferences for Truth Versus Hope Are Dynamic and Change During Late Lines of Palliative Chemotherapy. *J. Pain Symptom Manag.* 2019;57:746-752.
6. Back AL, Arnold RM, Baile WF, et al. Approaching difficult communication tasks in oncology 1. *CA Cancer J. Clin.* 2005;55:164-177.
7. Mack JW, Jacobson J, Frank D, et al. Evaluation of Patient and Family Outpatient Complaints as a Strategy to Prioritize Efforts to Improve Cancer Care Delivery. *Jt Comm J Qual Patient Saf.* 2017;43:498-507.
8. Mazor KM, Roblin DW, Greene SM, et al. Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response. *J. Clin. Oncol.* 2012;30:1784-1790..
9. Fallowfield LJ, Jenkins VA, Beveridge H. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat. Med.* 2002;16:297-303
10. Schofield P, Carey M, Love A, et al. 'Would you like to talk about your future treatment options?' Discussing the transition from curative cancer treatment to palliative care. *Palliat. Med.* 2006;20:397-406.
11. Webster, R. K.; Weinman, J.; Rubin, G. J. Explaining all without causing unnecessary harm: Is there scope for positively framing medical risk information?. *Patient Educ. Couns.* 2019;102:602-603..
12. Van Vliet LM, Francke AL, Westendorp J, et al. The Use of Expectancy and Empathy When Communicating With Patients With Advanced Breast Cancer; an Observational Study of Clinician-Patient Consultations*. Front. Psychiatry.* 2019;10:464.
13. Entwistle, V. A., et al. Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Quality and Safety in Health Care*. 2010;19:33

Box 2. Integrated quantitative and qualitative results

	Explanation	Harmful example	Helpful example	Exploration - tailoring ∆
(i) Information provision*				
Amount of information*	Patients' views vary: both too much information (i.e. overwhelming) and too little information (i.e. making the message unclear) can be harmful*	Too much*: *"The results of the blood test are unfortunately not as we had hoped. So I will now go through all the test results." (quantitative + qualitative ID 1022)*	*"The results of the blood test are unfortunately not as we had hoped. The tumor marker is rising; this means your cancer is becoming more active and growing again." (quantitative + qualitative ID 1022, 1002 and 1020)*	*"I can discuss all the results with you, or only the most important ones. What would you prefer at this point?" (quantitative + qualitative ID 1051)*
		Too little*: *"The results of the blood test are unfortunately not as we had hoped." (quantitative + qualitative ID 1058)*		*"I can also give you written information, or you can read it in your electronic record. Would you prefer that?" (qualitative ID 1034 and 1051)*
Providing information without empathy*	Information should not be provided without acknowledging its emotional impact*	*"Those were the scan results. So I will now discuss what treatment is required." (quantitative + qualitative ID 1055 and 1073)*	*"Those were the scan results. I can imagine you may need a moment for it all to sink in."* Depending on the patient's reaction, explore emotions, and ask permission to discuss treatment options." *(quantitative + qualitative ID 1059 and 1057)*	
Use of medical jargon*	Complex terms might lead to patients misunderstanding information*	*"I've looked at your test results and the result is positive; there are signs that the cancer is progressive." (quantitative + qualitative ID 1020 and 1061)*	*"I've looked at the test results and the result of the test is not good: the tumor marker has increased. This means the tumor is growing." (quantitative + qualitative ID 1061)*	
Making vague promises*	Vague promises are unsettling, especially if they are not met*	*"I will call you." (no indication of when the doctor will call). (quantitative + qualitative ID 1021)*	*"I will call you tomorrow between 4 and 5, once I have discussed this with the team. If I don't call, you can call me after that." (quantitative + qualitative ID 1021 and 1063)*	

	Explanation	Harmful example	Helpful example	Exploration - tailoring Δ
(ii) Prognosis*				
	Patients' views vary; it can be harmful if prognostic information is too specific (i.e. does not acknowledge inherent uncertainty) but also if it is too vague (i.e. it is unclear to the patient where they stand)*	Discussing the prognosis*: *"I can say something about your life expectancy, although it is different for everyone. We know that half of the women with your diagnosis are still alive after 2 years. So half the women live less than those 2 years, and the other half live longer." (quantitative + qualitative ID 1034)* Not discussing the prognosis*: *"I can't say much about your life expectancy; it's different for everyone. There are women who live a long time with the type of breast cancer you have, and other women who live less long. We don't know how it will go for you." (quantitative + qualitative ID 1049)*	Emphasizing the uncertainty of the prognosis Δ: *"We base life expectancy on data from large groups of people. Life expectancy is different for each person, so unfortunately we can't say exactly what it is for you personally." (qualitative ID 1024, 1063 and 1061)* Step-by-step assessment of the prognosis Δ: *"In your case, the best is if we start treatment and then assess the effect of the first treatment. Then we can take it from there. How long the treatment is effective is different for everyone." (qualitative ID 1045)* Referring to outliers Δ: *"There are always exceptions. People who live shorter, but also people who live longer than we sometimes think." (qualitative ID 1020, 1047 and 1061)*	*"Some people, but not all, want information about their life expectancy. It's different for everyone. What are your needs here? (qualitative and experts)*
(iii) Decision-making*Δ				
Not involving the patient in decision-making*	Being too directive and overlooking patients in decision-making *	*"You must start chemo within a specified time." (qualitative ID 1014, 1060 and 1074)*	*"You have a choice between chemotherapy and ... The advantages and disadvantages are ... I would be very interested to know what you yourself think about this. Of course there is time to think about it." (qualitative ID 1014, 1061, 1045, 1005 and 1016)*	*"If you want, I can also give you my advice?" (experts)*
	Patients' views vary on who should make a final treatment decision Δ			*"Some people want to make the final decision together; others want to do it themselves. What would you prefer?" (experts)*

	Explanation	Harmful example	Helpful example	Exploration - tailoring Δ
Discussion or non-discussion of refraining from anti-cancer therapy (in early disease stage)*	Patients' views vary: both discussing the option of no anti-cancer therapy (i.e. this takes away hope) and not discussing this option in early disease stage (i.e. it is a realistic possibility) can be perceived as harmful*	Decision to discuss the option*: *"I suggest stopping with chemotherapy." (qualitative ID 1040)*	*"The choice to be considered is whether or not you want further treatment. The advantages and disadvantages are … It is important to think about whether you still want this. It's not an easy decision, and it doesn't have to be made right now." (qualitative ID 1059, 1004 and 1055)*	
		Not discussing the options*: *"Chemo is still a possibility. Give yourself that chance." (qualitative ID 1020 + 1065)*		
	If the option is discussed, it is particularly harmful psychologically if the doctor says 'there is nothing more to be done'*	*"There's nothing more we can do for you." (qualitative ID 1040)*	*"We cannot cure the cancer, but there is still plenty we can do and will do to help you, including helping you come to terms with this news. We can help and treat you if you develop complaints. We will continue seeing you." (quantitative + qualitative ID 1020, 1024, 1058 and 1065)*	
(iv) Empathy*				
Not responding to emotions*	Not responding to patients' emotions, e.g. ignoring them, is deemed harmful*	Patient: *"I will get through this too. It's just that my husband is sick too."* Oncologist: *"Yes, you told me. There's not much I can do about that."* Patient: *"Yes … so yes …* (falls silent)*"* Oncologist: *"Let's measure your blood pressure." (quantitative + qualitative ID 1065)*	Patient: *"I will get through this too. It's just that my husband is sick too."* Oncologist: *"Yes, you told me. That's a lot for the two of you to deal with"* Patient: *"Yes … so yes …* (falls silent)*"* Oncologist: *"Are you worried about him? Would it perhaps help to talk about this with the social worker/psychologist/spiritual advisor?" (quantitative + qualitative ID 1034, 1055 and 1045)*	
Not listening to the patient*	Not listening to the patient, e.g. ignoring or downplaying reported complaints, is deemed harmful*	Patient: *"I've also been experiencing pain when walking."* Oncologist: *"That's a common side effect. And what about swallowing? Is that better now?" (quantitative + qualitative ID 1059 and 1081)*	Patient: *"I also been experiencing pain when walking."* Oncologist: *"Can you tell me anything more about it? Are you worried about it? Let's see if we can find something to improve that." (quantitative + qualitative ID 1004 and 1060)*	

	Explanation	Harmful example	Helpful example	Exploration - tailoring Δ
Providing reassurance before exploring whether the patient needs it*	Reassuring patients without e.g. exploring what patients think themselves is deemed harmful *	Patient: *“And I’m still getting headaches.”* Oncologist: *“You don’t have to worry about that. I assure you that that has nothing to do with your cancer.” (quantitative + qualitative ID 1022)*	Patient: *“And I’m still getting headaches.”* Oncologist: *“That’s too bad. Are you worried about it? What do you think is causing it?* Patient: *“No, I’m not that worried. I think it’s the same side effect again.” (quantitative + qualitative ID 1065)*	
Not seeing the patient as a person*	Not seeing the patient as a person and only focusing on the medical facts / the medical side is deemed harmful *	*“The tumor doesn’t seem to be growing so that’s going well - great! So we’ll continue treatment.” (quantitative + qualitative ID 1021 and 1063)*	*“The tumor doesn’t seem to be growing, which is good. But how are you feeling? Do you have any symptoms?” (quantitative + qualitative ID 1055, 1059 and 1063)*	
Not respecting the patient as an individual*	Not respecting the patient as an individual, e.g. by not using their name, is deemed harmful*	The oncologist calls a colleague during the consultation: Oncologist: *“The patient has increasing pain in her back.” (quantitative + qualitative ID 1003)*	Having checked that the patient agrees, the oncologist calls a colleague during the consultation: Oncologist: *“Ms. de Vries, born 19-3-1954, has increasing pain in her back.” (quantitative + qualitative ID 1022)*	
Giving a compliment without room to disagree*	Telling patients they look good is perceived as harmful; this occurs in daily life, and may not reflect how the patient feels*.	*“You look great.” (quantitative + qualitative ID 1020 and 1032)*	*“You look great, but I know that doesn’t always mean you feel that way. How do you feel?” (quantitative + qualitative ID 1043)*	

Exploration - Asking the patient Δ				
Asking what the patient knows: *“So what do you know about chemotherapy?” (qualitative ID 1051)*	Asking what the patient wants to do, or to achieve. *“What would you like the treatment to achieve?” (qualitative ID 1005)*	Asking probing questions if the patient is experiencing complaints: *“Where is the pain? When do you experience it? How often?” (qualitative ID 1021)*	Asking/checking if the patient has understood the information: *“I want to check that I’ve explained it properly. Can you repeat what I said?” (qualitative ID 1051 + pharos)*	Making time for questions: *“Do you have any more questions?” (qualitative ID 1004)*

* Original themes based on the quantitative results of the questionnaire and supported with qualitative comments (deduction)

Δ Additional themes based on the qualitative results (induction)

APPENDIX 1. SCOPING LITERATURE SEARCH

A scoping literate search was conducted and reported in line with the PRISMA guidelines.

Search strategy

PubMed and Google Scholar (first 4 pages) were searched by one author (JW on April 17, 2020). The search strategy consisted the following keywords in PubMed : ‘cancer AND communication AND (harm OR harmful OR complaint)’. Keywords in Scholar were: ‘cancer’. ‘communication’ and ‘harm’.

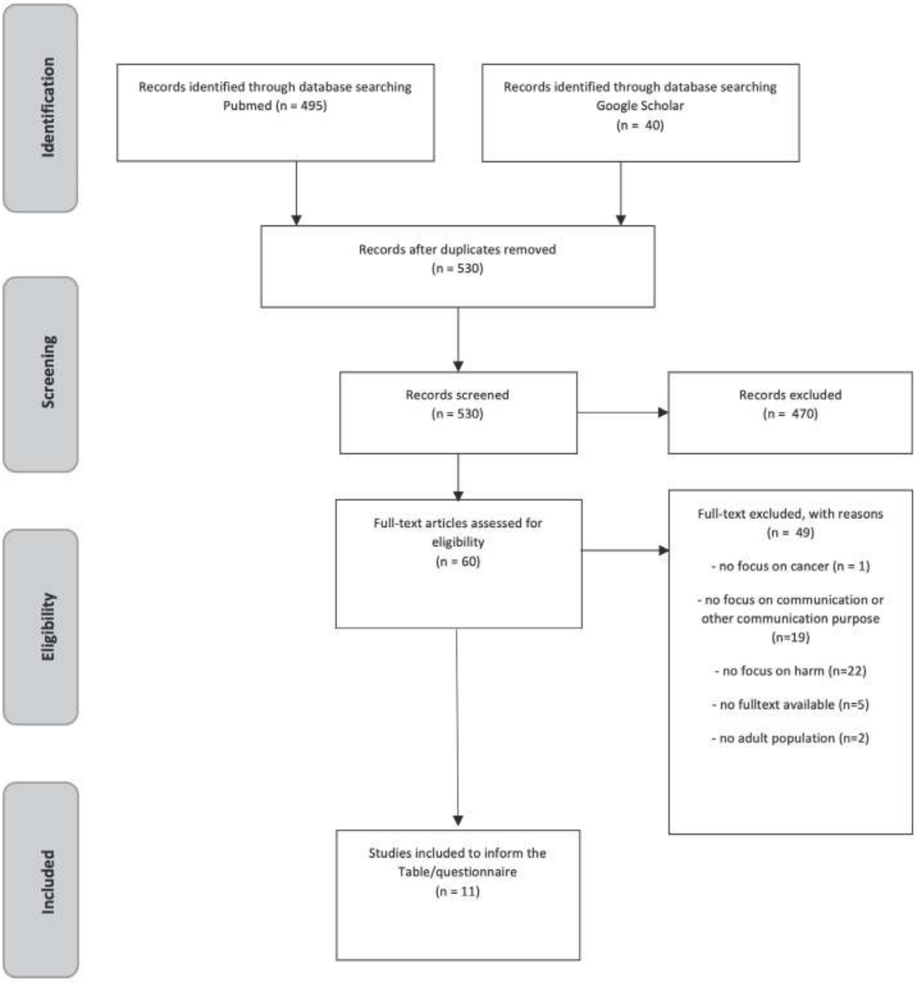
Search strategy	
PubMed	Cancer AND communication AND (harm OR harmful OR complaint) ((“neoplasms”[MeSH Terms] OR “neoplasms”[All Fields] OR “cancer”[All Fields]) AND (“communication”[MeSH Terms] OR “communication”[All Fields]) AND (“harm”[All Fields] OR “harmful”[All Fields] OR “complaint”[All Fields])) AND (“2000/01/01”[PDAT] : “3000/12/31”[PDAT])
Google Scholar	Cancer communication harm https://scholar.google.com/scholar?start=0&q=Cancer+communication+harm&hl=nl&as_sdt=0,5&as_ylo=2000

Study selection and data extraction

All database publications were entered in EndNote software and duplicates were removed. The database publications were reviewed by JW. Firstly the publications were screened based on title and abstract. Secondly the remaining publications were reviewed full text. Studies were included if they fulfilled the following criteria: publication in English or Dutch, after 2000, study focused on (potentially) harmful communication in adult cancer care. We only included studies after 2000 as we wanted to include potential harmful behaviors that are still common-practice and relevant.

The following data was extracted from each study: type of harmful and helpful communication. Data extraction of the included literature was done by one author (JW) and checked by a second author (LV). Disagreements were resolved by discussion between the authors.

Flow Diagram literature search



REFERENCES APPENDIX 1

1. Back AL, Arnold RM, Baile WF, et al. Approaching difficult communication tasks in oncology 1. CA *Cancer J. Clin.* 2005;55:164-177.
2. Bergqvist J, Strang P. Breast Cancer Patients' Preferences for Truth Versus Hope Are Dynamic and Change During Late Lines of Palliative Chemotherapy. *J. Pain Symptom Manag.* 2019;57:746-752.
3. Brom L, De Snoo-Trimp JC, Onwuteaka-Philipsen BD, et al. Challenges in shared decision making in advanced cancer care: a qualitative longitudinal observational and interview study. *Health Expect.* 2017;20:69-84.
4. Entwistle, V. A., et al. Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Quality and Safety in Health Care.* 2010;19:33.
5. Fallowfield LJ, Jenkins VA, Beveridge H. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat. Med.* 2002;16:297-303.
6. Mazor KM, Roblin DW, Greene SM, et al. Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response*. J. Clin. Oncol.* 2012;30:1784-1790.
7. McCartney, M.. The fight is on: military metaphors for cancer may harm patients. *BMJ*. 2014;349.
8. Schofield P, Carey M, Love A, et al. 'Would you like to talk about your future treatment options?' Discussing the transition from curative cancer treatment to palliative care*. Palliat. Med.* 2006;20:397-406.
9. Thorne SE, Hislop TG, Armstrong EA, et al. Cancer care communication: the power to harm and the power to heal? *Patient Educ. Couns.* 2008;71:34-40.
10. Webster, R. K.; Weinman, J.; Rubin, G. J. Explaining all without causing unnecessary harm: Is there scope for positively framing medical risk information?. *Patient Educ. Couns.* 2019;102:602-603.

APPENDIX 2. FINAL QUESTIONNAIRE THEMES AND EXAMPLES

Participants were asked whether they thought the situations presented were situations that might involve harmful communication (yes/no). Only if answered "yes", they were asked whether they thought the examples given were indeed i) harmful (yes/no) and ii) helpful (yes/no).

Theme/Situation	Example of harmful communication	Potentially helpful alternative
DECISION-MAKING		
Not respecting that patients can make their own decisions[1]	Oncologist: "You really must rest."	Oncologist: "You might want to consider getting sufficient rest."
Not involving the patient in treatment decision-making[2 3]	Oncologist: "I really want to get started with chemotherapy."	Oncologist: "It is possible to start chemotherapy, but I really want to know what your thoughts are about this."
Discussing the option of refraining from anti-cancer therapy[2]	Oncologist: "We can also choose not to do any more chemotherapy. Chemotherapy can prolong life, but it can also cause side effects. So choosing not to proceed with chemotherapy is also very much an option."	Oncologist: "We still have the option of using a new type of chemotherapy. It can prolong life, but it can also cause side effects."
NOT discussing the option of refraining from anti-cancer therapy[2]	Oncologist: "We also have the option of using a new type of chemotherapy. It can prolong life, but it can also cause side effects."	Oncologist: "We can also choose not to do a new type of chemotherapy. Chemotherapy can prolong life, but it can also cause side effects. So not doing that is also an option."
Discussing the end of anti-cancer therapy without stressing what is still possible*	Oncologist: "There's nothing more we can do for you."	Oncologist: "We cannot cure the cancer, but there is still plenty we can do to help, and to help and support you if you develop complaints, for instance."
INFORMATION PROVISION		
Giving information about life expectancy (prognosis)[3-5]	Oncologist: "I can say something about your life expectancy, although that is different for everyone. We know that half the women with your diagnosis are still alive after 2 years. So half the women live less than those 2 years, and the other half live longer."	Oncologist: " I can't say much about your life expectancy; it's different for everyone. There are women who live a long time with the type of breast cancer you have, and there are women who do not live very long. We don't know how it will go for you."
NOT giving information about life expectancy (prognosis)[3-5]	Oncologist: "I can't say much about your life expectancy; it's different for everyone. There are women who live a long time with the type of breast cancer you have, and there are women who live less long . We don't know how it will go for you."	Oncologist: "I can say something about your life expectancy, although that is different for everyone. We know that half the women with your diagnosis are still alive after 2 years. So half the women live less than those 2 years, and the other half live longer."

Theme/Situation	Example of harmful communication	Potentially helpful alternative
Providing information without empathy[3,5-7]	Oncologist: “That was the result of the scan. So I will now discuss which treatment follows.”	Oncologist: “I’ve just discussed the results of the scan. I can imagine you will need to take a moment for it to sink in. Can you tell me how you feel after receiving this information?”
Providing too much information[5,6,8]	Oncologist: “So I will now take you through all the test results.”	Oncologist: “I can take you through all the test results, but alternatively we can just discuss the most important ones. What would you prefer at this point?”
Providing too little information[2,3,9]	Oncologist: “The results of the blood test are unfortunately not as we had hoped.”	Oncologist: “The results of the blood test are unfortunately not as we had hoped. The tumor marker is rising; in your case this means the cancer is becoming more active and growing again.”
Use of medical jargon[9,10]	Oncologist: “I have looked at your test results and the result is positive; there are signs that the cancer is progressive.”	Oncologist: “I have looked at the test results and they are not good: the tumor is growing.”
Negative framing of side effects[11]	Oncologist: “Just over half of patients feel more tired as a result of treatment, but it is impossible to predict how you will respond.”	Oncologist: “Just under half of patients are not troubled by fatigue as a result of treatment, but it is impossible to predict how you will respond.”
Making vague promises*	Oncologist: “I will call you” (giving no indication of when).	Oncologist: “I will call you as soon as I have discussed this with the team tomorrow afternoon. So I expect to be able to call you between 4-5pm.”
EMPATHY		
Not responding to emotions[6,10,12]	Patient: “I will manage to deal with this too. It’s just that my husband is sick too.” Oncologist: “Yes, you told me.” Patient: “Yes ... so, well ... (falls silent)” Oncologist: “Let’s measure your blood pressure.”	Patient: “I will manage to deal with this too. It’s just that my husband is sick too.” Oncologist: “Yes, you told me.” Patient: “Yes ... so, well ... (falls silent)” Oncologist: “Are you very worried about him?”
Not listening to the patient[8]	Patient: “I’ve also been experiencing pain when walking.” Not too bad, but it is uncomfortable.” Oncologist: “OK, and what about swallowing? Has that been going better?”	Patient: “I’ve also been experiencing pain when walking.” Not too bad, but it is uncomfortable.” Oncologist: “Is that worrying you?”
Providing reassurance before exploring whether the patient needs it[6]	Patient: “And I’ve been having headaches again.” Oncologist: “You don’t have to worry about that. I can really reassure you that has nothing to do with your cancer.”	Patient: “And I’ve been having headaches again.” Oncologist: “That’s too bad for you. Are you worried about it? Patient: “Not really. I just wondered if you could prescribe that medication again - that helped the last time.”
Not seeing the patient as a person[6-8,13]	Oncologist: “The tumor doesn’t seem to be growing, so that’s going well - great!”	Oncologist: “The tumor doesn’t seem to be growing, but how have you been feeling?”

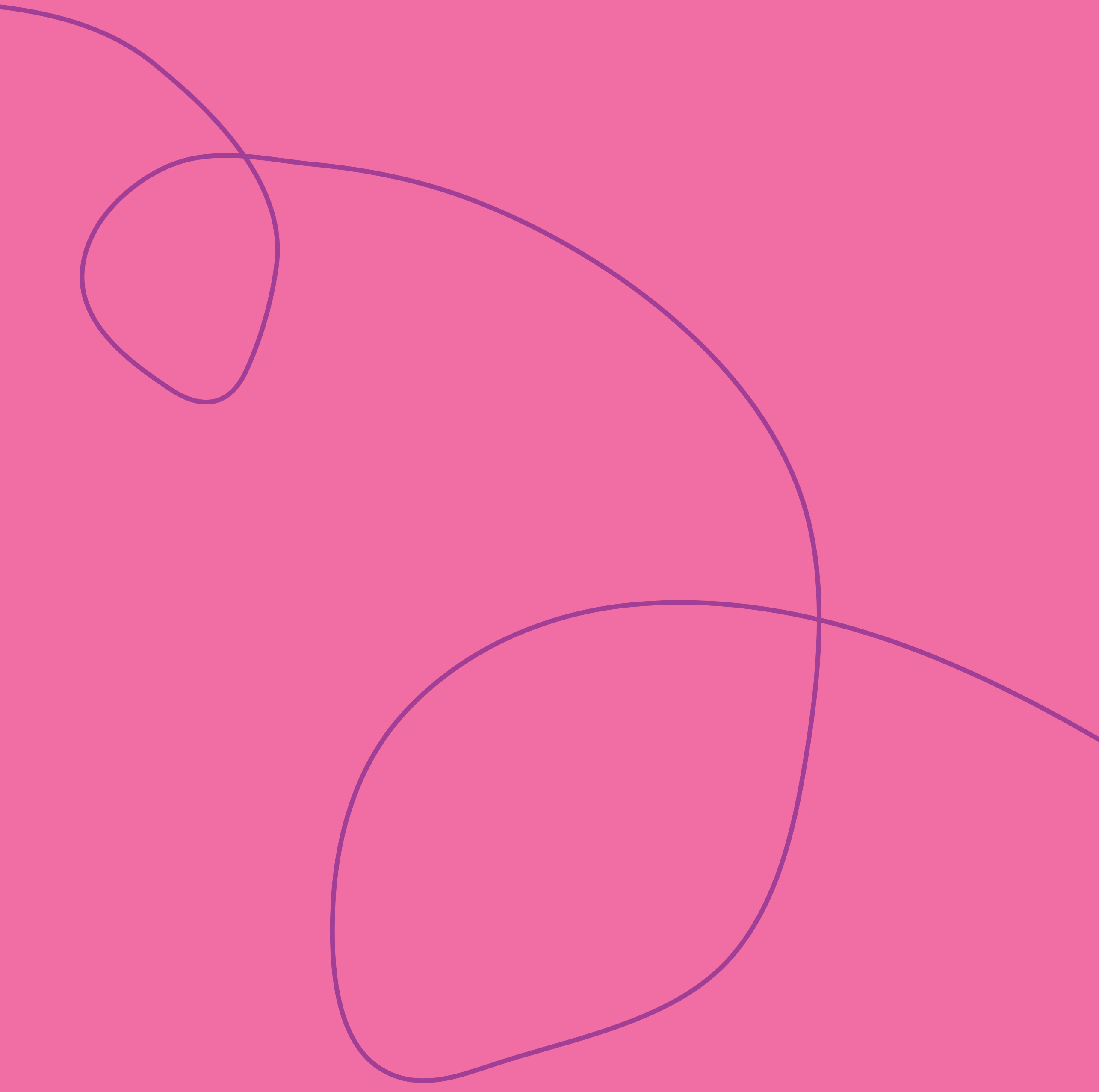
Theme/Situation	Example of harmful communication	Potentially helpful alternative
Not respecting the patient as an individual[1]	The oncologist calls a fellow oncologist in the patient's presence: The oncologist says: "**The patient** has been experiencing increasing pain in her back."	The oncologist calls a fellow oncologist in the patient's presence: The oncologist says: "**Ms. de Vries** has been experiencing increasing pain in her back".
Giving a compliment without room to disagree*	The oncologist says: "You're looking good" (which makes it hard to say you're not feeling good)	The oncologist says: "How are you feeling? You look great, but I know that doesn't always mean you're feeling that way."
WAR-METAPHORS		
Using war-metaphors**[14]	Oncologist: "I'm afraid we have lost the battle against cancer."	Oncologist: "Unfortunately, it seems that we cannot control the cancer with the treatment."

*Patient perspective

**War-metaphors: the results of this theme will be presented in a separate article.

REFERENCES APPENDIX 2

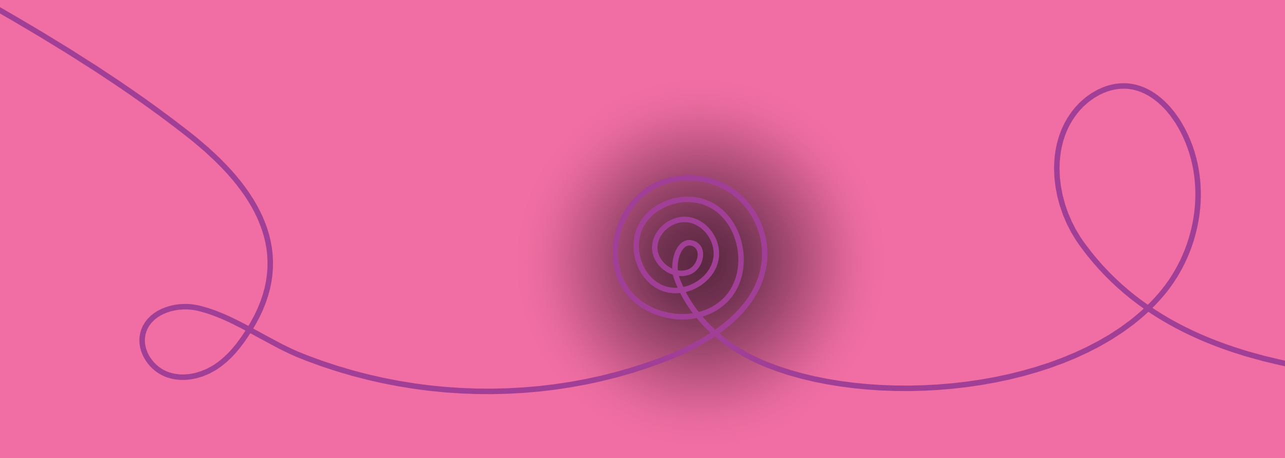
1. Mobbs N, Williams C, Weeks AD. Humanising birth: does the language we use matter? 2018
2. Brom L, De Snoo-Trimp JC, Onwuteaka-Philipsen BD, et al. Challenges in shared decision making in advanced cancer care: a qualitative longitudinal observational and interview study. *Health Expect*. 2017;20:69-84.
3. Thorne SE, Hislop TG, Armstrong EA, et al. Cancer care communication: the power to harm and the power to heal? *Patient Educ. Couns*. 2008;71:34-40
4. van Vliet LM. Balancing explicit with general information and realism with hope. Communication at the transition to palliative breast cancer care: *Utrecht University.* 2013.
5. Bergqvist J, Strang P. Breast Cancer Patients' Preferences for Truth Versus Hope Are Dynamic and Change During Late Lines of Palliative Chemotherapy. *J. Pain Symptom Manag.* 2019;57:746-752.
6. Back AL, Arnold RM, Baile WF, et al. Approaching difficult communication tasks in oncology 1. *CA Cancer J. Clin.* 2005;55:164-177.
7. Mack JW, Jacobson J, Frank D, et al. Evaluation of Patient and Family Outpatient Complaints as a Strategy to Prioritize Efforts to Improve Cancer Care Delivery. *Jt Comm J Qual Patient Saf.* 2017;43:498-507.
8. Mazor KM, Roblin DW, Greene SM, et al. Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response. *J. Clin. Oncol.* 2012;30:1784-1790..
9. Fallowfield LJ, Jenkins VA, Beveridge H. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat. Med.* 2002;16:297-303
10. Schofield P, Carey M, Love A, et al. 'Would you like to talk about your future treatment options?' Discussing the transition from curative cancer treatment to palliative care. *Palliat. Med.* 2006;20:397-406.
11. Webster, R. K.; Weinman, J.; Rubin, G. J. Explaining all without causing unnecessary harm: Is there scope for positively framing medical risk information?. *Patient Educ. Couns.* 2019;102:602-603..
12. Van Vliet LM, Francke AL, Westendorp J, et al. The Use of Expectancy and Empathy When Communicating With Patients With Advanced Breast Cancer; an Observational Study of Clinician-Patient Consultations. *Front. Psychiatry*. 2019;10:464.
13. Entwistle, V. A., et al. Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Quality and Safety in Health Care*. 2010;19:33
14. McCartney, M.. The fight is on: military metaphors for cancer may harm patients. *BMJ*. 2014;349



5

Harmful communication behaviors in cancer care: a systematic review of patients and family caregivers perspectives

This chapter is published as:
Westendorp, J., Geerse, O. P., van der Lee, M. L., Schoones, J. W., van Vliet, M. H., Wit, T., Evers, A. W. M. & van Vliet, L. M. (2023). Harmful communication behaviors in cancer care: A systematic review of patients and family caregivers perspectives. Psycho-Oncology, 32(12), 1827-1838.



ABSTRACT

Objective: Issues regarding clinician communication remain an important source of complaints within healthcare. This systematic review aims to determine cancer patients' and their family caregivers' views on which clinicians' communication behaviors can harm (i.e. eliciting negative feelings/consequences for patients/family caregivers).

Methods: We searched for all types of peer-reviewed studies that determined adult (≥18 years) cancer patients' and/or family caregivers' perspectives on which clinicians' communication behaviors can harm in several databases (PubMed, Embase, Web of Science, Cochrane Library, Emcare, PsycINFO and Academic Search Premier), supplemented by expert-consultation. Studies were screened using the Artificial intelligence (AI) screening tool of ASReview and data was analyzed using Thematic Analysis. To assess the quality of the studies the Qualsyst critical appraisal tool was used.

Results: A total of 47 studies were included. Four main themes of harmful communication behaviors were identified: 1) Lack of tailored information provision (e.g. giving too little or too much/specific information) 2) Lack of tailored decision making (ranging from; patient exclusion, to the patients' responsibility, and/or haste) 3) Lack of feeling seen and heard (seen as a disease, not as a human being; not listened to concerns and emotions) 4) Lack of feeling held and remembered (forgotten agreements; lack of care continuity).

Conclusions: Our results reveal an overview of patients' and family caregivers' perspectives on which clinicians' communication behaviors can harm. Harm could be prevented when information and decision involvement are tailored and patients' and family caregivers' needs to feel *seen, heard, held* and *remembered* are met.

BACKGROUND

What starts by hearing the words *"You have cancer.."* may be followed by difficult decisions, intensive treatments, side effects, anxiety and an uncertain future. Both for patients and their family caregivers (i.e. patients' loved ones including, but not limited to, relatives), the impact of cancer is enormous.[1-3] During the disease process patients and family caregivers experience a need for appropriate information (e.g. to make shared and well-informed decisions) and a need for support and empathy, in order to cope with their changing life perspectives.[4 5] Clinicians play a major role in meeting these needs.[6]

Helpful communication behaviors (e.g. responding to emotions, reassuring, providing tailored information) has been shown to consistently improve feelings of trust, satisfaction, recall of information and can decreases anxiety.[7-12] These helpful communication behaviors are increasingly incorporated into medical education.[13-17] Nevertheless, what is perceived as harmful communication is less clear, even though dissatisfaction with communication remains an important topic in patient-driven second opinions[18] and many complaints within the medical system are about communication.[19 20] It has also been shown that harmful communication might increase unnecessary psychosocial distress.[21] We define harmful communication behavior as clinicians' communication behavior which has the potential to unnecessarily harm (i.e. elicit negative feelings/consequences) patients or their family members. Recently, in a first-of-its-kind study, our research team explored the patient perspective of clinicians' harmful communication[22] and found, in line with other studies[23-27], that patients' communication preferences - e.g. about the preferred amount of information - often vary. This implies that there may be potential harm in not meeting their preferences.[22]

Importantly, while it is known that patients' family caregivers experience high levels of distress during the patients' disease trajectory[3 28], which communication behaviors they specifically perceive as harmful is also largely unknown. What we do know is that approximately 40 percent of family caregivers' needs are not met, due to lacking clinicians' communication behavior.[29] For example, family caregivers perceive deficits in receiving understandable information and being informed about who could help them with problems.[29]

We sought to better understand what patients and family caregivers specifically perceive as harmful communication behavior. The aim of this systematic review is therefore to determine cancer patients' and family caregivers' views on which clinicians' communication behaviors can harm. This may provide an important stepping stone to help clinicians improve their communication and further impact patient-reported outcomes by meeting communication needs.

METHODS

The systematic review protocol was published in the PROSPERO register (registration number: CRD42021236083) and adhered to the PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses).[30]

Database search

In cooperation with an experienced librarian (JS), a detailed search strategy was composed (see Appendix 1). The following databases were searched: PubMed, Embase (OVID-version), Web of Science, Cochrane Library, Emcare (OVID), PsycINFO (EBSCOhost) and Academic Search Premier. The query consisted of the combination of the following four concepts: I) Cancer II) Harmful communication III) Patients IV) Family caregivers. For these concepts, all relevant keyword variations were used. The search strategy was optimized for all consulted databases, taking into account the differences of the various controlled vocabularies as well as the differences of database-specific technical variations. The search was limited to the adult population and was performed on June 20, 2022. In addition to the database search, we e-mail consulted international experts (16 experts were approached, 13 responded, see Acknowledgments) in the field of clinician-patient communication for potentially relevant articles.

Eligibility

Studies were included if they met the following criteria: peer-reviewed article including data (e.g. qualitative studies, case reports, observational studies, RCT and systematic reviews), full text available, participants were adult (≥18 years) cancer patients (or survivors) AND/OR family caregivers, focus on cancer, reporting about harmful communication (i.e. eliciting negative feelings/consequences) by clinicians from a patients' or family caregivers' perspective.

Study screening

Title/abstract and full text screening were supported by a Microsoft Excel form to note the reasons for in- or exclusion. Following a pilot test of the Microsoft Excel form, 20 percent of the studies were double screened on title and abstract by JW/TW (absolute agreement was 90 percent). Disagreements were discussed with LV, until consensus was reached. Next, the Artificial Intelligence (AI) screening tool ASReview was used by JW for screening the rest of the studies on title and abstract.[31] Recently published systematic reviews described this tool as helpful in their screening process.[32-34] ASReview is a free and open-access machine learning technology used to save time and prevent from bias[35] and human errors.[36] To optimize the reliability of using ASReview we well prepared the AI screening process by means of the 20 percent double screening. The double screened included studies were manually added to ASReview in order to train the AI tool. ASReview then uses active learning to influence the order of articles based on relevance for the inclusion process. Sorting ensures that when many articles are excluded in a row, it can be assumed that the articles after can be labeled as irrelevant.[37 38] ASReview developers advised a screen-stop decision after 100-120 consecutively excluded studies. However, to ensure we would not miss any studies we decided on a screen-stop decision after 150 consecutively excluded studies.[39] JW/TW independently screened the remaining studies on full text and disagreements were solved by discussion (if needed with LV). Studies from the experts input were manually double-screened by JW/TW. LV double checked all the included studies of JW/TW on eligibility.

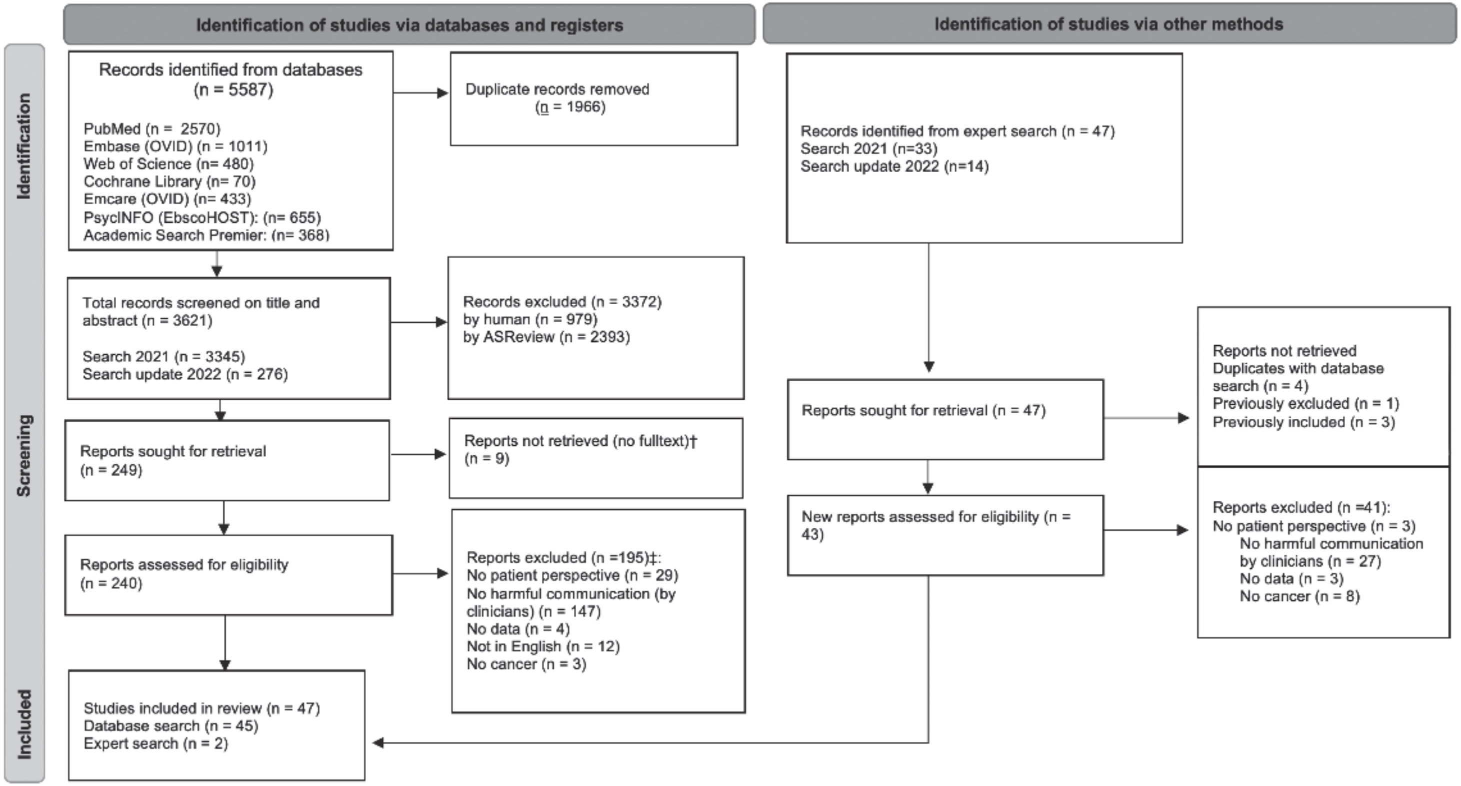
Data extraction and analysis

Several characteristics of the articles were extracted: first author, year of publication, country, sample size, participant characteristics (e.g. patient/family caregiver, age, type of cancer), type of clinician, study aim/design and type of harmful communication behavior. Initially, we aimed to perform a systematic review including a meta-analysis. However, due to the limited availability of quantitative data, a meta-analysis was not feasible. Consequently, we incorporated the quantitative data as harmful communication topics in the qualitative analysis. Thematic analysis was subsequently used to analyze the data concerning the harmful communication.[40] First, JW/TW independently read through the articles and identified the important reflections from participants on harmful communication. All quotations about harmful communication were highlighted in the articles and then copied to ATLAS.ti software. In step two, JW gave initial codes to all quotations (e.g. use of jargon, lack of support). Third, JW/TW/LV together discussed how to collate the codes into potential themes/groups (e.g. information provision, decision making). Then JW collated all codes under higher order themes and again discussed this with LV. Fourth, the themes were summarized and reviewed with all co-authors. Last, the co-authors' feedback was processed and final themes were defined.

Study quality

To assess the quality of the studies the Qualsyst critical appraisal tool by Kmet et al. [41] was used. Authors JW/TW independently assessed all studies and their agreement was calculated.

Figure 1. PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources



† First authors were e-mailed and asked for full text of these studies. When there was no response or possibility to provide full text, studies were excluded.

‡ Some studies were excluded due more than one reason

RESULTS

Literature Search

From 3621 database retrieved studies and 43 expert selected studies, in total 47 studies were included in this review (see Flowchart in Figure 1). These studies were published between 2002 and 2022, conducted in 14 countries (mostly USA, n=20) and involving a total of 4123 adult cancer patients and 231 family caregivers. Most patients (66%) were female and most (62%) family caregivers were male (three studies did not report gender). Eleven studies included family caregivers. Most studies focused on mixed types of cancer (n=20). Eighteen studies included patients with advanced cancer. Studies had qualitative designs (n=42) or used mixed methods (n=5; quantitative data were only used as input for qualitative themes). Quality of the included studies was either strong (n=44) or good (n=3)[41] and the agreement between JW/TW was 92 percent. Detailed study characteristics were provided in Appendix 2.

Harmful communication

Four main themes of harmful communication behaviors were identified: 1) Lack of tailored information provision 2) Lack of tailored decision making 3) Lack of feeling seen and heard 4) Lack of feeling held and remembered. (Sub)themes are described below with additional supporting quotations shown in Appendix 3.

Theme 1: Lack of tailored information provision

Too few and too many provided treatment options, and information about these options, could make it more difficult for patients to make well-considered decisions

Patients reported how both too few [22 42-48] and too many [22 49-53] provided treatment options, and information about these options, could harm because both make it difficult for patients to make well-considered decisions. For example, patients mentioned that sometimes information about complementary and alternative treatment was lacking, while they wanted to include this in their considerations. Discussing too many treatment options could overwhelm patients, especially when someone just received shocking news. In addition, family caregivers mentioned that too much information at once was difficult to process for the patient.[42]

Lack of information about treatment consequences could increase distress and make it more difficult to make well-informed decisions

Patients reported on how too little information on treatment consequences (e.g. side effects, fertility consequences)[25 42 43 45 46 48 50-59] could increase feelings of distress (e.g. anxiety and discouragement). A lack of information made patients feel uninformed about what to expect, which makes it more difficult for them to prepare for what is to come and to make well-informed decisions. When patients have to deal with potential consequences (e.g. side effects or fertility consequences) they were not prepared for, it could make patients feel upset and cause loss of confidence.

Too much test result information could overwhelm and too little keeps it uncertain
Patients reported that providing either too much and too little information about tests could be harmful.[22] Too much detailed information may be incomprehensible to patients and overwhelm them. Too little information (e.g. only mentioning it is good or bad) leaves the situation for patients unclear.

Prognostic information provision could be harmful when timing is poor and patients receive numeric or vague information
With regard to timing of prognostic information, patients especially perceived harm when prognostic information was discussed too early.[25 44 45 55 60-65] This could cause anxiety and take away hope, which some patients so desperately need to stay upright mentally and physically. In contrast, caregivers reported that it is harmful when prognostic information is discussed too late (too close to death)[66 67] as it takes away the time to say goodbye to a loved one. Starting too late [61 66 67] with discussing the approaching end of life (too close to death) could also cause false hope (for both patient and caregiver). For some, receiving numerical prognostic information was perceived as harmful [22 25 62 63 65 68] because this number is inherently uncertain, but it can get stuck in patients' minds, causing them to suffer mentally (e.g. increase anxiety). For others, vague or partial information about prognosis could be harmful [22 51 62 67] because it makes it unclear for patients and caregivers where they stand.

Contradictions in information (e.g. from different clinicians) may cause confusion and feelings of helplessness
Inconsistent information (different clinicians providing different information) made patients [25 42 46 50 51 53 55 56 60 63 69-71] and their family caregivers [60 66] confused, frustrated and could increase feelings of helplessness. As a result of conflicting information, family caregivers experience difficulties in understanding the situation of their loved one.

Jargon could diminish understanding and lead to anxiety
Clinicians using confusing language (e.g. medical jargon) that prevents patients [22 42 48 51 55 57 60 61] and their family caregivers [60 66] from fully comprehending the provided information which could increase confusion, uncertainty and fear.

Theme 2: Lack of tailored decision making

Exclusion from treatment decisions is impersonal and could cause distress
Excluding patients from the decision making process has been identified as potentially harmful [22 25 51 57 59 72-74] as it could increase patients' distress and make them feel like they do not participate in the conversation. Occasionally patients mentioned clinicians forcing treatments upon them, making them feel as if they are a medical case and not a person.

Making treatment choices entirely the patient's responsibility could be overwhelming and stressful
Leaving the treatment decision completely to the patient (lack of an advice) [50 51 58 62 70] may be undesirable because some patients get overwhelmed by this responsibility and believe that they don't have enough knowledge to make such a difficult and important decision.

Forcing patients to hasty decisions result in ill-considered choices due to lack of room for the options to sink in
Patients being forced by their clinician to make a hasty decision was perceived as harmful communication behavior [49 51 58 62] because then there was no room for the information and situation to sink in.

Theme 3: Lack of feeling seen and heard

Providing information in an inappropriate manner; rude, cold and uncaring
The manner in which information is provided to patients matters too. Patients [22 25 42 44 45 48-50 56 57 59-63 72 75] and family caregivers [25 42 60 66-68 72] described harmful manners of communication (causing dissatisfaction and anger): rude, uncaring, impolite, unpleasant, inhumanely, insensitively, thrown in the face, cold and uncivil.

Inadequately addressing concerns seriously left patients feeling dismissed and could lower feelings of confidence and trust
A lack of taking patients' concerns seriously (e.g. ignoring or not taking patients' physical complaints serious) is perceived as harmful by patients [22 42 44 45 49 50 71 76-78] because it left them feeling dismissed. This could lower their trust in the clinician. This theme was most frequently described by patients who were not taken seriously in early stages (prior to diagnosis). As a result, physical complaints and feelings of desperation may increase.

A lack of validation of, or not responding to, patients’ concerns and emotions could increase anxiety and feelings of loneliness
A lack of validation of the patients’ situation and their (emotional) concerns was perceived as harmful (e.g. failure to respond to patients’ emotional cues).[22 25 46 50 51 54 56 57 61-63 71 73 77-84] When patients’ concerns are not taken seriously (e.g. about side effects), it may increase anxiety and feelings of loneliness. Concrete examples of (well-intentioned) comments that could be perceived as harmful because they lack validation of patients’ situation are *“You look great”*[22] (gives patients no room to indicate if they don’t feel well at all) and *“Luckily you have the ‘good’ cancer”*[80] (downplayed the diagnosis / gives the feeling patients do not need much support).

Lack of a personal approach could give the impression that clinicians do not care about the patient and family caregiver as a person
Not seeing/treating the patient as a person was perceived as harmful.[22 25 51 56 57 60 62 63 72 78 82 84] A rushed attitude, not using someone’s name and no interest in someone’s life besides the disease was experienced as disrespectful and patients got the feeling that they are treated as a number, a diagnosis/case or a *‘piece of meat’.*[84]

Not taking into account the role and needs of family caregivers could cause feelings of marginalization
Both patients [54 71] and family caregivers themselves [25 42 46 66 67 79 85] mentioned that the role and needs of family caregivers should not be forgotten. When family caregivers were not included in conversations, were not aware of their loved one’s situation, and (existential) support for them was lacking, their distress could increase and they feel marginalized.

Theme 4: Lack of feeling held and remembered

Experiencing a lack of time for concerns to be properly heard could make patients feel like a burden
When clinicians’ (non)verbal communication shows that there is no or too little time for patients’ concerns to be properly heard [25 42 46 51 54 55 57 61-63 72 73 77-79 81-83], this could make patients feel like a burden, and therefore they were second guessing themselves with their worries/concerns. More specifically, patients with incurable cancer (and their family caregivers) mentioned that providers who exhibited a lack of time, made them feel dismissed and ‘written off’. Several of these patients interpreted such dismissals as messages they were no longer important because their disease could no longer be cured.

Specific harmful examples were cited by both patients and family caregivers. First, healthcare professionals explicitly mentioning how busy they are.[42] Second, nonverbal behavior such as hurried body language or looking at a watch.[62] Third, unexpectedly receiving information or a diagnosis by letter or telephone (resulting in unanswered questions and lingering concerns).[42 46 81] Fourth, the lack of room to ask questions in general [25 42 50 54 55 57 72 73 81], caused more persistent stress in patients.

Excessive waiting and not keeping appointments could increase distress

In several studies patients [22 45 46 55 57 66 81 82] and family caregivers [42 46 55 66] reported it as harmful when they had to wait excessively (e.g. for promised appointments or calls). Especially waiting for important information (e.g. test results), after the agreed time is exceeded, was perceived as harmful because patients are in suspense/fear which increases with time. Also vague promises (e.g. "*I call you on Friday..*")[22] were perceived as harmful because this leaves patients feeling unsettled and insecure.

Experiencing a lack of continuity of care could increase uncertainty, confusion and feelings of abandonment

Insufficient continuing care and (existential) support for patients' needs increases anxiety, uncertainty, confusion and feelings of loneliness.[22 43 50 54 55 57 59-61 71-73 77-79 86] Specifically stating that "*there is nothing more we can do for you*"[77] was experienced as extremely destroying because it takes away hope and made patients feel abandoned. Lack of continuation of the same care providers was also perceived as harmful to patients [57 60 71 78 86] and caregivers [60 66], because patients have to tell their story over and over to different clinicians.

DISCUSSION

This systematic review aimed to determine patients' and their family caregivers' views on which clinicians' communication behaviors can harm. A thematic analysis of the literature revealed that harm might occur when these four needs of patients and family caregivers were not met: 1) *need for tailored information provision*, 2) *need for tailored decision making*, 3) *need of feeling seen and heard,* and 4) *need of feeling held and remembered*.

As we found that both untailored information-provision (e.g. too little versus too much) and untailored decision-making (e.g. excluding patients versus making them feel responsible) were perceived as harmful, it is interesting to note that patients' reasons for preferring all information versus those who do not want all information and whether they want to be actively involved in decision-making seem to overlap. In line with other studies, patients reported a need for control and autonomy as reasons for preferring much information (e.g. about prognosis) and active participation in decision making[87 88]. Patients who prefer less information and a more paternalistic decision making approach do not feel capable enough to comprehend such important information and decisions.[87 89 90] Of course, this does not automatically mean that people who want much information also prefer to be actively involved in all decision-making, and vice-versa (although older literature does hint towards this[91 92]). This might be most apparent in patients with low health literacy, as patients might not ask many questions[93], but do benefit from receiving information[94] and want to be involved in decision-making.[95] To do so, in line with our results, strategies such as not using jargon and providing too much information at once are likely essential first steps to prevent harmful communication.[96] The perceived harmfulness of not feeling *seen, heard, held and remembered* adds to the large available literature on the importance of clinician-expressed empathy.[97-99] Within the wider construct of clinical empathy[100] both, the need to be seen (as human being) and the need to be heard (concerns should be listened to), overlap with what other researchers have previously described as the need to *feel known*[5] and to *'feeling heard and understood'.*[101] What our study adds is a new dimension of the need to feel *held and remembered* (continuous care). Previous studies show that patients perceive good institutional resources and care processes (e.g. kept agreements, same clinicians) as an important value.[78 102] However, never before was highlighted that these themes show an underlying need to be *held and remembered.*

Clinical implications

To prevent harm in information provision and decision making, tailoring is essential. First, the preferred amount of information someone wants can be tailored both in general (e.g. *"Some people prefer very detailed information, others prefer to hear only the rough picture, and then there are those in the middle. What kind of person are you?"* [5]), and in specific topics (e.g. about prognosis: "*Some people, but not all, want information about their life expectancy. It's different for everyone. What are your needs here?"*[22 23]). It's noteworthy to acknowledge potential friction that arises when the patient prefers not to receive detailed information about all treatment options (to avoid becoming overwhelmed) while the clinician is obligated to maintain the principles of complete informed consent. Helpful would be to provide all options without going into exhaustive details of all potential side effects.[103] Second, the preferred extent of involved decision-making can be tailored (e.g. "*Some people want to make decisions together; others want to do it themselves. What are your needs? Would you like to hear my recommendation at this point?*"[22 23]). We should note, however, that patients' preferences are no fixed beliefs, and are prone to change over time (e.g. when patients become sicker).[104 105] Repeatedly exploring patients' preferences can be helpful[106 107], while future studies can explore (using longitudinal methods) how patients' needs change during the disease process.[108] Moreover, we could speculate that when patients enter the incurable phase of their illness, their information and decision needs shift towards a *'what matters most'* approach[102 109 110], in which it is not always necessary to discuss all information and options. It might be more important to individually explore what matters most to someone (e.g. *"What are your most important goals?"*[111]), and to prepare for hypothetical deterioration[112] (e.g. *"It can be difficult to predict what will happen. I hope you will feel as well as possible for a long time, and we will work toward that goal. It's also possible that it may get harder to do things because of your illness, and I think it is important that we prepare for that*[111]*).*

To meet patients' and family caregivers' needs to feel *seen* and *heard,* an individual approach is desired, with acknowledgement for the (emotional) impact of cancer on their lives. Methods to do this are first, providing space after giving medical information (gives the patient the opportunity to assimilate the information and respond [23 113]) and second, responding to the patients' emotions (e.g. using NURSE: naming, understanding, respecting, supporting, exploring [5 23]) and not ignoring them. Showing interest in the patients' life and building a relationship (e.g. *"I know all the medical details, but tell me more about who you were before this illness and how this has affected you and your loved ones.*"[5]) could also help. However, the need to be *held and remembered* goes one step further: entering into a relationship with your patient and then maintaining this relationship. Not meeting these needs could increase feelings of abandonment and make patients feel like a burden, especially when patients have poor prognosis.[61 114 115] This emphasizes the importance of reassurance that continuity of care is guaranteed (e.g. *"We cannot cure the cancer, but there is still plenty we can do and will do to help you, including helping you come to terms with this news. We will continue seeing you."*[22]). Continuous support may become more challenging in the future as more people with cancer live longer[116] due to improved (experimental) treatment (which also increases mental burden[117]), expected decrease of clinicians[118] and increased use of digitalized healthcare systems.[119] Future research should focus on how to tackle this challenge, while still providing the best continuous support for patients and their family caregivers. Within the context of the last two themes, a reflection on the distinction between harmful communication at the systemic level versus the individual clinician's level is needed. Clinicians need to know what they can do on individual level to avoid causing harm within the constraints of the system he/she is working in. For instance, our data illustrates that patients perceive 'excessive waiting' (e.g. for test results) as harmful. Providing patients with a more concrete message while they are waiting can be helpful. For example: *"We will call you between 4 and 5. If we have not called by then, you can reach out to us yourself"*.[22] Additionally, literature indicates that insufficient time for conversations with the clinician is considered as unpleasant. This issue appear to be systemic and challenging for an individual healthcare provider to overcome. Nevertheless, literature demonstrates that small adjustments or behaviors can make a difference. For example, sitting instead of standing at the patient's bedside already gives patients the feeling that the consultation takes longer (without actually taking more time, possibly even less [120]). These approaches demonstrate that it is still possible to make a difference at the individual level.

Limitations and future directions

Our systematic review has limitations. First, we only included English and Dutch papers and thus overrepresenting papers from the global north. Future studies could investigate the cross-cultural difference in information needs of patients and family caregivers, as these needs are expected to vary widely.[121] [122] Secondly, due to the limited available data regarding the experiences of family caregivers, as compared to patients, it was challenging to draw distinctions between those two groups. This finding underscores the importance for future studies to conduct more in-depth research on the family caregivers perspective on harmful communication behavior. Thirdly, because many studies lacked data on disease stage, we were unable to make any determinations regarding a potential variation in harmful communication across clinical settings, which could be a valuable direction for future studies too. Lastly, we focused on clinicians' communication, while patients interact with many other healthcare staff. We do not know whether the same results would be found for other health care professionals or aligned staff. We cannot rule out that harmful communication behaviors reported in our study were expressed by others than clinicians themselves.

Since having difficult and emotional conversations with patients is a core task of clinician – which they feel untrained and ill-equipped for[123]– we hope this systematic review can provide clinicians with tools to have these consultations while preventing unnecessary potential harm. Communication trainings can assist to teach clinicians in avoiding these harmful communication behaviors and implement the helpful communication suggestions in clinical care, especially after studies have determined which behaviors have the greatest detrimental/ beneficial effects on patient-reported outcomes. Until then we hope this systematic review will inspire clinicians to embed communication's power for the better and not the worse.

Conclusions

Our results reveal a comprehensive overview of cancer patients' and family caregivers' perspectives on which clinicians' communication behaviors can harm. Harm could be prevented when information and decision involvement are tailored and patients' and family caregivers' needs to feel *seen, heard, held* and *remembered* are met. We hope this systematic review can provide clinicians with tools to communicate with patients and their family caregivers while preventing unnecessary potential harm.

REFERENCES

1. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *The lancet oncology* 2011;12(2):160-74.
2. Van den Beuken-van Everdingen M, De Rijke J, Kessels A, et al. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Annals of oncology* 2007;18(9):1437-49.
3. Götze H, Brähler E, Gansera L, et al. Anxiety, depression and quality of life in family caregivers of palliative cancer patients during home care and after the patient's death. *European journal of cancer care* 2018;27(2):e12606.
4. Bensing JM, Dronkers J. Instrumental and affective aspects of physician behavior. *Medical care* 1992:283-98.
5. van Vliet LM, Epstein AS. Current state of the art and science of patient-clinician communication in progressive disease: patients' need to know and need to feel known. *Journal of Clinical Oncology* 2014;32(31):3474.
6. Benedetti F. Placebo and the new physiology of the doctor-patient relationship. *Physiological reviews* 2013;93(3):1207-46.
7. Westendorp J, Stouthard J, Meijers MC, et al. The power of clinician-expressed empathy to increase information recall in advanced breast cancer care: an observational study in clinical care, exploring the mediating role of anxiety. *Patient education and counseling* 2021;104(5):1109-15.
8. Van Vliet LM, Francke AL, Meijers MC, et al. The use of expectancy and empathy when communicating with patients with advanced breast cancer; an observational study of clinician–patient consultations. *Frontiers in Psychiatry* 2019;10:464.
9. Hoffstädt H, Stouthard J, Meijers MC, et al. Patients' and clinicians' perceptions of clinician-expressed empathy in advanced cancer consultations and associations with patient outcomes. *Palliative Medicine Reports* 2020;1(1):76-83.
10. Hillen M, De Haes H, Stalpers L, et al. How can communication by oncologists enhance patients' trust? An experimental study. *Annals of oncology* 2014;25(4):896-901.
11. Patel S, Pelletier-Bui A, Smith S, et al. Curricula for empathy and compassion training in medical education: a systematic review. *PloS one* 2019;14(8):e0221412.
12. Schofield PE, Butow PN, Thompson JF, et al. Psychological responses of patients receiving a diagnosis of cancer. *Annals of oncology* 2003;14(1):48-56.
13. Smith KA, Vennik J, Morrison L, et al. Harnessing placebo effects in primary care: using the person-based approach to develop an online intervention to enhance practitioners' communication of clinical empathy and realistic optimism during consultations. *Frontiers in Pain Research* 2021:49.
14. Barth J, Lannen P. Efficacy of communication skills training courses in oncology: a systematic review and meta-analysis. *Annals of oncology* 2011;22(5):1030-40.
15. Fujimori M, Shirai Y, Asai M, et al. Development and preliminary evaluation of communication skills training program for oncologists based on patient preferences for communicating bad news. *Palliative & supportive care* 2014;12(5):379-86.
16. Back AL, Arnold RM, Baile WF, et al. Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Archives of internal medicine* 2007;167(5):453-60.
17. Westendorp J, Peerdeman, K. J., Meeuwis, S. H., van Vliet, L. M., Evers, A.W.M. Development of a Virtual Reality communication training for optimizing placebo and minimizing nocebo effects. in preparation

18. Hillen MA, Medendorp NM, Daams JG, Smets EM. Patient-driven second opinions in oncology: a systematic review. *The oncologist* 2017;22(10):1197-211.
19. Cohen-Mansfield J, Skornick-Bouchbinder M, Cohen R, Brill S. Treatment and communication–that is what matters: An analysis of complaints regarding end-of-life care. *Journal of Palliative Medicine* 2017;20(12):1359-65.
20. Abdelrahman W, Abdelmageed A. Understanding patient complaints. *BMJ: British Medical Journal* 2017;356
21. Thorne SE, Bultz BD, Baile WF. Is there a cost to poor communication in cancer care?: a critical review of the literature. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 2005;14(10):875-84.
22. Westendorp J, Evers AW, Stouthard JM, et al. Mind your words: Oncologists' communication that potentially harms patients with advanced cancer: A survey on patient perspectives. *Cancer* 2022;128(5):1133-40.
23. Back AL, Arnold RM, Baile WF, et al. Approaching difficult communication tasks in oncology. *CA Cancer J Clin* 2005;55(3):164-77. doi: 10.3322/canjclin.55.3.164 [published Online First: 2005/05/14]
24. Bergqvist J, Strang P. Breast Cancer Patients' Preferences for Truth Versus Hope Are Dynamic and Change During Late Lines of Palliative Chemotherapy. *J Pain Symptom Manage* 2019;57(4):746-52. doi: 10.1016/j.jpainsymman.2018.12.336. Epub 2019 Jan 11. [published Online First: 2019/01/15]
25. Thorne SE, Hislop TG, Armstrong EA, Oglov V. Cancer care communication: the power to harm and the power to heal? *Patient Educ Couns* 2008;71(1):34-40. doi:10.1016/j.pec.2007.11.010. Epub 2007 Dec 21. [published Online First: 2007/12/22]
26. van der Velden NC, Meijers MC, Han PK, et al. The effect of prognostic communication on patient outcomes in palliative cancer care: a systematic review. *Current Treatment Options in Oncology* 2020;21:1-38.
27. Hagerty RG, Butow PN, Ellis PA, et al. Cancer patient preferences for communication of prognosis in the metastatic setting. *Journal of clinical oncology* 2004;22(9):1721-30.
28. Van Roij J, Zijlstra M, Ham L, et al. Prospective cohort study of patients with advanced cancer and their relatives on the experienced quality of care and life (eQuiPe study): a study protocol. *BMC Palliative Care* 2020;19:1-9.
29. Friðriksdóttir N, Sævarsdóttir Þ, Halfdánardóttir SÍ, et al. Family members of cancer patients: Needs, quality of life and symptoms of anxiety and depression. *Acta Oncologica* 2011;50(2):252-58.
30. Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Annals of internal medicine* 2009;151(4):264-69.
31. Van De Schoot R, De Bruin J, Schram R, et al. An open source machine learning framework for efficient and transparent systematic reviews. *Nature machine intelligence* 2021;3(2):125-33.
32. Rakhshandehroo S, Duits N, Bergman D, et al. Psychopathology in female offenders of terrorism and violent extremism: a systematic review. *Frontiers in Psychiatry* 2023;14
33. Warren SL, Moustafa AA. Functional magnetic resonance imaging, deep learning, and Alzheimer's disease: A systematic review. *Journal of Neuroimaging* 2023;33(1):5-18.
34. Nagtegaal R, de Boer N, van Berkel R, et al. Why Do Employers (Fail to) Hire People with Disabilities? A Systematic Review of Capabilities, Opportunities and Motivations. *Journal of Occupational Rehabilitation* 2023:1-12.
35. Ferdinands G, Schram R, Bruin Jd, et al. Active learning for screening prioritization in systematic reviews-A simulation study. 2020

36. Wang Z, Nayfeh T, Tetzlaff J, et al. Error rates of human reviewers during abstract screening in systematic reviews. *PloS one* 2020;15(1):e0227742.
37. A machine learning approach for semi-automated search and selection in literature studies. Proceedings of the 21st International Conference on Evaluation and Assessment in Software Engineering; 2017.
38. Yu Z, Menzies T. FAST2: An intelligent assistant for finding relevant papers. *Expert Systems with Applications* 2019;120:57-71.
39. Penfornis KM, Van Vliet MH, Meijer E, Gebhardt WA. Mapping the evidence on identity processes and identity-related interventions in the smoking and physical activity domains: a scoping review protocol. *BMJ open* 2022;12(7):e058405.
40. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology* 2006;3(2):77-101.
41. Kmet LM, Cook LS, Lee RC. Standard quality assessment criteria for evaluating primary research papers from a variety of fields. 2004
42. Olsson EM. Interpersonal complaints regarding cancer care through a gender lens. *Int J Health Care Qual Assur* 2016;29(6):687-702. doi: 10.1108/IJHCQA-03-2014-0032. [published Online First: 2016/06/15]
43. Martinez Tyson DD, Vázquez-Otero C, Medina-Ramirez P, et al. Understanding the supportive care needs of Hispanic men cancer survivors. *Ethn Health* 2017;22(1):1-16. doi:10.1080/13557858.2016.1196649. Epub 2016 Jun 27. [published Online First: 2016/06/29]
44. Mazor KM, Greene SM, Roblin D, et al. More than words: Patients' views on apology and disclosure when things go wrong in cancer care. *Patient Education and Counseling* 2013;90(3):341-46. doi: 10.1016/j.pec.2011.07.010
45. Mazor KM, Roblin DW, Greene SM, et al. Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response. *J Clin Oncol* 2012;30(15):1784-90. doi:10.1200/JCO.2011.38.1384. Epub 2012 Apr 16. [published Online First: 2012/04/18]
46. Kimberlin C, Brushwood D, Allen W, et al. Cancer patient and caregiver experiences: communication and pain management issues. *J Pain Symptom Manage* 2004;28(6):566-78. doi: 10.1016/j.jpainsymman.2004.03.005. [published Online First: 2004/12/14]
47. Tasaki K, Maskarinec G, Shumay DM, et al. Communication between physicians and cancer patients about complementary and alternative medicine: exploring patients' perspectives. *Psychooncology* 2002;11(3):212-20. doi:10.1002/pon.552. [published Online First: 2002/07/12]
48. Evans N, Pasman HRW, Payne SA, et al. Older patients' attitudes towards and experiences of patient-physician end-of-life communication: a secondary analysis of interviews from British, Dutch and Belgian patients. *Bmc Palliative Care* 2012;11:10. doi: 10.1186/1472-684x-11-24
49. Adamson M, Choi K, Notaro S, Cotoc C. The Doctor-Patient Relationship and Information-Seeking Behavior: Four Orientations to Cancer Communication. *J Palliat Care* 2018;33(2):79-87. doi:10.1177/0825859718759881. Epub 2018 Mar 7. [published Online First: 2018/03/09]
50. Bentsen L, Pappot H, Hjerming M, et al. How Do Young Women with Cancer Experience Oncofertility Counselling during Cancer Treatment? A Qualitative, Single Centre Study at a Danish Tertiary Hospital. *Cancers* 2021;13(6):1355. doi: 10.3390/cancers13061355
51. Hillen MA, Gutheil CM, Smets EMA, et al. The evolution of uncertainty in second opinions about prostate cancer treatment. *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy* 2017;20(6):1264-74. doi: 10.1111/hex.12566

52. Haase KR, Avery J, Bryant-Lukosius D, et al. Patient and clinician perspectives of desired features for a web-based self-management program (icanmanage. ca): Exposing patients “hard work” of managing acute cancer. *Supportive Care in Cancer* 2021;29:1989-98.
53. Ormel I, Magalhaes M, Josephson D, et al. How to know what to know: Information challenges for women in the diagnostic phase of breast cancer. *Patient education and counseling* 2021;104(1):179-85.
54. Droog E, Armstrong C, MacCurtain S. Supporting patients during their breast cancer journey: the informational role of clinical nurse specialists. *Cancer Nurs* 2014;37(6):429-35. doi:10.1097/NCC.0000000000000109. [published Online First: 2014/01/11]
55. Mazor KM, Beard RL, Alexander GL, et al. Patients’ and family members’ views on patient-centered communication during cancer care. *Psychooncology* 2013;22(11):2487-95. doi:10.1002/pon.3317. Epub 2013 Jun 18. [published Online First: 2013/06/20]
56. Ussher JM, Parton C, Perz J. Need for information, honesty and respect: patient perspectives on health care professionals communication about cancer and fertility. *Reprod Health* 2018;15(1):2. doi:10.1186/s12978-017-0441-z. [published Online First: 2018/01/07]
57. Marcusson-Rababi B, Anderson K, Whop LJ, et al. Does gynaecological cancer care meet the needs of Indigenous Australian women? Qualitative interviews with patients and care providers. *BMC Health Serv Res* 2019;19(1):606. doi:10.1186/s12913-019-4455-9. [published Online First: 2019/08/30]
58. Brotzman LE, Crookes DM, Austin JD, et al. Patient perspectives on treatment decision-making under clinical uncertainty: chemotherapy treatment decisions among stage II colon cancer patients. *Translational behavioral medicine* 2021;11(10):1905-14.
59. El-Sayed E, Abdelgawad E, Dowidar NL, Mehanna AA. Breast Cancer Patients’ Experience about Involvement in Health Care: A Qualitative Study. *Journal of High Institute of Public Health* 2021;51(3):114-20.
60. Villalobos M, Coulibaly K, Krug K, et al. A longitudinal communication approach in advanced lung cancer: A qualitative study of patients’, relatives’ and staff’s perspectives. *Eur J Cancer Care (Engl)* 2018;27(2):e12794. doi: 10.1111/ecc.12794. Epub 2017 Nov 23. [published Online First: 2017/11/24]
61. Stajduhar KI, Thorne SE, McGuinness L, Kim-Sing C. Patient perceptions of helpful communication in the context of advanced cancer. *Journal of Clinical Nursing* 2010;19(13-14):2039-47. doi: 10.1111/j.1365-2702.2009.03158.x
62. Thorne S, Oliffe JL, Stajduhar KI, et al. Poor communication in cancer care: patient perspectives on what it is and what to do about it. *Cancer Nurs* 2013;36(6):445-53. doi: 10.1097/NCC.0b013e31827eeda4. [published Online First: 2013/01/26]
63. Thorne S, Oglov V, Armstrong EA, Hislop TG. Prognosticating futures and the human experience of hope. *Palliat Support Care* 2007;5(3):227-39. doi:10.1017/s1478951507000399. [published Online First: 2007/11/01]
64. Liu JE, Mok E, Wong T. Perceptions of Chinese cancer patients of the favorable and unfavorable words conveyed by their social support providers. *Cancer Nurs* 2005;28(5):348-54. doi:10.1097/00002820-200509000-00003. [published Online First: 2005/09/30]
65. Jindal SK, Karamourtopoulos M, Jacobson AR, et al. Strategies for discussing long-term prognosis when deciding on cancer screening for adults over age 75. *Journal of the American Geriatrics Society* 2022;70(6):1734-44.

66. Waldrop DP, Meeker MA, Kerr C, et al. The nature and timing of family-provider communication in late-stage cancer: A qualitative study of caregivers' experiences. *Journal of Pain and Symptom Management* 2012;43(2):182-94. doi: 10.1016/j.jpainsymman.2011.04.017
67. Sisk BA, Keenan MA, Schulz GL, et al. Bereaved caregivers perspectives of negative communication experiences near the end of life for adolescents and young adults with cancer. *Journal of adolescent and young adult oncology* 2022;11(5):498-505.
68. Islam KM, Opoku ST, Apenteng BA, et al. Coping with an advanced stage lung cancer diagnosis: Patient, caregiver, and provider perspectives on the role of the health care system. *Journal of Cancer Education* 2016;31(3):554-58. doi: 10.1007/s13187-015-0840-1
69. Xu LW, Vaca SD, Nalwanga J, et al. Life After the Neurosurgical Ward in Sub-Saharan Africa: Neurosurgical Treatment and Outpatient Outcomes in Uganda. *World Neurosurg* 2018;113:e153-e60. doi:10.1016/j.wneu.2018.01.204. Epub 2018 Feb 8. [published Online First: 2018/02/11]
70. Ziebland S, Evans J, McPherson A. The choice is yours? How women with ovarian cancer make sense of treatment choices. *Patient Educ Couns* 2006;62(3):361-7. doi: 10.1016/j.pec.2006.06.014. Epub 2006 Jul 28. [published Online First: 2006/08/01]
71. Beaver K, Williamson S, Briggs J. Exploring patient experiences of neo-adjuvant chemotherapy for breast cancer. *European Journal of Oncology Nursing* 2016;20:77-86. doi: 10.1016/j.ejon.2015.06.001
72. Lee SF, Kristjanson LJ, Williams AM. Professional relationships in palliative care decision making. *Support Care Cancer* 2009;17(4):445-50. doi:10.1007/s00520-008-0516-z. Epub 2008 Nov 6. [published Online First: 2008/11/07]
73. Blanch-Hartigan D, Chawla N, Moser RP, et al. Trends in cancer survivors' experience of patient-centered communication: Results from the Health Information National Trends Survey (HINTS). *Journal of Cancer Survivorship* 2016;10(6):1067-77. doi: 10.1007/s11764-016-0550-7
74. Flynn S, Hulbert-Williams NJ, Hulbert-Williams L, Bramwell R. "You don't know what's wrong with you": an exploration of cancer-related experiences in people with an intellectual disability. *Psychooncology* 2016;25(10):1198-205. doi:10.1002/pon.4211. Epub 2016 Aug 2. [published Online First: 2016/07/09]
75. Zebrack B, Chesler MA, Kaplan S. To foster healing among adolescents and young adults with cancer: what helps? What hurts? *Support Care Cancer* 2010;18(1):131-5. doi:10.1007/s00520-009-0719-y. Epub 2009 Aug 20. [published Online First: 2009/08/20]
76. Im EO, Lee SH, Liu Y, et al. A national online forum on ethnic differences in cancer pain experience. *Nurs Res* 2009;58(2):86-94. doi:10.1097/NNR.0b013e31818fcea4. [published Online First: 2009/03/18]
77. Friedrichsen MJ, Strang PM, Carlsson ME. Cancer patients' interpretations of verbal expressions when given information about ending cancer treatment. *Palliat Med* 2002;16(4):323-30. doi:10.1191/0269216302pm543oa. [published Online First: 2002/07/23]
78. Blackmore T, Chepulis L, Keenan R, et al. How do colorectal cancer patients rate their GP: a mixed methods study. *BMC Fam Pract* 2021;22:1-10.
79. Strang S, Strang P, Ternestedt BM. Existential support in brain tumour patients and their spouses. *Support Care Cancer* 2001;9(8):625-33. doi:10.1007/s005200100258. [published Online First: 2002/01/05]
80. Easley J, Miedema B, Robinson L. It's the "good" cancer, so who cares? Perceived lack of support among young thyroid cancer survivors. *Oncol Nurs Forum* 2013;40(6):596-600. doi: 10.1188/13.ONF.596-600. [published Online First: 2013/10/29]

81. Wiener RS, Clark JA, Koppelman E, et al. Patient vs Clinician Perspectives on Communication About Results of Lung Cancer Screening: A Qualitative Study. *Chest* 2020;158(3):1240-49. doi: http://dx.doi.org/10.1016/j.chest.2020.03.081
82. Pozzar RA, Berry DL. Preserving Oneself in the Face of Uncertainty: A Grounded Theory Study of Women With Ovarian Cancer. *Oncol Nurs Forum* 2019;46(5):595-603. doi: 10.1188/19.ONF.595-603. [published Online First: 2019/08/20]
83. Entwistle VA, McCaughan D, Watt IS, et al. Speaking up about safety concerns: multi-setting qualitative study of patients’ views and experiences. *Qual Saf Health Care* 2010;19(6):e33. doi: 10.1136/qshc.2009.039743 [published Online First: 2010/12/04]
84. Boehmer U, Case P. Sexual minority women’s interactions with breast cancer providers. *Women Health* 2006;44(2):41-58. doi:10.1300/j013v44n02_03. [published Online First: 2007/01/27]
85. Francis SR, Hall EO, Delmar C. Spouse caregivers’ experiences of suffering in relation to care for a partner with brain tumor: a qualitative study. *Cancer Nursing* 2022;45(2):E320-E28.
86. Palmer Kelly E, Meara A, Hyer M, et al. Characterizing Perceptions Around the Patient-Oncologist Relationship: a Qualitative Focus Group Analysis. *J Cancer Educ* 2020;35(3):447-53. doi:10.1007/s13187-019-1481-6. [published Online First: 2019/02/18]
87. van der Velden NC, van Laarhoven HW, Burgers SA, et al. Characteristics of patients with advanced cancer preferring not to know prognosis: a multicenter survey study. *BMC cancer* 2022;22(1):1-12.
88. Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. *Soc Sci Med* 2005;61(10):2252-64.
89. The paradox of choice: Why more is less; 2004. Ecco New York.
90. Brom L, Pasman HRW, Widdershoven GA, et al. Patients’ preferences for participation in treatment decision-making at the end of life: qualitative interviews with advanced cancer patients. *PloS one* 2014;9(6):e100435.
91. Davison BJ, Gleave ME, Goldenberg SL, et al. Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer nursing* 2002;25(1):42-49.
92. Hack TF, Degner LF, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Soc Sci Med* 1994;39(2):279-89.
93. Sørenson K, Van den Broucke S, Fullam J, et al. Consortium Health Literacy Project Europe. Health Literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* 2012;25:1053-8.
94. van Vliet LM, Noordman J, Mijnlieff M, et al. Health literacy, information provision and satisfaction in advanced cancer consultations: two observational studies using level of education as a proxy. *BMJ Support Palliat Care* 2021
95. Katz MG, Jacobson TA, Veledar E, Kripalani S. Patient literacy and question-asking behavior during the medical encounter: a mixed-methods analysis. *Journal of general internal medicine* 2007;22:782-86.
96. Noordman J, van Vliet L, Kaunang M, et al. Towards appropriate information provision for and decision-making with patients with limited health literacy in hospital-based palliative care in Western countries: a scoping review into available communication strategies and tools for healthcare providers. *BMC palliative care* 2019;18(1):1-10.
97. Lelorain S, Brédart A, Dolbeault S, Sultan S. A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psychooncology* 2012;21(12):1255-64. doi:10.1002/pon.2115. Epub 2012 Jan 11. [published Online First: 2012/01/13]

98. Visser LN, Tollenaar MS, van Doornen LJ, et al. Does silence speak louder than words? The impact of oncologists' emotion-oriented communication on analogue patients' information recall and emotional stress. *Patient Education and Counseling* 2019;102(1):43-52.
99. Uitterhoeve R, Bensing J, Dilven E, et al. Nurse–patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication. *Psycho-oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 2009;18(10):1060-68.
100. van Vliet LM, Back AL. The different faces of empathy in cancer care: from a desired virtue to an evidence-based communication process: Wiley Online Library, 2021:4137-39.
101. Edelen MO, Rodriguez A, Huang W, et al. A novel scale to assess palliative care patients' experience of feeling heard and understood. *Journal of pain and symptom management* 2022;63(5):689-97.e1.
102. Sanders JJ, Dubey M, Hall JA, et al. What is empathy? Oncology patient perspectives on empathic clinician behaviors. *Cancer* 2021;127(22):4258-65.
103. Colagiuri B, McGuinness K, Boakes RA, Butow PN. Warning about side effects can increase their occurrence: an experimental model using placebo treatment for sleep difficulty. *Journal of psychopharmacology* 2012;26(12):1540-47.
104. Parker SM, Clayton JM, Hancock K, et al. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management* 2007;34(1):81-93.
105. Rood J, Nauta I, Witte B, et al. Shared decision-making and providing information among newly diagnosed patients with hematological malignancies and their informal caregivers: Not "one-size-fits-all". *Psycho-Oncology* 2017;26(12):2040-47.
106. Clayton JM, Hancock KM, Butow PN, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *The Medical Journal of Australia* 2007;186(12):S77.
107. Van der Velden N, Van Der Kleij M, Lehmann V, et al. Communication about prognosis during patient-initiated second opinion consultations in advanced cancer care: an observational qualitative analysis. *International Journal of Environmental Research and Public Health* 2021;18(11):5694.
108. Harrison JD, Young JM, Price MA, et al. What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive care in cancer* 2009;17:1117-28.
109. Levit LA, Balogh E, Nass SJ, Ganz P. Delivering high-quality cancer care: charting a new course for a system in crisis. 2013
110. Bernacki R, Paladino J, Neville BA, et al. Effect of the serious illness care program in outpatient oncology: a cluster randomized clinical trial. *JAMA Intern Med* 2019;179(6):751-59.
111. Serious Illness Conversation Guide Training. Ariadne Labs. [Available from: https://www.ariadnelabs.org/resources/downloads/serious-illness-conversation-guide/ accessed June 27 2023.
112. Deckx L, Thomas HR, Sieben NA, et al. General practitioners' practical approach to initiating end-of-life conversations: a qualitative study. *Family practice* 2020;37(3):401-05.
113. van Vliet L, Francke A, Tomson S, et al. When cure is no option: how explicit and hopeful can information be given? A qualitative study in breast cancer. *Patient education and counseling* 2013;90(3):315-22.
114. McPherson CJ, Wilson KG, Murray MA. Feeling like a burden: Exploring the perspectives of patients at the end of life. *Soc Sci Med* 2007;64(2):417-27.

115. Van Vliet LM, Van Der Wall E, Plum NM, Bensing JM. Explicit prognostic information and reassurance about nonabandonment when entering palliative breast cancer care: findings from a scripted video-vignette study. *Journal of Clinical Oncology* 2013;31(26):3242-49.
116. Zwanenburg LC, Suijkerbuijk KP, van Dongen SI, et al. Living in the twilight zone: a qualitative study on the experiences of patients with advanced cancer obtaining long-term response to immunotherapy or targeted therapy. *Journal of Cancer Survivorship* 2022:1-11.
117. Spoozak L, Wulff-Burchfield E, Brooks JV. Rallying cry from the place in between, 2020:451-52.
118. Howley EK. The US physician shortage is only going to get worse. Here are potential solutions. *Time Magazine* 2022
119. Dowling M, Efstathiou N, Amanda D, et al. Cancer nursing research priorities: A rapid review. *European Journal of Oncology Nursing* 2023:102272.
120. Swayden KJ, Anderson KK, Connelly LM, et al. Effect of sitting vs. standing on perception of provider time at bedside: a pilot study. *Patient education and counseling* 2012;86(2):166-71.
121. Communication About Advance Directives and Advance Care Planning in an East Asian Cultural Context: A Systematic Review. Oncology Nursing Forum; 2022.
122. Mystakidou K, Parpa E, Tsilika E, et al. Cancer information disclosure in different cultural contexts. *Supportive care in cancer* 2004;12:147-54.
123. Holley JL, Carmody SS, Moss AH, et al. The need for end-of-life care training in nephrology: national survey results of nephrology fellows. *American Journal of Kidney Diseases* 2003;42(4):813-20.

APPENDIX 1. SEARCH STRATEGY

(((”Neoplasms”[mesh] OR ”cancer”[all fields] OR ”cancers”[all fields] OR ”carcinoma”[all fields] OR ”carcinomas”[all fields] OR ”adenocarcinoma”[all fields] OR ”adenocarcinomas”[all fields] OR ”tumor”[all fields] OR ”tumors”[all fields] OR ”tumour”[all fields] OR ”tumours”[all fields] OR ”malignancy”[all fields] OR ”malignancies”[all fields] OR ”neoplasm”[all fields] OR ”neoplasms”[all fields] OR ”leukemia”[all fields] OR ”leukaemia”[all fields] OR ”lymphoma”[all fields] OR ”lymphomas”[all fields] OR ”Medical Oncology”[mesh] OR ”oncology”[all fields] OR ”oncolog*”[all fields]) AND ((”Communication”[Mesh] OR ”communication”[tw] OR ”communicat*”[tw] OR ”nonverbal communication”[mesh] OR ”health communication”[mesh] OR ”Language”[Mesh] OR ”Communications Media”[Mesh]) AND (”Health Personnel”[Mesh] OR ”Health Personnel”[tw] OR ”physician*”[tw] OR ”clinician*”[tw] OR ”doctor*”[tw] OR ”nurse*”[tw] OR ”health care providers”[tw] OR ”health care provider”[tw] OR ”healthcare providers”[tw] OR ”healthcare provider”[tw] OR ”doctor-patient communication”[tw] OR ”physician-patient communication”[tw] OR ”nurse-patient communication”[tw] OR ”clinician-patient communication”[tw] OR ”patient-staff”[tw] OR ”Physician-Patient Relations”[Mesh])) AND (”Patient harm”[mesh] ”Patient harm”[tw] OR ”harm”[tw] OR ”harmful”[tw] OR ”harms”[tw] OR ”harming”[tw] OR ”harmed”[tw] OR ”complaint”[tw] OR ”complain*”[tw] OR ”hurt”[tw] OR ”hurtful”[tw] OR ”hurt*”[tw] OR ”damage”[tw] OR ”damag*”[tw] OR ”negative effect”[tw] OR ”negative effects”[tw] OR ”unhelpful”[tw] OR ”unhelpful*”[tw] OR ”difficult communication”[tw] OR ”not helpful”[tw] OR ”not helping”[tw] OR ”not beneficial”[tw] OR ”not adaptive”[tw] OR ”not adapted”[tw] OR ”Attitude of Health Personnel”[Mesh]) AND (”Patients”[Mesh] OR ”patient”[tw] OR ”patients”[tw] OR ”patient*”[tw] OR ”Caregivers”[mesh] OR ”carer”[tw] OR ”carers”[tw] OR ”Caregivers”[tw] OR ”Caregiver”[tw] OR ”Caregivers”[tw] OR ”Caregiver”[tw] OR ”Family”[mesh] OR ”Family”[tw] OR ”relatives”[tw] OR ”kinship”[tw] OR ”kin”[tw] OR ”stepfamily”[tw] OR ”Parents”[tw] OR ”mothers”[tw] OR ”fathers”[tw] OR ”Siblings”[tw] OR ”Spouses”[tw] OR ”daughters”[tw] OR ”sons”[tw] OR ”Parent”[tw] OR ”mother”[tw] OR ”father”[tw] OR ”Sibling”[tw] OR ”Spouse”[tw] OR ”daughter”[tw] OR ”son”[tw] OR ”loved one”[tw] OR ”loved ones”[tw]) NOT ((”Infant”[mesh] OR ”infant”[ti] OR ”infants”[ti] OR ”Child”[mesh] OR ”child”[ti] OR ”children”[ti] OR ”Adolescent”[mesh] OR ”adolescent”[ti] OR ”adolescents”[ti] OR ”adolescence”[ti]) NOT (”Adult”[mesh] OR ”adult”[ti] OR ”adults”[ti] OR ”elderly”[ti]))) OR ((”Neoplasms”[majr] OR ”cancer”[ti] OR ”cancers”[ti] OR ”carcinoma”[ti] OR ”carcinomas”[ti] OR ”adenocarcinoma”[ti] OR ”adenocarcinomas”[ti] OR ”tumor”[ti] OR ”tumors”[ti] OR ”tumour”[ti] OR ”tumours”[ti] OR ”malignancy”[ti] OR ”malignancies”[ti] OR ”neoplasm”[ti] OR ”neoplasms”[ti] OR ”leukemia”[ti] OR ”leukaemia”[ti] OR ”lymphoma”[ti] OR ”lymphomas”[ti] OR ”Medical Oncology”[majr] OR ”oncology”[ti] OR ”oncolog*”[ti]) AND (”Communication”[majr]

OR ”communication”[ti] OR ”communicat*”[ti] OR ”nonverbal communication”[majr] OR ”health communication”[majr] OR ”Language”[majr] OR ”Communications Media”[majr]) AND (”Patient harm”[majr] ”Patient harm”[ti] OR ”harm”[ti] OR ”harmful”[ti] OR ”harms”[ti] OR ”harming”[ti] OR ”harmed”[ti] OR ”complaint”[ti] OR ”complain*”[ti] OR ”hurt”[ti] OR ”hurtful”[ti] OR ”hurt*”[ti] OR ”damage”[ti] OR ”damag*”[ti] OR ”negative effect”[ti] OR ”negative effects”[ti] OR ”unhelpful”[ti] OR ”unhelpful*”[ti] OR ”difficult communication”[ti] OR ”not helpful”[ti] OR ”not helping”[ti] OR ”not beneficial”[ti] OR ”not adaptive”[ti] OR ”not adapted”[ti] OR ”Attitude of Health Personnel”[majr]) AND (”Patients”[majr] OR ”patient”[ti] OR ”patients”[ti] OR ”patient*”[ti] OR ”Caregivers”[majr] OR ”carer”[ti] OR ”carers”[ti] OR ”Caregivers”[ti] OR ”Caregiver”[ti] OR ”Caregivers”[ti] OR ”Caregiver”[ti] OR ”Family”[majr] OR ”Family”[ti] OR ”relatives”[ti] OR ”kinship”[ti] OR ”kin”[ti] OR ”stepfamily”[ti] OR ”Parents”[ti] OR ”mothers”[ti] OR ”fathers”[ti] OR ”Siblings”[ti] OR ”Spouses”[ti] OR ”daughters”[ti] OR ”sons”[ti] OR ”Parent”[ti] OR ”mother”[ti] OR ”father”[ti] OR ”Sibling”[ti] OR ”Spouse”[ti] OR ”daughter”[ti] OR ”son”[ti] OR ”loved one”[ti] OR ”loved ones”[ti]) NOT ((”Infant”[mesh] OR ”infant”[ti] OR ”infants”[ti] OR ”Child”[mesh] OR ”child”[ti] OR ”children”[ti] OR ”Adolescent”[mesh] OR ”adolescent”[ti] OR ”adolescents”[ti] OR ”adolescence”[ti]) NOT (”Adult”[mesh] OR ”adult”[ti] OR ”adults”[ti] OR ”elderly”[ti]))))

APPENDIX 2. CHARACTERISTICS FROM THE INCLUDED STUDIES

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[1]	Adamson, 2018, USA	N=10		70% female 30% male	M = 56 R=31-75	60% breast, 20% head and neck, 10% prostate, 10% lymphoma	Stage I = 1, Stage II = 3, Stage III = 3, Stage IV = 3	Physicians	To explore how cancer patients' interpretations of the physician's role as information giver affect the communication relationship with the physician and their information-seeking behavior regarding different aspects of their cancer care.	Qualitative study. Semi structured qualitative interview. Interviews were coded and analyzed using inductive thematic analysis.	0.93 (S)
[2]	Beaver, 2016, UK	N=20		100% female	M=48	Breast cancer		Healthcare providers: doctors, nurses, oncologists,	To explore the experiences of women who received neo-adjuvant chemotherapy for breast cancer to determine psycho-social, information and support needs .	Qualitative study with individual (audio-recorded) in-depth interviews. Interview data were analyzed using thematic analysis.	0.80 (S)
[3]	Bentsen, 2021, Denmark	N=12		100% female	M=28, R=20-35	Myeloid Leukaemia 8.3%, Lymphoblastic Leukaemia 8.3%, Brain 8.3%, Breast 16.67%, Hodgkin 25%, Non-Hodgkin 8.3%, Ovarian 25%		Fertility doctors, oncology specialists	To examine how female AYA cancer patients and survivors experienced initial and specialized onco-fertility counselling and to present their specific suggestions on how to improve the onco-fertility counselling.	Qualitative study. Individual semi-structured interviews. Data was analyzed using thematic analysis.	0.90 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[4]	Blackmore, 2021, New Zealand	N=195		55.9% male 44.1% female	<40 2.1%, 40-49 7.7% 50-59 15.4% 60-69 24.1% 70-79 33.8%. 80= 16.9%	Colorectal cancer		General practitioners	To investigate patient-reported confidence and ratings of their GP following the diagnostic process.	Mixed-methods analysis of responses to a structured questionnaire and free text comments. Chi square analysis was determined and free text comments were analyzed using a thematic framework.	0.93 (S)
[5]	Blanch-Hartigan, 2016, USA	N=1794		42.4% male 57.6% female	18-49 17%, 50-64 33%, 65-74 23.9%, >75 25.1%	Breast 13.5%, colorectal 4.2%, prostate 8.9 %, melanoma 5.6%, other female cancers 11.2%, other cancers 39.4%, multiple cancers 17.3%		Healthcare providers, oncology providers	To examine patient-provider communication among cancer survivors using a large population-based data resource.	Mixed-methods. National data from Health Information National Trends Survey (HINTS) were merged with combined replicate weights using the jackknife replication method. Linear and logistic regression were used to analyze the data.	0.97 (S)
[6]	Boehmer, 2006, USA	N=39		100% female	M=49.2	Breast cancer	In situ 23.1%, stage I 33.3%, Stage II 23.1%, stage III 5.1%, Stage IV 12.8%, unknown 2.6%	Surgeons (36), Radiologist (22), Oncologist (31)	To describe sexual minorities' experiences with breast cancer care physicians.	Qualitative study with tape recorded in depth semi structured interviews, analyzed from a Grounded Theory perspective.	0.80 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[7]	Brotzman, 2022, USA	N = 31		55% male 44% female	M = 63 R = 26 - 89. 20-39 N=1, 40-59 N=12, 60-79 N=12, 80-99 N=6.	Stage 2 colon cancer	Stage II	Oncologist, Surgeon	To investigate patient perspectives and experiences in treatment decisions for ACT under clinical uncertainty.	Qualitative study with semi structured interviews. Analyzed using a thematic analysis.	0.90 (S)
[8]	Droog, 2014, Ireland	N=302		300 female 2 male		Breast cancer		N=14 (9 breast cancer specific clinical nurse specialists, 1 breast cancer specific clinical nurse manager, 4 oncology liaison nurses	To examine the informational role of CNSs in supporting patients during their breast cancer journey and to understand the extent of its impact on their care	Mixed methods. A questionnaire was developed (closed and open end-items). Positive response scores for each dimension of care were calculated. Quotations were used to add further explanation to the respective positive scores.	0.81 (S)
[9]	Easley, 2013, Canada	N=12		91,7% female 8,3% male	M = 34 R=28-38	Thyriod cancer		Healthcare providers	To describe the survivorship experience of young adult patients with thyroid cancer.	Qualitative, descriptive study. Telephone interviews were conducted. For analysis research paradigm constructivist was used.	0.85 (S)
[10]	El-Sayed, 2021, Egypt	N = 30		100% female	18-36 N=2, 36-50 N=11, >50 N=17	Breast cancer, 6 newly diagnosed, 6 postsurgical, 6 chemo therapy, 6 radio therapy, 6 follow-up.	Stage I N = 4, Stage II N = 14, Stage III N = 6, Stage IV N = 6.	Physicians, Surgeons, Oncologists	To explore breast cancer patients' experience and satisfaction with involvement in their cancer care.	Qualitative study with semi structured interviews. The analysis of interview transcripts was based on an inductive approach.	0.93 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[11]	Entwistle, 2010, UK	N=10		100% female		Breast cancer		Healthcare providers	To explore patients' and family members' experiences of and views about speaking up about safety concerns at the point of care	Qualitative study using individual interviews and focus group with thematic coding framework.	0.90 (S)
[12]	Evans, 2012, The Netherlands, Belgium, UK	N=77 cancer N=23 non cancer		67% male 33% female	M=78.5			Physicians, general practitioners	To understand the factors which influence older patients' communication with physicians	Qualitative study with secondary thematic analysis and interviews.	0.80 (S)
[13]	Flynn, 2016, UK	N=6	N=5	50% female 50% male	M=58.3 R= 35-76	Plasma cytoma and bowel (1), Testicular and stomach (2), Breast (2), Ovarian and lung(1)	16.6% palliative	Oncology professionals (e.g. doctors/ nurses)	To establish the cancer-related experiences of people with an ID	Qualitative interview study. Transcripts were analyzed using grounded theory.	0.90 (S)
[14]	Francis, 2022, Norway, Denmark		N=10	70% female 30% male	M = 59 R = 36-76	Brain tumor patients in PMBT therapeutic oncology treatment after neurosurgical resection		Nurses	To investigate spouses' experiences of suffering in their role as main caregiver of a partner with PMBT.	A hermeneutical qualitative study with semi structured interviews. Data were analyzed according to Brinkmann and Kvale's 5-step analysis guide.	0.93 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[15]	Friedrichsen, 2002, Sweden	N=30		40% male 60% female	20-49 13.3%, 50-69 33.3%, 70-89 53.33%	Gastrointestinal 36.7%, Urogenital 20%, Haematological 13.3%, Sarcoma 13.3% and others 16.7%	curative/ palliative 50%, palliative 30%, no treatment 20%	Doctors	To ascertain what significance verbal expressions had for cancer patients when they were given information about ending active tumor treatment, and what message they felt they received	Qualitative study. Tape-recorded semi-structured interviews were performed and analyzed using a qualitative phenomenographical approach. Analysis has been done according to Dahlgren and Fallsberg's seven steps.	0.90 (S)
[16]	Haase, 2021, Canada	N = 16		75% female 25% male	M=52 R=35-78	Lymphoma 43,75%, Lung (18.75%), Breast (31.25%), Colorectal (25%)	Early stage 25%, Advanced 56.25% not sure & unknown N= 3	N = 19, resident/ fellow N = 3, medical oncologist N = 3, Registered Nurse N = 8. Social worker N= 1, Other = 3	To explore patient and clinician perspectives about cancer self-management and preferences for content and design features of a web-based self-management support program during the diagnosis and acute phase of cancer treatment	Qualitative study with semi structured interviews. Data were thematically analyzed using the NVivo qualitative software.	0.90 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[17]	Hillen, 2017, The Netherlands	N=23		100% male	M=65 R=52-73	100% prostate cancer	Advanced N=9	Physicians: urologists, doctors, surgeons,	To investigate how uncertainty influences men with prostate cancer to seek second opinions n how second opinions may affect these patients' sense of uncertainty and subsequent experiences with their care	Qualitative study with semi-structured interviews. Analysis was performed using the constant comparative method.	0.93 (S)
[18]	Im, 2009, USA	N=75		85% female 13% male	M=48.51 R=24-81	Colorectal 4%, Breast 43%, Leukemia 5%, Lymphoma 3%, Gynecological 11%, Endocrine 5%, Lung 8%, Gastrointestinal 3%, Combined 5%, Others 13%	Stage 0 = 5.3%, stage 1 = 14.7%, stage II = 25.3%, stage 4 palliative 17,3%	Healthcare providers, hospital workers, doctors, nurses,	To explore similarities and differences in cancer pain experience among four major ethnic groups in the United States	Cross-sectional qualitative study. Online forums were analyzed using thematic analysis involving line-by line coding, categorization, and thematic extraction.	0.90 (S)
[19]	Islam, 2016, USA	N=7	N=9	13 male 23 female (including caregivers and physicians)		Lungcancer	Advanced	10 physicians and 10 nurses	describes patient, caregiver, and provider perspectives on the role of the health care system in helping patients cope with an advanced stage lung cancer diagnosis	Qualitative study with audio recorded focus groups and thematic analysis.	0.85 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[20]	Jindal, 2022, USA	N= 30		63% female 37% male	M=81 R=76 - 89 76 - 79 N = 13 80 - 84 N = 13 85 - 89 N = 4			Internal Medicine 82% Internal Medicine/ Geriatrics 7% Family Medicine 2% Nurse practitioner 9%	To learn Primary Care Providers and adults >75 years' perspectives on discussing long-term (10 year) prognosis and potential language for these conversations.	Qualitative study. Interview audio recordings. NVivo 11 qualitative analysis and Braun and Clarke's methods for thematic analysis.	0.93 (S)
[21]	Kimberlin, 2004, USA	N=22	N=15	Patients: 31.8% male 68.18% female IC: 33.33% male 66.67 female	IC: R=27-88			Healthcare providers	Explores the question "What do cancer patients and family caregivers of cancer patients perceive to be barriers and facilitators of effective communication regarding pain management issues and what specific suggestions would they make to patients, caregivers and providers to improve their communication process	Qualitative study. Focus groups and personal interviews (audiotaped), analyzed and coded on themes.	0.90 (S)
[22]	Lee, 2009, Australia	N=14 12 cancer 1 neurological 1 heart disease	N=7	50% male 50% female (all patients)	R= 28 - 93		100% palliative	N=18. Medical (4), nursing (12), counselling (2) disciplines	To describe the significant issues hat influence the processes of care decision making, from the perspective of patients with advanced illness	Qualitative interview study. A systematic approach using grounded theory to collect and analyze the data was used to develop a theory of decision making.	0.83 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[23]	Liu, 2005, China	N=20		50% male 50% female	M=51 R= 27 - 69			Nurses	To describe the experience and expectations of Chinese cancer patients with regard to the favorable and unfavorable words conveyed by their social support providers.	Qualitative study with in-depth interviews analyzed using content analysis.	0.90 (S)
[24]	Marcusson-Rababi, 2019, Australia	N=8		100% female	M=52 R=33-68	Gynaecological cancers including endometrial, ovarian, cervical and vulva.		N=18, senior surgical (1), medical oncologist (1), senior social worker (1) Indigenous liaison Officer (2), Physiotherapist (2), pharmacist (3), pastoral care worker (3),oncology nurses (4)	To explore the experiences of Inigenous women in cancer care	Qualitative interview with in-depth interviews thematically analyzed using an interpretative phenomenological approach.	0.80 (S)
[25]	Martinez Tyson, 2017, USA	N=18		100% men	M = 60 R=39-70	Skin & prostate 6%, Colon 22%, Prostate 17%, Prostate & lymphoma 6%, Prostate & pancreas 6%, Kidney 11%, Bladder 6%, Multiple myeloma 22%, Missing 17%		N=5: social worker, oncologists, patient navigator, psychologist	To explore the supportive care needs of Hispanic men who had been diagnosed with cancer within the last 5 years	Qualitative study. Focusgroups were conducted and analyzed using applied thematic analysis techniques.	0.90 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[26]	Mazor, 2013, USA	N=120	N=17	88% female	R=37-81			Clinicians	To explore patients' and family members' views on communication during cancer care and to identify those aspects of clinician-patient communication which were most important to patients and family members	Qualitative study with secondary data analysis with constant comparative method and coding paradigm of grounded theory.	0.88 (S)
[27]	Mazor, 2012, USA	N=78		96.2% female 3.8% male	R=21-60	Breast 89.7%, gastrointestinal 10.3%		Healthcare providers: clinicians, nurses	To explore cancer patients' perceptions of preventable, harmful events; the impact of these events; and interactions with clinicians after such events.	Qualitative study. In-depth telephone interviews were transcribed and coded using directed content analysis.	0.83 (S)
[28]	Mazor, 2013, USA	N=78		96% female 4% male	M = 58 R= 36-79	Breast 89.7%, Gastrointestinal 10.3%		Clinicians	To examine whether patients consider recommended responses to be appropriate and desirable, and whether clinicians' actions after adverse events are consistent with recommendations.	Qualitative study. Using in-depth interviews. Transcripts were coded using directed content analysis.	0.93 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[29]	Olsson, 2016, Sweden	N=52	N=64	Patient: 71,15% female 28,85% male IC: 40,6% female 59,38% men				Healthcare providers: physicians, GP's, nurses	To investigate healthcare customer complaints concerning interpersonal matters in cancer care	Qualitative Study. Complaints registered by the Patients' Advisory Committee were sampled and analyzed using qualitative content analysis.	0.93 (S)
[30]	Ormel, 2021, Canada	N = 35		100% female		Breast cancer		Healthcare providers	To explore how women describe efforts to seek, appraise and interpret information during the diagnostic phase of her breast cancer care.	Qualitative study with audio/video recording and thematic analysis was used.	0.87 (S)
[31]	Palmer, 2020, USA	N=25		84% female 16% male	M=58.4	Breast (56%), gynecologic (16%), skin (6%), oral (6%), non-Hodgkin's lymphoma (6%)	x	Oncologists, healthcare team, physicians	To characterize the experience of cancer patients and their caregiver/family members regarding the relationship with their oncologist, healthcare team and hospital environment	Qualitative study with focus groups and semi structured interviews recorded with digital audio recording device	0.93 (S)
[32]	Pozzar, 2019, USA	N=18		100% female	R= >49 - <70	Ovarian cancer	Stage I or II = 11 Stage III or IV advanced = 7	Health care providers, gynecologic oncologist	To describe the cancer care process as it is perceived by women with ovarian cancer.	Qualitative study. Individual interviews were conducted. Data were qualitatively analyzed using open coding, constant comparison and member checking.	0.85 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[33]	Sisk, 2021, USA	N=27	N = 27 parent 52%, spouse 33%, other 7%, partner 4%, child 4%	Patient: Male 56% Female 44% IC: Male 26% Female 74%	Age at death: 15-21(26%) 22-29 (30%), 30-39 (44%)			Doctors	to examine caregivers of AYAs who died of cancer to understand their negative communication experiences	Qualitative study with semi structured interviews. Thematic analysis was used.	0.90 (S)
[34]	Stajduhar, 2021, Canada	N=34		23.5% male 76.5% female	M=59 R=34-79	Breast, prostate, non-Hodgkin's lymphoma, lung, ovarian	100% palliative	Healthcare providers: doctors and physicians	To describe what patients with advanced cancer identify as helpful in their communication encounters with health care providers	Qualitative study with secondary analysis, interpretive description methodology was used. Interviews were audio-taped. Data analyzed by the constant comparative method.	0.80 (S)
[35]	Strang, 2001, Sweden	N=20	N=16, spouses(14) children(2)		R=23-70	Brain tumour		N=16: nurses	To describe opinions of nurses, brain tumor patients and their next-of-kin concerning support in existential crises ad how this is prioritized.	Qualitative study. Explorative, tape-recorded, semi structured interviews Analysis of the data was inspired by phenomenography.	0.88 (S)
[36]	Tasaki, 2002, USA	N=93		31.18% male 68.82% female	<40 = 7 40-49 =19 50-59=27 60-69=21 70-79=16 80+=3	Breast 37.63%, Gastrointestinal 11.83%, prostate 18.3% , all other cites 32.26%	Advanced n=33	Oncologists , PCP, surgeon, physisians	To identify barriers to communication between physicians and cancer patients regarding complementary and alternative medicine by exploring the perspectives of patients	Qualitative study with tape recorded interviews and qualitative data analysis.	0.83 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[37]	Thorne, 2007, Canada	N=200		26.5% male 73.5% female	<30 0.5%, 30-39 4.5%, 40-49 18%, 50-59 32.5%, 60-69 26.5%, >70 18%	Breast 50%, Prostate 14%, Gastrointestinal 10%, Lymphoma/ leukemia 7%, head and neck %%, Cervix/ Utures/Ovary 5%, oter 6%	17% palliative	Clinicians, physicians oncologist,	To understand of how prognostic communications are received and interpreted by patients	Qualitative study with interviews using NVivo for systematic indexing, retrieval, and analysis.	0.90 (S)
[38]	Thorne, 2008, Canada	N=82		77% female 23% male	<30 1% 30-39 2% 40-49 20% 50-59 38% 60-69 23% >70 16%	Breast 50%, Prostate 13%,Gastrointestinal 6%,Lymphoma/ leukemia 11%, head and neck 2%,cervix/ uterus/ovary 5%, other 12%	16% palliative	Urogolists, doctors	To examine the belief held by many cancer patients that communication with their care providers has a meaningful part to play in shaping their disease outcomes.	Qualitative study. Interview data set was qualitatively analyzed using extracted thematic patterns.	0.78 (G)
[39]	Thorne, 2013, Canada	N=125		27.2% male 72.8% female	<39 8%, 40-49 16.8%, 50-59 35.2%, 60-69 29.6%, >70 10.4%	Breast 37.6%, Hematologic 12%, Prostate 9.6%, Gastrointestinal 9.6%, Lung 10.4%, Gynecological 7.2%, Melanoma 5.8%, other 8.3%	8% palliative	doctors, oncologists, clinicians,	To understand helpful and unhelpful communication from the patient perspective and to document changes in patient needs and priorities over time.	Qualitative study. Using a qualitative longitudinal approach informed by interpretive description methodology. Constant comparative analysis was used.	0.75 (G)
[40]	Ussher, 2018, Australia	N=78		78% female 22% male	M= 45.1, R= 18 - 58	breast, gynaecological, hematologic, gastrointestinal, neurologic heaad and neck, skin, musculoskeletal, genitourinary, respiratory		Healthcare providers	To examine the construction and subjective experience of communication with health professionals about fertility in the context of cancer, from the perspective of women and men cancer survivors	Mixed method design with telephone interviews using chi square tests and thematic analysis.	0.89 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[41]	Villalobos, 2018, Germany	N=9	N=9	Patient: 66.67 % male 33.33% female IC:33.33% male 66.67 female	Patient M=63 IC M=54	Primarily metastatic lung cancer		2 physicians, 3 nurses, 1 social worker, 3 chaplains, 3 dietitians, 1 music therapist, 2 psycholgists	To explore the patients' and family-caregivers' needs and preferences regarding communication, quality of life and care over the trajectory of the disease (1) and to assess health professionals' views on a longitudinally structured, forward-thinking communication aproach based on defined milestones (2).	Qualitative study with semi-structured interviews. Analyzed using qualitative content analysis according to Mayring.	0.90 (S)
[42]	Waldrop, 2012, USA	N=46	N=52 (48% spouses, 42% adult children, 10% other)	Patient: 46% female 54% male	Patient: M=77.2 (R=68-94) IC: M=69.9 (R=26-88)	Lung 28%, Pancreas 13%, Colon 11%, liver 7%, Esophagus 7%, Unknown 7%, Stomach 4%, Melanoma 4%, other 19%	Advanced	(Radiation) Oncologists, (primary) physicians, nurses, doctors,	To explore and describe family caregivers' accounts of the nature and timing of communication they had with a loved one's health care provider	Qualitative study, exploratory descriptive design with (audio-taped) semi-structured in-depth in-person interviews and theoretical analysis.	0.90 (S)
[43]	Westendorp, 2022, The Netherlands	N = 74		92% female 8% male	M = 57	Breast (78%) Colon (3%) Lung (7%), Kidney (3%), Prostate (3%), other N = 9 (12%).	Advanced	Oncologists	To explore the perspectives of patients with advanced cancer about potentially harmful communication behavior by oncologists and to suggest helpful alternatives	Mixed methods study using self-created questionnaire. Results were analyzed quantitatively and qualitatively (content analysis).	0.95 (S)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[44]	Wiener, 2020, USA	N=49		18,37% female 82% male		Lung cancer		N=36: 16 (44%) primary care providers, 15 (42%) pulmonologists, 5 (14%) Lung cancer screening nurse coordinators	To characterize perceptions of communication and results notification after LCS from the patient and clinician perspectives, including how their impressions correspond and diverge, and their impressions of how communication may affect distress.	Qualitative study. Interviews and focus groups were conducted. Transcripts were analyzed using conventional content analysis.	0.90 (S)
[45]	Xu, 2011, USA	N=21		100% men	M=57.8, R= 48 - 70	Prostate cancer		N=18 (12 urologists, 6 radiation oncologists)	To explore how black and white American men with prostate cancer made their treatment decision. To gain an in-depth understanding of men's perspectives on selecting their prostate cancer treatment	Conceptual/ qualitative study. Interviews were analyzed using immersion/ crystallization analysis technique.	0.90 (S)
[46]	Zebrack, 2010, USA	N=17			R= 18 - 35			Doctors, nurses	To identify aspects of behavior that may promote or inhibit healthy psychosocial adjustment for AYA's	Qualitative study with audio-recorded group interviews. Inductive and deductive techniques of coding and analysis of were performed.	0.68 (G)

	First Author, Year, Country	Sample							Aim	Method/design	Quality score †
		Patient	Family Caregivers	Gender	Age	Cancer sites	Stage	Type of clinician			
[47]	Ziebland, 2006, UK	N=43		100% female	M = 54 age at interview, M= 50 age at diagnosis	Ovarian cancer		Doctors, GP, clinicians, oncologists,	To explore the different descriptions of treatment decisions in the narratives of women with ovarian cancer.	Qualitative study. Interviews were conducted, audio tape recorded and transcribed. Thematic qualitative analysis constant comparison were used.	0.80 (S)

† Study quality: Strong ≥ 0.80; Good 0.60-0.79; Adequate 0.50-0.59; Poor < 0.50

REFERENCES OF APPENDIX 2

1. Adamson, M., et al., The Doctor-Patient Relationship and Information-Seeking Behavior: Four Orientations to Cancer Communication. J Palliat Care, 2018. 33(2): p. 79-87.
2. Beaver, K., S. Williamson, and J. Briggs, *Exploring patient experiences of neo-adjuvant chemotherapy for breast cancer.* European Journal of Oncology Nursing, 2016. 20: p. 77-86.
3. Bentsen, L., et al., *How Do Young Women with Cancer Experience Oncofertility Counselling during Cancer Treatment? A Qualitative, Single Centre Study at a Danish Tertiary Hospital.* Cancers, 2021. 13(6): p. 1355.
4. Blackmore, T., et al., *How do colorectal cancer patients rate their GP: a mixed methods study.* BMC Family Practice, 2021. 22: p. 1-10.
5. Blanch-Hartigan, D., et al., *Trends in cancer survivors' experience of patient-centered communication: Results from the Health Information National Trends Survey (HINTS).* Journal of Cancer Survivorship, 2016. 10(6): p. 1067-1077.
6. Boehmer, U. and P. Case, *Sexual minority women's interactions with breast cancer providers.* Women Health, 2006. 44(2): p. 41-58.
7. Brotzman, L.E., et al., *Patient perspectives on treatment decision-making under clinical uncertainty: chemotherapy treatment decisions among stage II colon cancer patients.* Translational behavioral medicine, 2021. 11(10): p. 1905-1914.
8. Droog, E., C. Armstrong, and S. MacCurtain, *Supporting patients during their breast cancer journey: the informational role of clinical nurse specialists.* Cancer Nurs, 2014. 37(6): p. 429-35.
9. Easley, J., B. Miedema, and L. Robinson, *It's the "good" cancer, so who cares? Perceived lack of support among young thyroid cancer survivors.* Oncol Nurs Forum, 2013. 40(6): p. 596-600.
10. El-Sayed, E., et al., *Breast Cancer Patients' Experience about Involvement in Health Care: A Qualitative Study.* Journal of High Institute of Public Health, 2021. 51(3): p. 114-120.
11. Entwistle, V.A., et al., *Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences.* Qual Saf Health Care, 2010. 19(6): p. e33.
12. Evans, N., et al., *Older patients' attitudes towards and experiences of patient-physician end-of-life communication: a secondary analysis of interviews from British, Dutch and Belgian patients.* Bmc Palliative Care, 2012. 11: p. 10.
13. Flynn, S., et al., *"You don't know what's wrong with you": an exploration of cancer-related experiences in people with an intellectual disability.* Psychooncology, 2016. 25(10): p. 1198-1205.
14. Francis, S.R., E.O. Hall, and C. Delmar, *Spouse caregivers' experiences of suffering in relation to care for a partner with brain tumor: a qualitative study.* Cancer Nursing, 2022. 45(2): p. E320-E328.
15. Friedrichsen, M.J., P.M. Strang, and M.E. Carlsson, *Cancer patients' interpretations of verbal expressions when given information about ending cancer treatment.* Palliat Med, 2002. 16(4): p. 323-30.
16. Haase, K.R., et al., *Patient and clinician perspectives of desired features for a web-based self-management program (icanmanage. ca): Exposing patients "hard work" of managing acute cancer.* Supportive Care in Cancer, 2021. 29: p. 1989-1998.
17. Hillen, M.A., et al., *The evolution of uncertainty in second opinions about prostate cancer treatment.* Health Expectations: An International Journal of Public Participation in Health Care & Health Policy, 2017. 20(6): p. 1264-1274.
18. Im, E.O., et al., *A national online forum on ethnic differences in cancer pain experience.* Nurs Res, 2009. 58(2): p. 86-94.

19. Islam, K.M., et al., *Coping with an advanced stage lung cancer diagnosis: Patient, caregiver, and provider perspectives on the role of the health care system.* Journal of Cancer Education, 2016. 31(3): p. 554-558.
20. Jindal, S.K., et al., *Strategies for discussing long-term prognosis when deciding on cancer screening for adults over age 75.* Journal of the American Geriatrics Society, 2022. 70(6): p. 1734-1744.
21. Kimberlin, C., et al., *Cancer patient and caregiver experiences: communication and pain management issues.* J Pain Symptom Manage, 2004. 28(6): p. 566-78.
22. Lee, S.F., L.J. Kristjanson, and A.M. Williams, *Professional relationships in palliative care decision making.* Support Care Cancer, 2009. 17(4): p. 445-50.
23. Liu, J.E., E. Mok, and T. Wong, *Perceptions of Chinese cancer patients of the favorable and unfavorable words conveyed by their social support providers.* Cancer Nurs, 2005. 28(5): p. 348-54.
24. Marcusson-Rababi, B., et al., *Does gynaecological cancer care meet the needs of Indigenous Australian women? Qualitative interviews with patients and care providers.* BMC Health Serv Res, 2019. 19(1): p. 606.
25. Martinez Tyson, D.D., et al., *Understanding the supportive care needs of Hispanic men cancer survivors.* Ethn Health, 2017. 22(1): p. 1-16.
26. Mazor, K.M., et al., *Patients' and family members' views on patient-centered communication during cancer care.* Psychooncology, 2013. 22(11): p. 2487-95.
27. Mazor, K.M., et al., *Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response.* J Clin Oncol, 2012. 30(15): p. 1784-90.
28. Mazor, K.M., et al., *More than words: Patients' views on apology and disclosure when things go wrong in cancer care.* Patient Education and Counseling, 2013. 90(3): p. 341-346.
29. Olsson, E.M., *Interpersonal complaints regarding cancer care through a gender lens.* Int J Health Care Qual Assur, 2016. 29(6): p. 687-702.
30. Ormel, I., et al., *How to know what to know: Information challenges for women in the diagnostic phase of breast cancer.* Patient education and counseling, 2021. 104(1): p. 179-185.
31. Palmer Kelly, E., et al., *Characterizing Perceptions Around the Patient-Oncologist Relationship: a Qualitative Focus Group Analysis.* J Cancer Educ, 2020. 35(3): p. 447-453.
32. Pozzar, R.A. and D.L. Berry, *Preserving Oneself in the Face of Uncertainty: A Grounded Theory Study of Women With Ovarian Cancer.* Oncol Nurs Forum, 2019. 46(5): p. 595-603.
33. Sisk, B.A., et al., *Bereaved caregivers perspectives of negative communication experiences near the end of life for adolescents and young adults with cancer.* Journal of adolescent and young adult oncology, 2022. 11(5): p. 498-505.
34. Stajduhar, K.I., et al., *Patient perceptions of helpful communication in the context of advanced cancer.* Journal of Clinical Nursing, 2010. 19(13-14): p. 2039-2047.
35. Strang, S., P. Strang, and B.M. Ternestedt, *Existential support in brain tumour patients and their spouses.* Support Care Cancer, 2001. 9(8): p. 625-33.
36. Tasaki, K., et al., *Communication between physicians and cancer patients about complementary and alternative medicine: exploring patients' perspectives.* Psychooncology, 2002. 11(3): p. 212-20.
37. Thorne, S., et al., *Prognosticating futures and the human experience of hope.* Palliat Support Care, 2007. 5(3): p. 227-39.
38. Thorne, S.E., et al., *Cancer care communication: the power to harm and the power to heal?* Patient Educ Couns, 2008. 71(1): p. 34-40.

39. Thorne, S., et al., *Poor communication in cancer care: patient perspectives on what it is and what to do about it.* Cancer Nurs, 2013. 36(6): p. 445-53.
40. Ussher, J.M., C. Parton, and J. Perz, *Need for information, honesty and respect: patient perspectives on health care professionals communication about cancer and fertility.* Reprod Health, 2018. 15(1): p. 2.
41. Villalobos, M., et al., *A longitudinal communication approach in advanced lung cancer: A qualitative study of patients', relatives' and staff's perspectives.* Eur J Cancer Care (Engl), 2018. 27(2): p. e12794.
42. Waldrop, D.P., et al., *The nature and timing of family-provider communication in late-stage cancer: A qualitative study of caregivers' experiences.* Journal of Pain and Symptom Management, 2012. 43(2): p. 182-194.
43. Westendorp, J., et al., *Mind your words: Oncologists' communication that potentially harms patients with advanced cancer: A survey on patient perspectives.* Cancer, 2022. 128(5): p. 1133-1140.
44. Wiener, R.S., et al., *Patient vs Clinician Perspectives on Communication About Results of Lung Cancer Screening: A Qualitative Study.* Chest, 2020. 158(3): p. 1240-1249.
45. Xu, L.W., et al., *Life After the Neurosurgical Ward in Sub-Saharan Africa: Neurosurgical Treatment and Outpatient Outcomes in Uganda.* World Neurosurg, 2018. 113: p. e153-e160.
46. Zebrack, B., M.A. Chesler, and S. Kaplan, *To foster healing among adolescents and young adults with cancer: what helps? What hurts?* Support Care Cancer, 2010. 18(1): p. 131-5.
47. Ziebland, S., J. Evans, and A. McPherson, *The choice is yours? How women with ovarian cancer make sense of treatment choices.* Patient Educ Couns, 2006. 62(3): p. 361-7.

APPENDIX 3. RESULTS THEMATIC ANALYSIS

Theme	Quotes	Studies	
		Patient	**Family Caregiver**
1 Lack of tailored information provision			
Too few and too many provided treatment options, and information about these options, could make it more difficult for patients to make well-considered decisions	*“Doctors are more inclined now to give you the whole holus bolus of the whole thing, whether it’s applicable in your particular circumstances or not. Well I think one has to realize that they want to know something about it— what’s happening to them. Whether or not they can assimilate all of that information in one sitting because you have to wait until the shock subsides.”* [1] “However, a few relatives also believed that the patient had been given too much information at too early a stage, which was difficult to process: *“Rather than receiving support from staff, he has been provided with too much and too detailed information”* [2] […] the major concerns and sources of stress discussed by participants were related to not having enough information about the treatment they received, the long-term side effects (e.g. impotency, incontinence, and fatigue), and the availability of other treatment options and/or alternative/complimentary medicine. For instance, a prostate cancer survivor explained that *“while providers allowed patients to make treatment decisions, insufficient information is provided about treatment options. They [the doctors] don’t pressure you to operate, but I think that person making the decision should have…it should be explained to him more clearly…the decision that [he] is making and if there is an option or another treatment…why not?” [3]* “Patients also expressed dissatisfaction with the amount of information provided by their physician about their illness and treatment options. A common complaint was that information was something that needed to be sought and was not routinely provided” [4]	Too few: [2-9] Too many: [9-14]	Too little: [2, 7]

Theme	Quotes	Studies	
		Patient	Family Caregiver
Lack of information about treatment consequences could increase distress and make it more difficult to make well-informed decisions	“Where communication with health care providers left them feeling uninformed, patients reported feeling ‘‘demoralized.’’ As one explained, *‘‘A lack of information and the resultant lack of understanding of what to expect increases the level of fear across all the procedures one goes through.*’”[15] “In particular, female patients significantly commented on a lack of information received regarding possible changes in their emotions during their care. *“I felt that I didn’t get enough information about possible changes in my emotions. Chemo affects the brain, your whole personality. I lost my confidence. (I.D. 298)*” [16] *“No one told me any of the side effects. We had to go on the computer and find the side effects because I was bloated, aggressive, assertive, you name it, gained 50 pounds, could not sleep for four straight days. Not one person told me you might get manic. And here I was, flipping out, shouldn’t have things been driving, all sorts of so knowing ahead of time would have been nice.”*[7]	[2-4, 6, 7, 11-21]	[2, 7, 17]
Too much test result information could overwhelm and too little keeps it uncertain	“Patients’ views vary: both too much information (i.e. overwhelming) and too little information (i.e. making the message unclear) can be harmful: Too much: “The results of the blood test are unfortunately not as we had hoped. So I will now go through all the test results.” [9]	[9]	
Prognostic information provision could be harmful when timing is poor and patients receive numeric or vague information	*“I do not want to know that in six months I won’t be here. Because I don’t think like that, and I don’t want to hear that from a doctor. .What it did to me was that it took me very down, and it took a lot of people to bring me back up again. To think that, okay, no I can do this. I can get through this as opposed to no, you know, sort of giving up hope and thinking “Well what’s the point?” Because that’s what he was basically saying to me was “What’s the point of your being here? Why are we wasting our time on you?” That’s what came out.”* [1] Informal caregiver: *“I just wish those doctors had been clear with me because I needed a little more time to say goodbye than what I did’’* [22] “They often found it more difficult to reframe or compartmentalize numeric information than prognostic information communicated to them in other forms, and they described facts and numbers as conveying a level of certainty that was incompatible with an uncertainty that supported the value of hope.”[1]	[1, 5, 6, 9, 12, 15, 17, 23-28]	[22, 23, 29]

Theme	Quotes	Studies	
		Patient	Family Caregiver
Contradictions in information (e.g. from different clinicians) may cause confusion and feelings of helplessness	*“So [hospital B] was telling me one thing; kind of standard procedure protocol. And [hospital F] which I have a lot of respect for was telling me something quite different. So I was sort of confused by that, so I thought I’m going to get a third opinion. (P021, 59 y, early stage)”* [12] “Families struggled to comprehend a situation and receiving different messages from collaborating providers underscores this. A daughter’s words illustrate: *This one is telling us this and that one was telling us something else. We’re going to radiation every day to shrink it. We’re waiting for Dr. L because if we shrink it enough he’s going to come back from his vacation and he’s going to do surgery and this nurse is saying, ‘‘Oh no, we’re just making her comfortable.”* [29]	[1, 2, 7, 11, 12, 14, 15, 17, 18, 23, 30-32]	[23, 29]
Jargon could diminish understanding and lead to anxiety	“Many patients actively tried to get information, but found it difficult to get straight answers. Sometimes the patients expressed confusion due to the physician’s using difficult medical terminology”[2] “With respect to Clarity, patients reacted negatively to clinicians’ use of jargon and ‘rattling things off’, and valued explanations that they could understand. The use of jargon or convoluted explanations led to uncertainty, lack of comfort in or satisfaction with the interactions, and sometimes, increased anxiety.”[17]	[2, 4, 9, 12, 17, 19, 23, 25]	[23, 29]
2. Lack of tailored decision making			
Exclusion from treatment decisions is impersonal and could cause distress	“When patients felt excluded from the decision-making because of the communication style of their cancer care provider, they experienced extreme distress *‘‘The urologist that I was referred to told me what was best for me. When I asked questions, based on my research, my understanding of the situation was not acknowledged and I felt I was not a participant in the conversation, simply a listener.’*[15] *“I was told what was about to happen, I don’t have any input, I can’t say yes, I want or no, I don’t, because they do what they like* (PT 16). *You just feel like you’re one of these hundreds of cattle that are going through this bloody thing, you know, a number, but anyway, that’s, you know, you just go it, whatever they say you do* (PT 14)” [19] *“The first two doctors, I really felt were trying to push me towards surgery. […] I guess that I sort of felt like if I could use the analogy that when you’re a hammer, everything looks like a nail.* (P012, 64 y, early stage)” [12]	[9, 12, 15, 19, 21, 33-35]	[22]

Theme	Quotes	Studies	
		Patient	Family Caregiver
Making treatment choices entirely the patient’s responsibility could be overwhelming and stressful	*‘‘I think it is quite bizarre actually that an oncologist says to you, ‘There’s two chemotherapies you can have, you can have just one or you can have both, what do you want?’ You know, it’s I try and think well if you go to your GP they don’t say ‘What antibiotics do you want?’* [31] “Several patients attributed the excess of information in such circumstances as a misapplication of the philosophy of shared decision making: *It’s just a whole conflict of informed consent that has come up a number of times and you know. And it’s all, it’s all ballyhooed and everything, informed consent is such a wonderful thing blah, blah, blah. But again I’ve had doctors say to me, ‘‘Well what do you want to do? Which to me is kind of laughable because, you know what, if there are different options, is it up to me to make a decision? What informed consent is sounds like a nice concept, but how can I decide with no medical background what is the best option? “* [26] “Several participants felt somewhat responsible for their own treatment regarding fertility. This led to an overwhelming level of active decision-making. This often included dilemmas regarding choice of chemotherapy, administration of hormone substitution and finding an oocyte donor. There was no guidance from the oncology specialists. They also described having to be self-reliant and that they learned to take the initiative if they wanted onco-fertility counselling: as a patient you are told *‘we are in control of your chemo and we are in control of your blood tests, we are in control of everything’,. . . it was almost as if my fertility was my own responsibility”*(Participant, 31 years old) [11]	[11, 12, 20, 26, 31]	
Forcing patients to hasty decisions result in ill-considered choices due to lack of room for the options to sink in	“One patient with advanced disease remembered being asked to make a difficult treatment decision immediately on receiving unexpected bad news. *‘‘I was very disoriented mentally because I just, I’d never been told things like that.’’*[26] “Often these patients feel rushed or unable to fully comprehend their situation when information is given or decisions need to be made.”[10]	[10, 12, 20, 26]	

Theme	Quotes	Studies	
		Patient	**Family Caregiver**
3. Lack of feeling seen and heard			
Providing information in an inappropriate manner; rude, cold and uncaring	“Most complaints were filed by relatives. When the diagnosis was conveyed face-to-face, patients and relatives complained that the information was given inappropriately: “in a cold way,” “inhumanely,” “insensitively,” or “thrown in the face.” They expressed being sad and shocked by the information and called for more empathy when healthcare staff disclosed the cancer diagnosis: “After the examinations, a physician entered her room and informed her in an unempathetic way that she had cancer. Then the physician said she had a phone call to make and left the room. She (the physician) did not return.” [2] “Also categorized here were patients’ reports that the clinician or another person in the healthcare system, displayed a cold or uncaring manner, sometimes tied to the delivery of the diagnosis, treatment decision making, or interactions during chemotherapy sessions. Breakdowns in information exchange and manner were not mutually exclusive; some patients described both.” [5] *“Yeah, got to put up with rude doctors, rude nurses constantly . . . Oh, it just made me angry. I just don’t feel like going to see doctors anymore.”* [19]	[1, 2, 4-6, 9-11, 15, 18, 19, 21, 23, 25, 26, 33, 36]	[2, 15, 22-24, 29, 33]
Inadequately addressing concerns seriously left patients feeling dismissed and could lower feelings of confidence and trust	“For some participants, feeling dismissed and not taken seriously by their GP directly influenced a low feeling of confidence and trust: [confidence]….not in the first GP, who shrugged of stomach pain as a stomach virus (Female, age 74, stage unknown, TDI>120 days)” [37] “After finishing treatment, I made a list of about 10 side effects that are still happening. And the doctors aren’t interested in it because they’re not gonna make you die.’’ [10] *“So I spent perhaps a week in the hospital. But was a bit … alone … because the hospital didn’t know what they were doing because you get all these different doctors in the hospital and there’s not one set. I had blisters in my mouth and everything … I kept saying, “I can’t swallow, it’s hurting.” And they just kept saying, “Oh well, you’ll be fine. You know, it’s just normal.” And I’m thinking…. Yeah, I know it’s probably normal but …. They gave me antibiotics in tablet form which I couldn’t swallow, the nurse kept putting “Refused to take medication” which I wasn’t refusing. It’s just that I couldn’t swallow any medication at all.’* (ID 13)” [32]	[2, 5, 6, 9-11, 32, 37-39]	

Theme	Quotes	Studies	
		Patient	**Family Caregiver**
A lack of validation of, or not responding to patients' concerns and emotions could increase anxiety and feelings of loneliness	*"Many participants told us that they felt that the emotional gravity of fertility was not recognised by HCP's involved in their cancer care. As one woman said, Like, it was all quite, you know, they were all just sort of trying to distract us and being quite cheerful. And – but it just felt really invalidating and really painful to be the only person that was aware of what this chemotherapy meant to me. I'd like for everybody who's involved in these treatments that can affect our fertility, to be aware of the emotional impact of these treatments on us. They should be sensitive (female, 36, breast)." [18]* *"When I ask about my chemo brain to my consultant, the answer is, "Oh it's just subjective. It doesn't exist." And you know there is no point discussing it any further because all the information is all anecdotal. … I couldn't remember the name of Shakespeare's wife for goodness sake, I am an English teacher. I, you know I couldn't believe it, it was unbelievable. It was terrifying actually.'(ID 03)"* [32]	[1, 7, 9, 11, 12, 15, 16, 18, 19, 25, 26, 32, 34, 37, 39-45]	[7, 22]
Lack of a personal approach could give the impression that clinicians do not care about the patient and family caregiver as a person	*"She was abrupt, like I was just a number on a piece of paper. And [it felt like] "So we're going to lose you, so that's okay."* [1] *"And that starts for me with introducing themselves as if I were as equal a person as they are. I'm a patient and they're the doctor, but we're still human beings, and I want to be treated like a real person, not just like a patient who is a piece of meat to them. And the handshake is a connection of people. . . . Again, if they're Dr. X, I want my last name used. I'm perfectly happy for everybody to be first names. . . . But I don't want them to be a doctor and me to be a [first name]."* [45]	[1, 9, 12, 15, 18, 19, 23, 26, 33, 37, 43, 45]	[23]
Not taking into account the role and needs of family caregivers could cause feelings of marginalization	"Some relatives reported that they had suffered from depression after their spouse's diagnosis and they asserted that the depression was a direct consequence of the fact that nobody had talked with them in this situation of life and death. Instead, the relatives had been rejected and felt they were in the way, and the staff did not seem to understand that the relatives' lives had also been shaken to their foundations by the threat of death in the family. *"If I'd been able to talk with someone then, then I wouldn't have had any depression at all. No, no one asked any questions about anything. Nobody at all asked if I wanted to talk."* (35-year-old man)."[40] *"So, I don't think perhaps there was much support for him (husband). I don't think there was. Or if it was there, we never looked for it. Maybe it's there and we didn't look for it. I don't know. Maybe he's … he was kind of always tagged on. Looking back on it now, I feel quite sorry for him actually because he was more or less ignored all the way through it. So even if I was speaking to a doctor or a nurse, (name of husband) was just there as a shadow."* [32].	[16, 32]	[2, 7, 15, 22, 29, 40, 46]

Theme	Quotes	Studies	
		Patient	Family Caregiver
4. Lack of feeling held and remembered			
Experiencing a lack of time for concerns to be properly heard could make patients feel like a burden	“Such a connection was important in situations of advanced disease because many patients worried they were medically uninteresting and personally less rewarding for providers to be involved with because of their poor prognosis. One participant recalled the impact of unhelpful communication in this regard: *‘Some of the impression that I got was that you have a terminal illness, there’s not much we can do for you so we’re not really interested’.*” [25] *“Sometimes the staff made patients feel like a burden and were taking advantage of the healthcare system: When she called, she was informed about how busy all the physicians were and felt that she caused trouble stealing the time of the physicians.”* [2] *“He acts kind of like he cares, but one time he said, ‘I don’t have time for anecdotes.’ And then one time my husband was there, and he [the doctor] was looking at his watch!’’* [26]	[1, 2, 7, 12, 15-17, 19, 25, 26, 33, 34, 37, 39, 40, 42-44]	[2, 22, 24, 29]
Excessive waiting and not keeping appointments could increase distress	“Patients experienced fear, anxiety, and other negative emotions while awaiting important information such as test results or surgery outcomes. Delays in information provision extended patients’ uncertainty and contributed to patients’ and family members’ emotional distress. those who felt that their clinicians could have, but did not provide information that would have helped them prepare saw this as a serious and sometimes harmful omission.” [17] “Not responding to questions you pose via the electronic record. Not calling back at all. Or saying you’ll be called on Friday and then not having time, so you end up spending the whole day waiting. (ID-1021)”[9]	[6, 7, 9, 17, 19, 29, 42, 43]	[2, 7, 17, 29]

Theme	Quotes	Studies	
		Patient	Family Caregiver
Experiencing lack of continuity of care could increase uncertainty, confusion and feelings of abandonment	“Patients reported wanting more contact and follow-up care after treatment. Without sufficient follow-up, patients felt confused and anxious about their treatment plan and prognosis.. *“I just don’t feel that I can go to the appointment or whatever, it’s like they think, okay, she’s not even looking after herself, so why bother. My doctor said he’s coming to see me, he didn’t. Nothing has been done. I just feel like I’m left here and they don’t care. “*- PT, 16.” [19] “Abandoning words indicated that from a medical standpoint, there was nothing else to do for the patient. All that was left was to wait for death. A common example of such a sentence was, `There’s nothing more to do’, `It’s not certain that we have time’ or `I do not have anything more to say or do for you’. This gave the patient a feeling of abandonment and the idea that no treatment or support whatsoever was available. Even if the doctor later told them about the resources available in terms of medical palliative treatment or support, the negative feeling remained. *I thought that they took away my hope when they said they could not do anything more. I lost my hope. I just wished that I could go to sleep and not wake up anymore. There was nothing more to do.”* [39]	[3, 9, 11, 16, 17, 19, 21, 23, 25, 32-34, 37, 39, 40, 47]	[2, 7, 22, 23, 29]

REFERENCES OF APPENDIX 3

1. Thorne, S., et al., *Prognosticating futures and the human experience of hope.* Palliat Support Care, 2007. **5**(3): p. 227-39.
2. Olsson, E.M., *Interpersonal complaints regarding cancer care through a gender lens.* Int J Health Care Qual Assur, 2016. **29**(6): p. 687-702.
3. Martinez Tyson, D.D., et al., *Understanding the supportive care needs of Hispanic men cancer survivors.* Ethn Health, 2017. **22**(1): p. 1-16.
4. Evans, N., et al., *Older patients' attitudes towards and experiences of patient-physician end-of-life communication: a secondary analysis of interviews from British, Dutch and Belgian patients.* Bmc Palliative Care, 2012. **11**: p. 10.
5. Mazor, K.M., et al., *More than words: Patients' views on apology and disclosure when things go wrong in cancer care.* Patient Education and Counseling, 2013. **90**(3): p. 341-346.
6. Mazor, K.M., et al., *Toward patient-centered cancer care: patient perceptions of problematic events, impact, and response.* J Clin Oncol, 2012. **30**(15): p. 1784-90.
7. Kimberlin, C., et al., Cancer patient and caregiver experiences: communication and pain management issues. J Pain Symptom Manage, 2004. **28**(6): p. 566-78.
8. Tasaki, K., et al., *Communication between physicians and cancer patients about complementary and alternative medicine: exploring patients' perspectives.* Psychooncology, 2002. **11**(3): p. 212-20.
9. Westendorp, J., et al., *Mind your words: Oncologists' communication that potentially harms patients with advanced cancer: A survey on patient perspectives.* Cancer, 2022. **128**(5): p. 1133-1140.
10. Adamson, M., et al., *The Doctor-Patient Relationship and Information-Seeking Behavior: Four Orientations to Cancer Communication.* J Palliat Care, 2018. **33**(2): p. 79-87.
11. Bentsen, L., et al., *How Do Young Women with Cancer Experience Oncofertility Counselling during Cancer Treatment? A Qualitative, Single Centre Study at a Danish Tertiary Hospital.* Cancers, 2021. **13**(6): p. 1355.
12. Hillen, M.A., et al., *The evolution of uncertainty in second opinions about prostate cancer treatment.* Health Expectations: An International Journal of Public Participation in Health Care & Health Policy, 2017. **20**(6): p. 1264-1274.
13. Haase, K.R., et al., *Patient and clinician perspectives of desired features for a web-based self-management program (icanmanage. ca): Exposing patients "hard work" of managing acute cancer.* Supportive Care in Cancer, 2021. **29**: p. 1989-1998.
14. Ormel, I., et al., *How to know what to know: Information challenges for women in the diagnostic phase of breast cancer.* Patient education and counseling, 2021. **104**(1): p. 179-185.
15. Thorne, S.E., et al., *Cancer care communication: the power to harm and the power to heal?* Patient Educ Couns, 2008. **71**(1): p. 34-40.
16. Droog, E., C. Armstrong, and S. MacCurtain, *Supporting patients during their breast cancer journey: the informational role of clinical nurse specialists.* Cancer Nurs, 2014. **37**(6): p. 429-35.
17. Mazor, K.M., et al., *Patients' and family members' views on patient-centered communication during cancer care.* Psychooncology, 2013. **22**(11): p. 2487-95.
18. Ussher, J.M., C. Parton, and J. Perz, *Need for information, honesty and respect: patient perspectives on health care professionals communication about cancer and fertility.* Reprod Health, 2018. **15**(1): p. 2.

19. Marcusson-Rababi, B., et al., *Does gynaecological cancer care meet the needs of Indigenous Australian women? Qualitative interviews with patients and care providers.* BMC Health Serv Res, 2019. **19**(1): p. 606.
20. Brotzman, L.E., et al., *Patient perspectives on treatment decision-making under clinical uncertainty: chemotherapy treatment decisions among stage II colon cancer patients.* Translational behavioral medicine, 2021. **11**(10): p. 1905-1914.
21. El-Sayed, E., et al., *Breast Cancer Patients' Experience about Involvement in Health Care: A Qualitative Study.* Journal of High Institute of Public Health, 2021. **51**(3): p. 114-120.
22. Sisk, B.A., et al., *Bereaved caregivers perspectives of negative communication experiences near the end of life for adolescents and young adults with cancer.* Journal of adolescent and young adult oncology, 2022. **11**(5): p. 498-505.
23. Villalobos, M., et al., *A longitudinal communication approach in advanced lung cancer: A qualitative study of patients', relatives' and staff's perspectives.* Eur J Cancer Care (Engl), 2018. **27**(2): p. e12794.
24. Islam, K.M., et al., *Coping with an advanced stage lung cancer diagnosis: Patient, caregiver, and provider perspectives on the role of the health care system.* Journal of Cancer Education, 2016. **31**(3): p. 554-558.
25. Stajduhar, K.I., et al., *Patient perceptions of helpful communication in the context of advanced cancer.* Journal of Clinical Nursing, 2010. **19**(13-14): p. 2039-2047.
26. Thorne, S., et al., *Poor communication in cancer care: patient perspectives on what it is and what to do about it.* Cancer Nurs, 2013. **36**(6): p. 445-53.
27. Liu, J.E., E. Mok, and T. Wong, *Perceptions of Chinese cancer patients of the favorable and unfavorable words conveyed by their social support providers.* Cancer Nurs, 2005. **28**(5): p. 348-54.
28. Jindal, S.K., et al., *Strategies for discussing long-term prognosis when deciding on cancer screening for adults over age 75.* Journal of the American Geriatrics Society, 2022. **70**(6): p. 1734-1744.
29. Waldrop, D.P., et al., *The nature and timing of family-provider communication in late-stage cancer: A qualitative study of caregivers' experiences.* Journal of Pain and Symptom Management, 2012. **43**(2): p. 182-194.
30. Xu, L.W., et al., *Life After the Neurosurgical Ward in Sub-Saharan Africa: Neurosurgical Treatment and Outpatient Outcomes in Uganda.* World Neurosurg, 2018. **113**: p. e153-e160.
31. Ziebland, S., J. Evans, and A. McPherson, *The choice is yours? How women with ovarian cancer make sense of treatment choices.* Patient Educ Couns, 2006. **62**(3): p. 361-7.
32. Beaver, K., S. Williamson, and J. Briggs, *Exploring patient experiences of neo-adjuvant chemotherapy for breast cancer.* European Journal of Oncology Nursing, 2016. **20**: p. 77-86.
33. Lee, S.F., L.J. Kristjanson, and A.M. Williams, *Professional relationships in palliative care decision making.* Support Care Cancer, 2009. **17**(4): p. 445-50.
34. Blanch-Hartigan, D., et al., *Trends in cancer survivors' experience of patient-centered communication: Results from the Health Information National Trends Survey (HINTS).* Journal of Cancer Survivorship, 2016. **10**(6): p. 1067-1077.
35. Flynn, S., et al., *"You don't know what's wrong with you": an exploration of cancer-related experiences in people with an intellectual disability.* Psychooncology, 2016. **25**(10): p. 1198-1205.
36. Zebrack, B., M.A. Chesler, and S. Kaplan, *To foster healing among adolescents and young adults with cancer: what helps? What hurts?* Support Care Cancer, 2010. **18**(1): p. 131-5.

37. Blackmore, T., et al., *How do colorectal cancer patients rate their GP: a mixed methods study.* BMC Family Practice, 2021. **22**: p. 1-10.

38. Im, E.O., et al., *A national online forum on ethnic differences in cancer pain experience.* Nurs Res, 2009. **58**(2): p. 86-94.

39. Friedrichsen, M.J., P.M. Strang, and M.E. Carlsson, *Cancer patients' interpretations of verbal expressions when given information about ending cancer treatment.* Palliat Med, 2002. **16**(4): p. 323-30.

40. Strang, S., P. Strang, and B.M. Ternestedt, *Existential support in brain tumour patients and their spouses.* Support Care Cancer, 2001. **9**(8): p. 625-33.

41. Easley, J., B. Miedema, and L. Robinson, *It's the "good" cancer, so who cares? Perceived lack of support among young thyroid cancer survivors.* Oncol Nurs Forum, 2013. **40**(6): p. 596-600.

42. Wiener, R.S., et al., *Patient vs Clinician Perspectives on Communication About Results of Lung Cancer Screening: A Qualitative Study.* Chest, 2020. **158**(3): p. 1240-1249.

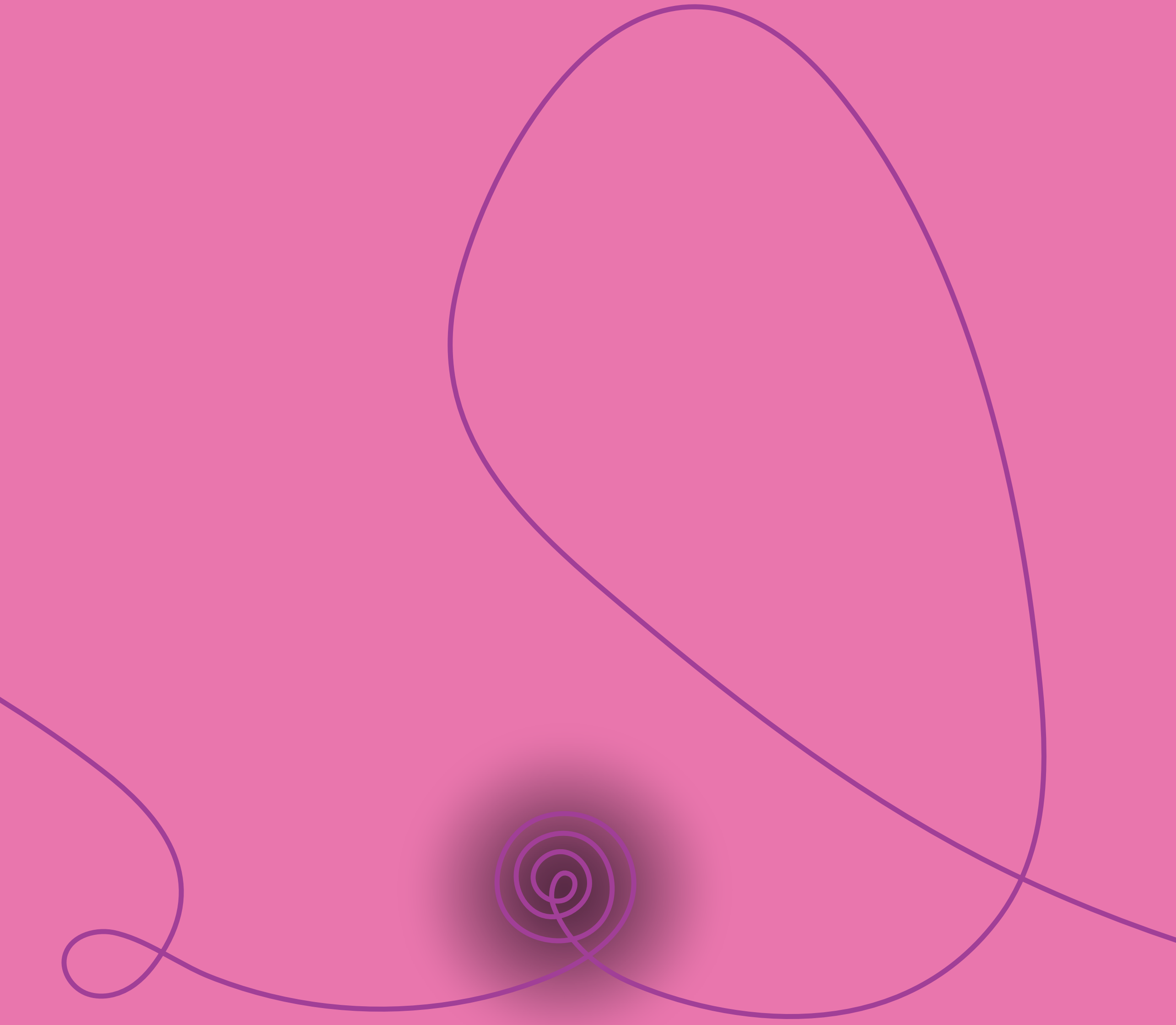
43. Pozzar, R.A. and D.L. Berry, *Preserving Oneself in the Face of Uncertainty: A Grounded Theory Study of Women With Ovarian Cancer.* Oncol Nurs Forum, 2019. **46**(5): p. 595-603.

44. Entwistle, V.A., et al., *Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences.* Qual Saf Health Care, 2010. **19**(6): p. e33.

45. Boehmer, U. and P. Case, *Sexual minority women's interactions with breast cancer providers.* Women Health, 2006. **44**(2): p. 41-58.

46. Francis, S.R., E.O. Hall, and C. Delmar, *Spouse caregivers' experiences of suffering in relation to care for a partner with brain tumor: a qualitative study.* Cancer Nursing, 2022. **45**(2): p. E320-E328.

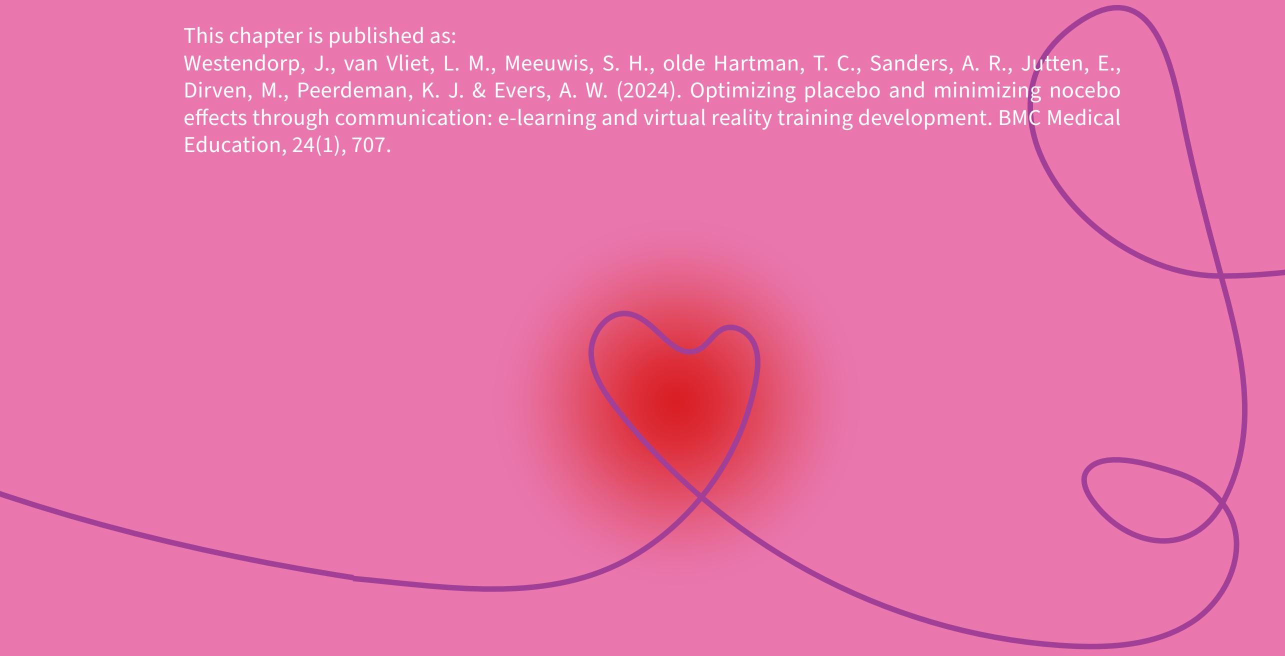
47. Palmer Kelly, E., et al., *Characterizing Perceptions Around the Patient-Oncologist Relationship: a Qualitative Focus Group Analysis.* J Cancer Educ, 2020. **35**(3): p. 447-453.



6

Optimizing placebo and minimizing nocebo effects through communication: e-learning and virtual reality training development

This chapter is published as:
Westendorp, J., van Vliet, L. M., Meeuwis, S. H., olde Hartman, T. C., Sanders, A. R., Jutten, E., Dirven, M., Peerdeman, K. J. & Evers, A. W. (2024). Optimizing placebo and minimizing nocebo effects through communication: e-learning and virtual reality training development. BMC Medical Education, 24(1), 707.



ABSTRACT

Background: The effects of many treatments in healthcare are determined by factors other than the treatment itself. Patients' expectations and the relationship with their healthcare provider can significantly affect treatment outcomes and thereby play a major role in eliciting placebo and nocebo effects. We aim to develop and evaluate an innovative communication training, consisting of an e-learning and virtual reality (VR) training, for healthcare providers across all disciplines, to optimize placebo and minimize nocebo effects through healthcare provider-patient communication. The current paper describes the development, mid-term evaluation, optimization, and final evaluation of the communication training, conducted in The Netherlands.

Methods: The development of both the e-learning and the VR training consisted of four phases: 1) content and technical development, 2) mid-term evaluation by healthcare providers and placebo/communication researchers, 3) optimization of the training, and 4) final evaluation by healthcare providers. To ensure the success, applicability, authenticity, and user-friendliness of the communication training, there was ongoing structural collaboration with healthcare providers as future end users, experts in the field of placebo/communication research, and educational experts in all phases.

Results: Placebo/communication researchers and healthcare providers evaluated the e-learning positively (overall 7.9 on 0–10 scale) and the content was perceived as useful, accessible, and interesting. The VR training was assessed with an overall 6.9 (0–10 scale) and was evaluated as user-friendly and a safe method for practicing communication skills. Although there were some concerns regarding the authenticity of the VR training (i.e. to what extent the virtual patient reacts like a real patient), placebo and communication researchers, as well as healthcare providers, recognized the significant potential of the VR training for the future.

Conclusions: We have developed an innovative and user-friendly communication training, consisting of an e-learning and VR training (2D and 3D), that can be used to teach healthcare providers how to optimize placebo effects and minimize nocebo effects through healthcare provider-patient communication. Future studies can work on improved authenticity, translate the training into other languages and cultures, expand with additional VR cases, and measure the expected effects on providers communication skills and subsequently patient outcomes.

BACKGROUND

The effects of many regular clinical treatments in healthcare are partially determined by factors other than the treatment itself.[1 2] Patients' expectations and the relationship with their healthcare provider can significantly affect treatment outcomes and thereby play a major role in placebo and nocebo effects.[3] We define placebo and nocebo effects as the changes in patient outcomes that can be explained by the expectations someone has about the treatment.[4] The underlying biopsychosocial processes involved in placebo and nocebo effects have been extensively studied. These processes include learning mechanisms (e.g. patients' previous experiences or clinicians' suggestions) and the healthcare provider-patient relationship (e.g. emphatic behavior) that can influence patient expectations and trust.[3 5-8] As the healthcare provider-patient interaction plays such an important role in eliciting placebo and nocebo effects[9-12], training healthcare providers' communication with their patients is pivotal for optimizing healthcare.

Experts in placebo research consented that there are several strategies to optimize placebo effects and minimize nocebo effects through communication in clinical practice.[4 13] For example, healthcare providers could enhance treatment effects if they outline the expected benefits from treatment[14], prevent side effects by fine-tuning the information they give to patients[15-17], and increase trust and satisfaction through an empathetic attitude.[18-21] However, experts also agree that these communication strategies are currently underutilized, and that healthcare providers should preferably be trained to address placebo and nocebo effects via their communication.[13]

Our goal was to develop and evaluate an innovative communication training for healthcare providers to optimize placebo and minimize nocebo effects through healthcare provider-patient communication. We aimed for the training to be suitable for healthcare providers across disciplines at every level, whether they are actively practicing or still in training, thus ensuring its broad applicability. The communication training will exist of two advanced eHealth components: an e-learning and virtual reality (VR) training. Using these eHealth techniques has the potential for great outreach as it can be easily offered online. Other advantages over hiring teachers or actors are: costs-efficiency, standardized teaching and practicing, safe learning environment, and opportunities for extensive repetitive practice.[22-25] Additionally, the use of virtual patients yields comparable learning effects compared to role-playing actors.[26 27] The aim of the communication training was threefold: 1) to familiarize healthcare providers with state-of-the art knowledge on placebo and nocebo effects, 2) to raise awareness about the role of placebo and nocebo effects in everyday clinical practice, and 3) to teach communication techniques that can optimize placebo effects and minimize nocebo effects in clinical practice. The current paper describes the development, mid-term evaluation, optimization, and final evaluation of the communication training.

METHODS

The content of the communication training was based on the most recent scientific insights and expert consensus on placebo and nocebo effects, which has been investigated systematically during the first[4] and second[13] official Society for Interdisciplinary Placebo Studies (SIPS) conferences in 2017 and 2019. The training consists of two parts. First, the background theory, empirical evidence and communication skills are taught in an e-learning. Second, hands-on practice is offered in a VR training. Both the e-learning and the VR tool were developed in Dutch.

The e-learning was developed first and its content was the starting point for the VR training. The development of both the e-learning and the VR training took place between May 2021 and October 2022 and was divided into four phases: 1) content and technical development, 2) mid-term evaluation by healthcare providers and placebo/communication researchers, 3) optimization of the training, and 4) final evaluation by healthcare providers. To ensure the success, applicability, authenticity, and user-friendliness of the training, in all phases there was ongoing structural collaboration with a group of experts. This group consisted of all authors and the experts mentioned in the acknowledgements, in total including two general practitioners, two anesthesia practitioners (one physician and one physician assistant), one VR expert (and his team members) who developed the VR application, one educational expert (and her team members) who developed the e-learning, and fifteen national and international researchers (most with backgrounds in biomedical and health sciences, some of whom are also working in clinical practice). The authors together set up the content and design of the training. Throughout the phases, updates were consistently shared with the other experts for feedback and approval. The studies were conducted in The Netherlands and approved by the Ethical Committee of Psychology Research of Leiden University (2022-03-01-A.W.M. Evers-V2-3783 and 2022-06-10-A.W.M. Evers-V2-4051).

E-Learning development and evaluation

Content determination

For the development of the e-learning we collaborated with a non-profit medical education provider, the Dutch Institute for Rational Use of Medicine (IVM). To determine the specific design and content topics of the e-learning, a brainstorm session was organized with an expert group of national and international clinicians and placebo/communication researchers (i.e. all authors and experts mentioned in acknowledgements). Subsequently, a content framework was created in collaboration with an education developer from IVM, which was sent to the expert group for approval. All involved experts agreed on the topics to be included (Figure 1).

E-learning structure

The e-learning structure is based on leading didactic theories.[28-31] To activate and motivate, the e-learning starts with a welcome video, followed by an audio message from a general practitioner (AS) who already makes extensive use of the communication techniques. Second, healthcare providers are challenged to think about their own knowledge and skills, and what they want to improve. Third, an introduction about placebo and nocebo effects in clinical practice is given. This introduction is followed by five substantive modules (Figure 1). Each module contains a video, which focuses on background knowledge, and textual information, which focuses on practical skills. Subsequently, an assignment is given ('step-by-step case') in which the healthcare provider can practice the learned techniques on an own (imaginary) patient. During this assignment, several questions are asked on how to act in a certain situation, followed by specific automated feedback. In a final take home assignment, the healthcare provider is encouraged to plan a moment to apply the learned knowledge in clinical practice. The e-learning ends with an optional test (15 multiple choice questions; pass after ≥ 10 correct answers) after which accreditation points could be obtained (Dutch accreditation available for: ABC 1, Kwaliteitsregister V&V and Verpleegkundig Specialisten Register). Thirty five test questions were developed to provide variety when a test had to be retaken.

Figure 1. Overview of the e-learning's main structure and contents

Introduction: Placebo and nocebo effects in clinical practice
Mechanisms behind placebo and nocebo effects
Impact of patients' expectations on treatment outcomes
Communication as promising avenue for enhancing expectancy effects
Module 1: Optimizing the provider-patient relationship
Impact of healthcare provider-patient relationship on patient outcomes
Techniques to improve provider-patient relationship
Module 2: Asking about patients' expectations
Importance of knowing patients' expectations
How to ask about patients' expectations
Module 3: Discussing treatment rationale
Explaining treatment goals/mechanisms and positive expectations about treatment outcomes
Impact of specific word usage when performing a medical intervention
Module 4: Discussing risks and side effects
Risks of highlighting potentially negative treatment outcomes
Best ways of framing information about risks and side effects
Module 5: Explaining placebo and nocebo effects to the patient
Potential positive effects of informing patients about placebo and nocebo effects
Ways to explain placebo and nocebo effects to patients

E-learning optimization and evaluation

Design

The e-learning was evaluated twice: mid-term evaluation and final evaluation. The mid-term evaluation took place directly after finishing the development of the first version of the e-learning and the collected feedback was used for optimization of the e-learning. In the final evaluation, the e-learning was re-evaluated by a new group of participants to measure if the adjustments led to improvement and to determine if the training was ready to be used in practice.

Participants

In both evaluations, we asked healthcare providers (future users) to evaluate the e-learning. During the mid-term evaluation we additionally included placebo/communication researchers to assess the e-learning for accuracy and quality of the content. In both evaluations, participants were recruited from the professional network of the research group members, for example researchers and healthcare professionals from Leiden University Medical Center (LUMC) and Radboud University Medical Center (RadboudUMC). In the final evaluation, participants were also recruited via (social) media (e.g. on LinkedIn and in the newsletter of IVM). Healthcare providers could follow the e-learning for free and they indicated whether they agreed to use their data for research before they started. In the mid-term evaluation, placebo/communication researchers (*N*=4) and healthcare providers (nurse *N*=3; unknown *N*=2) assessed the quality of the e-learning (whether the content is correct) and tested the user experience and realism of the e-learning. In the final evaluation, the e-learning was evaluated by healthcare providers (physician *N*=5; nurse *N*=4, other [unspecified] *N*=9).

Procedure & Materials

In both evaluations, participants went through the e-learning by themselves, at a self-chosen moment, from their own computers. No researcher was present during this process. To evaluate the e-learning two questionnaires were designed: 1) General questionnaire and 2) Specific questionnaire. The General questionnaire, offered through the e-learning environment, included 14 questions: Five questions about the participants' background (e.g. 'What is your job function?'), five multiple choice questions (e.g. 'Do you think that the e-learning is user-friendly? yes/ reasonable/not really/no'), three open ended questions (e.g. 'How can we improve the e-learning?'), and one rating ('What grade do you give this e-learning? scale 1-10'). Table 1 (first column) shows the multiple choice questions. The Specific questionnaire, sent by e-mail, included 14 rating questions (scale 1-10) to evaluate each separate part of the e-learning (see the first column of Table 2; e.g. 'How would you rate the quality of the information in Module 1? 1= very poor quality 10= very good quality'), and one open question ('Do you have any additional feedback?'). During the mid-term evaluation, participants completed both questionnaires. During the final evaluation, participants completed only the General questionnaire.

Table 1. Results e-learning evaluations General questionnaire

Questions and answer options	**Mid-term evaluation (N=7)**		**Final evaluation (N=18)**	
	Frequency	**Percent**	**Frequency**	**Percent**
1. Do you think that the e-learning is user friendly?				
Yes	3	43	13	72
Reasonable	4	57	5	28
Not really	0	0	0	0
No	0	0	0	0
2. Do you think the structure of the e-learning is logical?				
Yes	6	86	16	89
Reasonable	1	14	2	11
Not really	0	0	0	0
No	0	0	0	0
3. What do you think of the level of the e-learning?				
Too easy	0	0	2	11
Easy	3	43	4	22
Doable	4	57	12	67
Difficult	0	0	0	0
Too difficult	0	0	0	0
4. Can you apply what you have learned from the e-learning in daily practice?				
Yes	2	29	13	72
Reasonable	5	71	5	28
Not really	0	0	0	0
No	0	0	0	0
5. How long did it take to complete the e-learning?				
30 minutes	0	0	1	6
1 hour	2	29	12	67
1.5 hour	4	57	4	22
2 hours	1	14	1	6
>2 hours	0	0	0	0

Table 2. Results e-learning Specific questionnaire (mid-term evaluation only)

Questions [a]	**N**	**Mean**	**SD**
What did you think of the …			
1. way the information was given in the introduction?	9	7.50	1
2. quality of the information in the introduction of the e-learning?	9	8.00	1
3. way the information was given in the modules?	9	8.11	0.93
4. quality of the information in module 1?	9	8.22	0.97
5. quality of the information in module 2?	9	8.44	0.73
6. quality of the information in module 3?	9	8.00	0.87
7. quality of the information in module 4?	9	7.72	0.97
8. quality of the information in module 5?	9	7.67	1.22
9. way the step-by-step case was presented?	7	8.29	0.75
10. quality of the questions in the step-by-step case?	7	7.86	0.90
11. quality of the tips given in the step-by-step case?	7	8.00	0.82
12. take home-message assignment?	8	5.88	1.64
13. way the final test was provided?	8	8.25	1.28
14. quality of the final test?	9	7.94	1.38

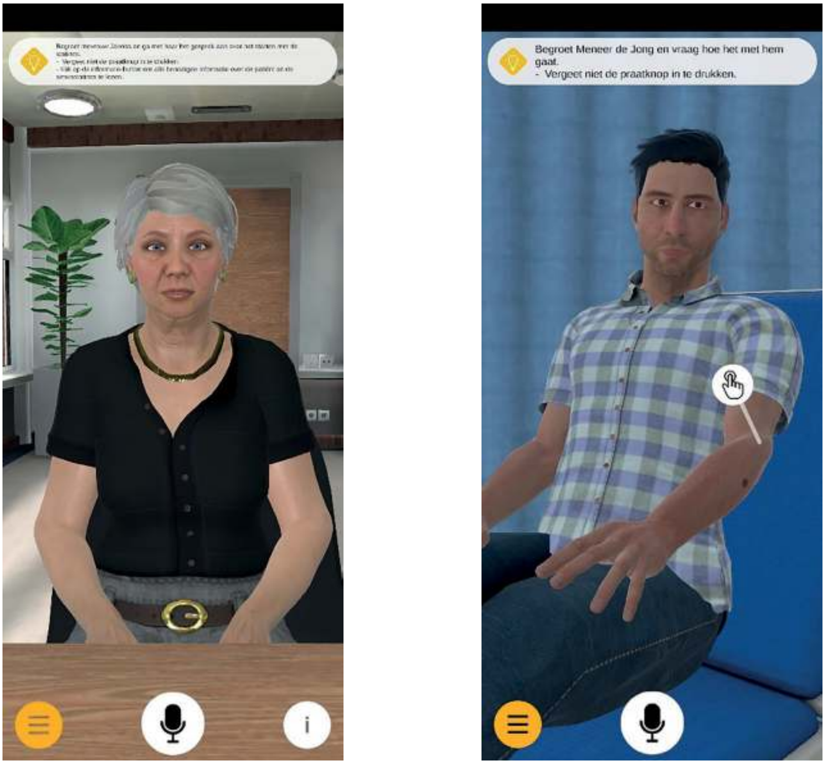
a scale 1-10: 1= not user-friendly/ bad quality 10= very user-friendly/perfect quality

VR training development and evaluation

Content Determination

In the VR training, healthcare providers interact with simulated patients in two different scenarios while using VR headsets. The VR training focused on training those techniques that have been agreed upon by the expert group in determining the content of the e-learning, as described above. To optimize placebo effects, the provider is taught to explain why the chosen treatment is offered, to emphasize what its short- and long-term benefits are, and to display a warm and empathic attitude (e.g. by maintaining eye contact with the virtual patient). To minimize nocebo effects, the provider learns techniques such as how to identify patients at risk by recognizing negative expectancy patterns, and how to carefully introduce potential side effects of a treatment. For development of the VR training, we collaborated with The Simulation Crew (TSC). TSC is a Dutch company that specializes in developing interactive VR communication training courses using Artificial Intelligence (AI) based speech technology and simulation techniques for training and feedback. In order to ensure that the VR training fits well with conversations in clinical practice, there was structural collaboration with two clinicians (ToH and AS). During the creation of the patient cases, roleplay sessions with three nurses were conducted. Throughout the development process, intensive consultations took place between the researchers, VR developers, and involved clinicians. The researchers took into account the empirical evidence, the VR developers the developmental feasibility, and the clinicians the comparison with clinical practice. Two patient cases were designed (Figure 2). The names within the described cases have been contrived for development of the training and do not pertain to actual individuals under any circumstances. In selecting the features of the patients, we endeavored to be as diverse as possible, by incorporating variations in gender and age.

Figure 2. Brief description of the patient cases in the VR training



Begroet Meneer de Jong en vraag hoe het met hem gaat.
- Vergeet niet de praatknop in te drukken.

Case 1 – Mrs Jakobs
Healthcare providers are instructed to prescribe a drug (Statins) to Mrs. Jakobs, a 72-year-old woman, recently diagnosed with Diabetes. Mrs. Jakobs has a lot of negative expectations about this drug due to negative stories from her neighbor about side effects. She prefers not to take the Statins. When practicing the case, the healthcare provider will consistently work on optimizing placebo effects and minimizing nocebo effects by inquiring about the her expectations, addressing her concerns, highlighting the medication's positive effects, and framing side effects carefully.

Case 2 – Mr de Jong
Healthcare providers are to remove a spot from the arm of Mr. de Jong, a 39-year-old man, after administering a local anesthetic injection. Mr. de Jong is very anxious about the procedure because he is afraid that the anesthetic will not work, as he has experienced in the past. When practicing the case, the healthcare provider will consistently work on optimizing placebo effects and minimizing nocebo effects by addressing his concerns, reassuring, explaining the procedure properly, emphasizing the positive effects of the injection, and using words carefully during the procedure.

VR training structure

The two patient cases were integrated into an app, which can be utilized in 2D on mobile devices and in 3D with the Oculus Quest 2 VR headsets. Only the 3D version was tested in this study since the 2D version was developed later. Healthcare providers can talk aloud in the VR environment and the patient talks back. Artificial Intelligence (AI) tools, such as *speech recognition* and *natural language processing/understanding*, ensured that providers can freely interact with the patients in the VR environment and that they can explore the impact of different communication strategies on the patient. During the mid-term evaluation, the patient had a computer voice. To ensure natural responses from the virtual patients, between the mid-term and final evaluation TSC recorded all possible reactions with motion capture (gestures), facial capture (facial expression), and human voice. Moreover, the AI tracked and detected gaze direction which was used for feedback on keeping eye contact with the patient. After completing the consultation with the virtual patient, healthcare providers received personalized feedback on how they communicated with the patient, and what they could do to improve their skills.

VR training optimization and evaluation

Design

The VR training (3D version) was evaluated twice: during a mid-term evaluation and a final evaluation. During the mid-term evaluation, both patient cases were assessed separately because case 2 was developed after the first evaluation of case 1. During the final evaluation, both cases were re-evaluated to measure if the adjustments led to improvement and to determine if the training was ready to be used in practice.

Participants

In both evaluations, we asked healthcare providers (future users) to evaluate the VR training. During the mid-term evaluation we additionally included placebo/communication researchers to assess the training for accuracy and quality of the content. In both evaluations, participants were recruited from the professional network of the research group members, for example researchers and healthcare professionals from Leiden University Medical Center (LUMC) and Radboud University Medical Center (RadboudUMC). During the mid-term evaluation, placebo/communication researchers (*N*=7) and healthcare providers (physician *N*=7, nurse *N*=2) assessed the VR training on quality, user experience, and authenticity (i.e. to what extent the virtual conversation corresponds with a real conversation). During the final evaluation, the VR training was evaluated by healthcare providers (nurse *N*=10; physician *N*=8; psychologist *N*=2; unknown *N*=2; researcher *N*=1). Five participants were part of both evaluations.

Procedure & Materials

Both evaluations were in person and several test days were organized in collaboration with TSC. In addition, some individual test appointments were scheduled. The procedure and materials were the same for both evaluations. Participants put on the VR headsets and went through one or both VR cases, having a conversation with the virtual patient multiple times. Participants' interim feedback was noted by the researcher/TSC and the first impression was discussed and noted after the test. At the end of the appointment, all participants were asked to complete an evaluative questionnaire. The questionnaire contained five questions about the participants' background (e.g. 'What is your job function?'), multiple choice questions (e.g. 'do you think the structure of the case is logical? Yes/Reasonable/Not really/No'), ratings (e.g. 'how user-friendly do you find the VR training? scale 1-10'), and room for comments. See the first column of Table 3 for the multiple choice questions and ratings.

Table 3 Results virtual reality training evaluations

Questions	Mid-term evaluation				Final Evaluation			
	Case 1		Case 2		Case 1 and 2			
	N	M; SD	N	M; SD	N	M; SD		
1. How user-friendly do you think the VR tool is?[a]	9	7.11; 2.09	7	7.36; 1.55	23	7.17; 1.07		
2. How did you rate working with VR-glasses?[b]	9	7.22; 2.33	7	8.57; 0.53	23	7.43; 1.56		
3. What rating would you give the VR tool?[c]	9	5.94; 2.13	7	7.36; 0.48	22	6.91; 1.19		
					Case 1		Case 2	
					N	M; SD	N	M; SD
4. What did you think of the quality of the feedback?[c]	9	7.00; 1.00	7	7.14; 0.63	18	6.78; 1.44	17	6.85; 1.25
5. What rating would you give the patient case?[c]	X	x	x	x	18	6.89; 0.96	18	7.42; 1.03
	Frequency	Percent	Frequency	Percent	Frequency	Percent	Frequency	Percent
6. Do you think the structure of the case is logical?								
Yes	2	22	5	71	8	44	14	78
Reasonable	6	67	2	29	9	50	3	17
Not really	1	11	0	0	1	6	1	6
No	0	0	0	0	0	0	0	0
7. What do you think of the level of the case?								
Too easy	0	0	0	0	0	0	0	0
Easy	2	22	2	29	3	18	3	17
Doable	2	22	5	71	10	59	13	72
Difficult	5	56	0	0	4	24	2	11
Too difficult	0	0	0	0	0	0	0	0
8. Can you apply what you have learned in the case in daily practice?								
Yes	2	22	4	67	8	44	9	50
Reasonable	5	56	2	33	7	39	8	44
Not really	1	11	0	0	2	11	1	6
No	1	11	0	0	1	6	0	0

a scale 1-10: 1= not user-friendly 10= very user-friendly; b scale 1-10: 1= very hard 10= very easy; c scale 1-10: 1= bad quality 10= perfect quality

RESULTS

Participant characteristics

The background characteristics of all participants are summarized in Table 4.

Table 4 Demographic characteristics of participants

					VR training			
	Mid-term evaluation		**Final evaluation**		**Mid-term evaluation**		**Final evaluation**	
	(N=9)a		(N=18)b		Case 1 (N=9)c Case 2 (N=7)		Case 1 only (N=5) Case 2 only (N=5) Both cases (N=13)	
	Frequency	**M; SD**				**M; SD**	**Frequency**	**M; SD**
Age (years)	7	36.57; 12.57			16	40.80; 12.14	23	49.65; 10.88
	Frequency	**Percent**	**Frequency**	**Percent**	**Frequency**	**Percent**	**Frequency**	**Percent**
Gender								
Male	0	0	3	17	6	38	8	35
Female	7	100	14	78	10	63	15	65
Other	0	0	1	6	0	0	0	0
Education								
Low*	0	0	1	6	0	0	1	4
High**	7	100	17	94	16	100	22	96
Job function[d]								
Researcher	4	57	0	0	7	44	1	4
Physician/ physician in training	0	0	5	28	7	44	8	35
Nurse/ nurse specialist	3	43	4	22	2	13	10	43
Psychologist/ pedagogue	0	0	0	0	0	0	2	9
Other (unspecified)	0	0	9	50	0	0	0	0
Job Experience (years)[e]								
0-5	2	29	3	18	8	53	7	32
6-10	3	43	2	12	3	20	3	14
11-20	1	14	5	29	4	27	6	27
>20	1	14	7	41	0	0	6	27

a demographic characteristics data was missing for 2 participants; b around 100 healthcare providers followed the e-learning, 34 gave informed consent and 18 completed the questionnaire;
c two participants tested both cases; d In the final evaluation of the VR training job function data was missing for 2 participants; e job experience data was missing for 1 participant in all evaluations except mid-term e-learning; * primary, pre-vocational and vocational; ** advanced secondary and tertiary

E-learning optimization and evaluation

Mid-term evaluation

During the mid-term evaluation, all components of the e-learning were rated positively (range $M = 7.5$ – $M = 8.4$) except the *take-home assignment* ($M = 5.9$, $SD = 1.64$) (Table 2). The alternation between the different types of information (e.g. text, video, assignment) was experienced as positive, as well as the structure, user-friendliness, and level of the e-learning (Table 1). The e-learning as a whole was assessed with a 7.9 ($N = 7$, $SD = 0.90$). Figure 3 shows some qualitative comments of participants per study.

Figure 3. Qualitative quotes evaluation studies

E-learning	
Mid-term evaluation	**Final evaluation**
What is good	**What is good**
“Alternation between the different ways of providing information was good. Structure was clear. Information was accessible and interesting. Nice to see a different face every time” *“The level seems fine to me for a non-expert in the field.”*	*“Concrete, practical example sentences for each module.”* *“Many open doors, but I am aware that the practice is sometimes a bit more complicated.”* *“Design, amount of information and usefulness of the information was good. Even though I am not a doctor, I will certainly use the knowledge and tips I have gained in my nursing role.”* *“I didn’t really have any expectations, but it is very nice for a GP practice to offer this to employees to gain more insight.”*
What could be better	**What could be better**
“Guiding the participant a little more throughout the course, using a little easier language here and there, even more concrete examples and tips, maybe a little more visual support.” *“The video’s with the researchers are given a lot of emphasis, while you would rather see (video’s) of practical situations.”*	*“Make it clear that it is mainly for care providers who (will) be involved in direct patient care. Perhaps show something with examples of sharing the conversation with the patient?”* *“Patient case studies on video. Not all people in the videos spoke with equal ease. Sometimes some slips and glitches.”* *“Movies a bit boring, maybe you can do something with graphics appearing while talking? And I wonder if 1 same person is better every video, now a bit separate from each other.”*
VR Training	
Mid-term evaluation	**Final evaluation**
What is good	**What is good**
“Glasses fit comfortably, controllers are comfortable to hold, clear instructions.” Case 1 *“You can practice a bit with conversation techniques and it is useful to see how they can come across / how people can react to them.”* Case 1 *“Very useful for practicing different ways of saying something.”* Case 2 *“It feels very secure, you can do this on your own, not for a group in role play.”* – tool in general	*“It is user-friendly, practicing beforehand is an advantage to be more involved in the conversation.”* – tool in general *“I think very valuable to use in education.”* Case 1 *“The feedback provided by the tool was good and tailored.”* Case 2 *“Hiring actors is much more expensive, would favor e-learning first then VR, then actor.”* – tool in general
What could be better	**What could be better**
“Difficult to move forward in a conversation if you don’t say the right thing.” Case 1 *“The situation with VR is still different from practice, especially interaction with the patient is a bit more difficult than when you have a real-life patient in front of you. But the casuistry is applicable.”* Case 2	*“Visually good, still understands too little.” – tool in general* *“I have no experience with prescribing a statin, so it is difficult to provide information.”* Case 1 *“Feedback is good, but not always realistic. The computer does not recognize everything.”* Case 2 *“The computer doesn’t understand silences.”* Case 2

Optimization

Based on the quantitative and qualitative analysis of the mid-term evaluation, the following adjustments were made to optimize the e-learning:

- The *take home assignment* was offered as an optional, instead of a required part of the training.
- We added a clear overview screen at the beginning of the e-learning with the aim, the structure, the welcome video and an overview of the chapters.
- More example phrases, that healthcare providers can use in daily practice, were added (e.g. how to explore expectations).
- Detailed feedback on grammar and the general layout of the e-learning was processed when possible.

Final evaluation

The e-learning improved in terms of user-friendliness ('yes' from 43% to 72%) and applicability in practice ('yes' from 29% to 72%), see Table 1. The overall assessment was equal in both evaluation moments ($N = 7$, $M = 7.9$, $SD = 0.90$ vs. $N = 18$, $M = 7.9$, $SD = 0.76$). Quotes of participants confirmed that the added practical examples were helpful: e.g. *"Design, amount of information and usefulness of the information was good. Even though I am not a doctor, I will certainly use the knowledge and tips I have gained in my nursing role"*. Enhancing the quality of the videos or including healthcare provider-patient interaction videos are potential suggestions for improvement (see quotes in Figure 3).

VR training optimization and evaluation

Mid-term evaluation

During the mid-term evaluation, case 1 was rated less positively than case 2 ($M = 5.9$; SD = 2.13 vs. $M = 7.4$; $SD = 0.48$). More than half of the participants scored case 1 as *difficult*, however all participants perceived case 2 as either *doable* or *easy*. In both cases, participants indicated that the interaction with the simulated patient was difficult because the tool does not always understand everything they said (due to speech recognition limitations). This resulted in a stiff and sometimes unnatural conversation flow. The user-friendliness, on the other hand, was immediately assessed as sufficient in both cases ($M = 7.1$; $SD = 2.09$ and $M = 7.4$; $SD = 1.55$, respectively), see Table 3 and Figure 3.

Optimization

The first step towards VR training improvement was that all possible reactions/ movements of the virtual patient were recorded by an actor in a motion-sensitive suit.

This improvement gave the simulated patient a more human appearance. The following adjustments were also made to optimize the VR training:

- The recognition and vocabulary of the simulated patient was expanded, allowing the system to better understand what the participant is saying and improve the responses.
- After the participant welcomed the patient, the patient starts talking directly instead of waiting for a question from the trainee, which makes the start of the conversation smoother.
- More instructions were added to guide the participant through the conversation.
- The visuals were optimized (e.g. enhanced legibility of the computer screen in the virtual environment).

Final evaluation

The final evaluation showed that case 1 improved in terms of structure, level and overall rating (see Table 3). Case 2 was assessed almost equal as in the mid-term evaluation. In both cases about half of the participants perceived the acquired knowledge as directly *applicable* in clinical practice (44% and 50%, respectively), almost the other half perceived it as *reasonably applicable* (39% and 44%, respectively). The comments also indicated that the VR training was perceived as valuable: e.g. *“I think very valuable to use in education”*. For additional quotes, see Figure 3. The VR training as a whole was assessed with a 6.9 ($N = 22$, $SD = 1.19$). Instances where the avatar does not understand the participant or gives inappropriate responses remain a focus point for improvement in the future.

DISCUSSION

We developed and evaluated an innovative communication training, consisting of an e-learning and VR training, for healthcare providers to optimize placebo and minimize nocebo effects through healthcare provider-patient communication. Results of the evaluation studies show that both healthcare providers and communication/placebo researchers were mostly positive about the communication training. The e-learning was experienced as user-friendly and the content was perceived as accessible, interesting, and easily applicable in clinical practice. Enhancing the quality of the videos or including healthcare provider-patient interaction videos are potential suggestions for improvement. The VR training was experienced as user-friendly as well, and as offering a safe learning environment. Instances where the VR avatar does not understand the participant or gives inappropriate responses remain a focus point for improvement in the future.

The growing acknowledgement of the power of communication in healthcare is a positive development that results in an increase in communication training programs for healthcare providers. Existing communication training courses often focus on shared decision making[32], person centered care[33], or serious illness communication.[34-36] Fewer training courses focus on how to utilize placebo effects in clinical practice.[37-39] What our training adds to the existing training courses is that we focus on both optimizing placebo effects, and also minimizing nocebo effects. In addition to educating healthcare providers about the potential impact of expectations and empathy, we also train them in effectively informing patients about placebo and nocebo effects. We utilize various learning methods, including text, video, assignments, and virtual reality, and aim to be accessible to healthcare providers in all disciplines.

Setting up this e-learning and VR training presented some limitations and taught us some lessons that may also be helpful for others. First an issue, common in interdisciplinary collaborations[40], that arose at the initial stage of the development was that the researchers and educational experts (IVM and TSC) experienced lack of expertise in each other's field. Learning each other's language was time-consuming, but frequent consultation at the beginning of the project has been helpful. The growth of knowledge of each other's field is reflected in the finding that VR case 2, which was developed after a first version of case 1 was evaluated, was immediately assessed better than case 1. Second, a well-known problem of VR is that it remains difficult to be authentic (i.e. to what extent the virtual patient reacts like a real patient) due to technical challenges.[23 40 41] In our VR training, we decided to use the technique *natural language processing*, instead of the more conventional *choice-based dialogue*. The use of *natural language processing* enables a real conversation with the virtual patient, however it is also more challenging and time-consuming to ensure a smooth conversation flow. Our results reveal that the authenticity did improve as we progressed in the development. More use of the VR training will improve speech recognition, due to the self-learning abilities of the applied AI. Third, during the final evaluation of the e-learning, we were not able to ascertain the specific medical roles of the participants involved, as the response option 'other' could not be elaborated upon. Fourth, the initial plan was to develop and evaluate the e-learning and the VR training simultaneously as one product. However, due to practical considerations (e.g. time constraints and the distribution of required expertise among multiple partners) separate developmental and evaluation phases were needed. Consequently, this separation led to relatively small sample sizes for all evaluations, which are a limitation of this study. Nonetheless, the separate development has also resulted in an additional benefit: the e-learning and VR training are two self-contained, full-fledged and complementary training tools. These tools can be offered independently or combined as a full training. Combining both training tools, starting with the e-learning followed by the VR training, may enhance the effectiveness of the training.[35]

Development of this first-of-its-kind communication training offers opportunities for future directions. In a follow-up study the effect of this training on healthcare providers' communication should be studied. To assess the improvement of healthcare providers' theoretical knowledge, the e-learning test can serve as a measurement instrument for both pre- and post-training evaluations. In the VR training, healthcare providers' communication is already being assessed through a scoring system, which is currently used to determine the personalized feedback. The score could potentially serve as a pre- and post-measurement, or it can be studied whether there is an enhancement in the scores when healthcare providers go through the case studies multiple times. Next, it can be investigated whether the acquired communication skills impact patient outcomes on both short- and long-term levels. Some potentially expected outcomes may include increased treatment effectiveness, higher levels of satisfaction and trust, as well as reduced anxiety and perceived side effects.[18 42-44] Another direction for the future is translation of the training. The current training has been developed from a Dutch (East European) perspective and is only available in Dutch. Translating the training to other languages and cultures is an important next step, where cultural differences and preferences must be taken into account.[45 46] A last valuable direction is expanding the VR training with more specific cases to connect even better with healthcare providers from all (para)medical disciplines (e.g. physiotherapists and psychologists). When developing new cases in the future, it is important to strive for diversity in patient features, such as gender, age, and culture. In future AI developments, it's essential to stay informed about ongoing advancements, potential biases, and ethical discussions.

Availability

The e-learning and VR training (2D and 3D) are already offered in The Netherlands and available via the websites of IVM and TSC. After completing the e-learning, Dutch accreditation is available for: ABC 1, Kwaliteitsregister V&V and Verpleegkundig Specialisten Register.

Training introduction video: https://www.youtube.com/watch?v=3N6r_Syk2SA
IVM: https://www.medicijngebruik.nl/scholing/e-learning/4942/behandeleffecten-verbeteren-via-communicatie
TSC: https://thesimulationcrew.com/producten/placebo/

Conclusion

To conclude, we have developed an innovative and user-friendly communication training that can be used to teach healthcare providers how to optimize placebo effects and minimize nocebo effects through healthcare provider-patient communication. The training consists of an e-learning and VR training (2D and 3D) which can be followed separately or together. Placebo/communication researchers and healthcare providers have provided a favorable evaluation of the training. However, the training's potential effect on the communication of healthcare providers has not yet been studied. Future studies can focus on translating the training into other languages and cultures, improving the authenticity of the VR training, expanding with additional VR cases, and measuring the expected effects on healthcare provider communication skills, and subsequently, on patient outcomes.

Acknowledgements

We thank the expert group of national and international clinicians and placebo/communication researchers for their involvement in the development of this communication training: Adam Hirsh, Jeremy Howick, Luana Colloca, Fabian Wolters, Judy Veldhuijzen, Antoinette van Laarhoven, Henriët van Middendorp, Aleksandrina Skvortsova, Hans van Lennep, Simone Meijer, Marc Godfried, Bram Thiel. We thank nurses Liz Tenhagen, Suzanne Kok en Kim Nijboer-Vliegen for their contribution to the role plays. We would like to thank the employees of the Dutch Institute for Rational Use of Medicine (IVM) and The Simulation crew (TSC) for their contribution to the development of the training. We would like to thank research assistants Marrit Veenstra and Eva Rümke for their support in data collection and analysis. Last, we would like to express our gratitude to all healthcare providers and placebo/communication researchers who participated in the evaluation studies of the training.

Authors' contributions

Study conceptualization: AE,SM, KP and LvV; Training development: JW, LvV, KP, SM, ToH, AS, EJ, MD, and AE. Data collection and analyzation: JW. JW drafted the full manuscript and all authors contributed to the revision of the manuscript. All authors read and approved the final manuscript.

Funding

This project was funded by a European Research Council grant awarded to prof. dr. A.W.M. Evers (ERC proof of concept grant; 966785-COMMUNICATE-HEAL-TH).

Ethics declarations

Ethics approval and consent to participate

Ethical permission was obtained from the Ethical Committee of Psychology Research of Leiden University (2022-03-01-A.W.M. Evers-V2-3783 and 2022-06-10-A.W.M. Evers-V2-4051). Informed consent was obtained from all participants.

Competing interests

Author Eric Jutten is CEO of The Simulation Crew. The Simulation Crew sells the VR training. The other authors have no conflicts of interest to declare.

Abbreviations

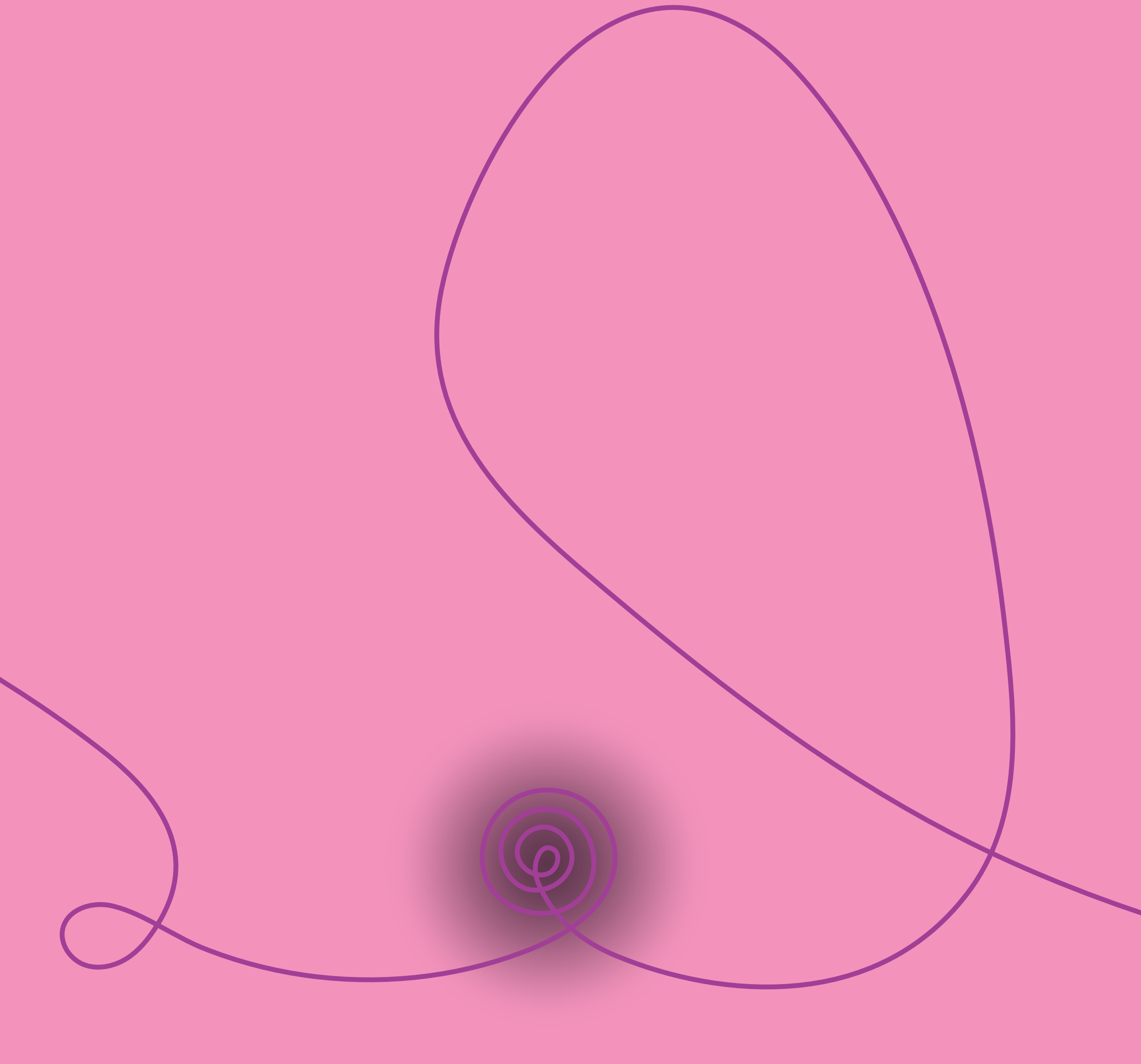
VR	Virtual reality
IVM	Dutch Institute for Rational Use of Medicine (Instituut Verantwoord Medicijngebruik)
TSC	The Simulation Crew

REFERENCES

1. Kaptchuk TJ, Miller FG. Placebo effects in medicine. *N Engl J Med* 2015;373(1):8-9.
2. Finniss DG, Kaptchuk TJ, Miller F, Benedetti F. Biological, clinical, and ethical advances of placebo effects. *The Lancet* 2010;375(9715):686-95.
3. Benedetti F. Placebo and the new physiology of the doctor-patient relationship. *Physiological reviews* 2013;93(3):1207-46.
4. Evers AW, Colloca L, Blease C, et al. Implications of placebo and nocebo effects for clinical practice: expert consensus. *Psychotherapy and psychosomatics* 2018;87(4):204-10.
5. Schedlowski M, Enck P, Rief W, Bingel U. Neuro-bio-behavioral mechanisms of placebo and nocebo responses: implications for clinical trials and clinical practice. *Pharmacological reviews* 2015;67(3):697-730.
6. Colloca L, Benedetti F. Placebo analgesia induced by social observational learning. *PAIN®* 2009;144(1-2):28-34.
7. Colagiuri B, Livesey EJ, Harris JA. Can expectancies produce placebo effects for implicit learning? *Psychonomic bulletin & review* 2011;18:399-405.
8. Bensing JM, Verheul W. The silent healer: the role of communication in placebo effects. *Patient education and counseling* 2010;80(3):293-99.
9. Howe LC, Goyer JP, Crum AJ. Harnessing the placebo effect: Exploring the influence of physician characteristics on placebo response. *Health Psychology* 2017;36(11):1074.
10. Greville-Harris M, Dieppe P. Bad is more powerful than good: the nocebo response in medical consultations. *The American Journal of Medicine* 2015;128(2):126-29.
11. Colloca L, Finniss D. Nocebo effects, patient-clinician communication, and therapeutic outcomes. *Jama* 2012;307(6):567-68.
12. Bishop FL, Coghlan B, Geraghty AW, et al. What techniques might be used to harness placebo effects in non-malignant pain? A literature review and survey to develop a taxonomy. *BMJ open* 2017;7(6):e015516.
13. Evers AW, Colloca L, Blease C, et al. What should clinicians tell patients about placebo and nocebo effects? Practical considerations based on expert consensus. *Psychotherapy and psychosomatics* 2021;90(1):49-56.
14. Blythe JS, Thomaidou MA, Peerdeman KJ, et al. Placebo effects on cutaneous pain and itch: a systematic review and meta-analysis of experimental results and methodology. *PAIN* 2022:10.1097.
15. Colagiuri B, McGuinness K, Boakes RA, Butow PN. Warning about side effects can increase their occurrence: an experimental model using placebo treatment for sleep difficulty. *Journal of psychopharmacology* 2012;26(12):1540-47.
16. Krauss BS. “This may hurt”: predictions in procedural disclosure may do harm. *BMJ* 2015;350
17. Thomaidou MA, Blythe JS, Peerdeman KJ, et al. Learned nocebo effects on cutaneous sensations of pain and itch: A systematic review and meta-analysis of experimental behavioral studies on healthy humans. *Psychosomatic Medicine* 2023:10.1097.
18. Hillen M, De Haes H, Stalpers L, et al. How can communication by oncologists enhance patients’ trust? An experimental study. *Annals of oncology* 2014;25(4):896-901.
19. Patel S, Pelletier-Bui A, Smith S, et al. Curricula for empathy and compassion training in medical education: a systematic review. *PloS one* 2019;14(8):e0221412.

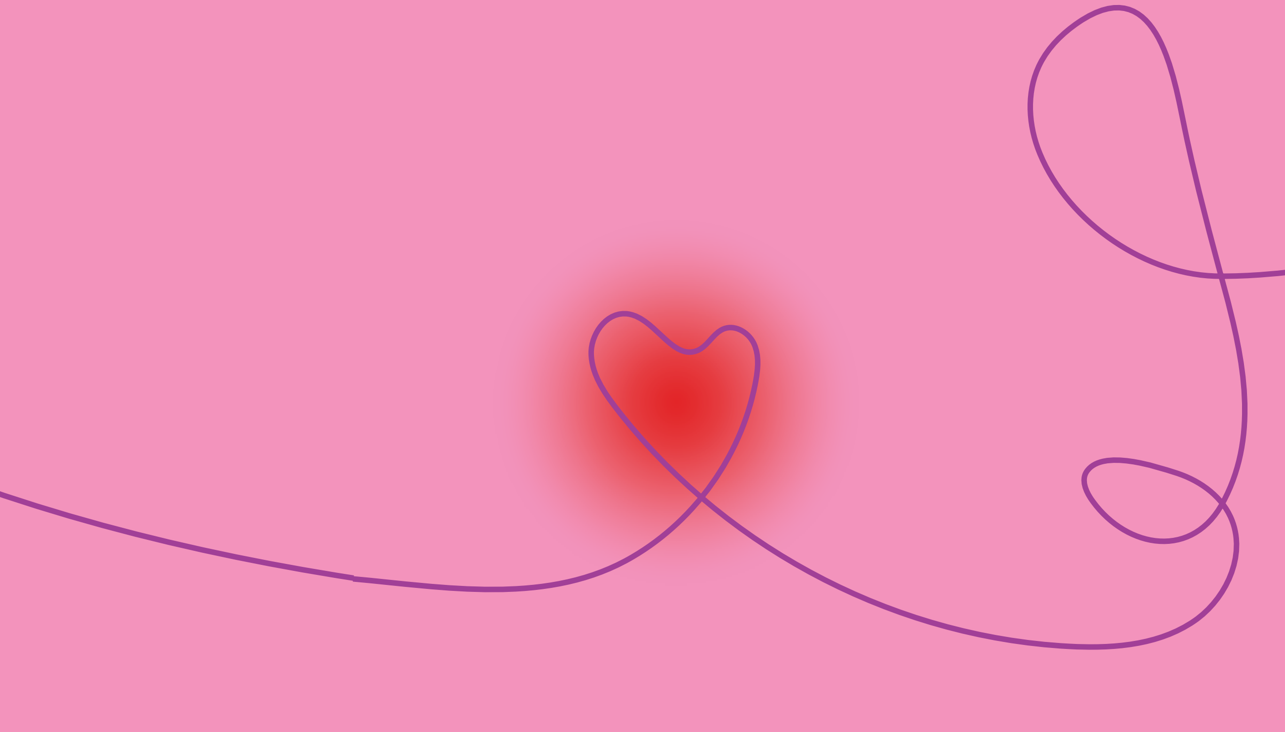
20. van Vliet LM, Epstein AS. Current state of the art and science of patient-clinician communication in progressive disease: patients' need to know and need to feel known. *Journal of Clinical Oncology* 2014;32(31):3474.
21. Van Vliet LM, Francke AL, Meijers MC, et al. The use of expectancy and empathy when communicating with patients with advanced breast cancer; an observational study of clinician–patient consultations. *Frontiers in Psychiatry* 2019;10:464.
22. Kron FW, Fetters MD, Scerbo MW, et al. Using a computer simulation for teaching communication skills: A blinded multisite mixed methods randomized controlled trial. *Patient education and counseling* 2017;100(4):748-59.
23. Ruthenbeck GS, Reynolds KJ. Virtual reality for medical training: the state-of-the-art. *Journal of Simulation* 2015;9:16-26.
24. Larsen CR, Soerensen JL, Grantcharov TP, et al. Effect of virtual reality training on laparoscopic surgery: randomised controlled trial. *Bmj* 2009;338
25. Seymour NE. VR to OR: a review of the evidence that virtual reality simulation improves operating room performance. *World journal of surgery* 2008;32:182-88.
26. Quail M, Brundage SB, Spitalnick J, et al. Student self-reported communication skills, knowledge and confidence across standardised patient, virtual and traditional clinical learning environments. *BMC medical education* 2016;16:1-12.
27. Training medical communication skills with virtual patients: Literature review and directions for future research. International Conference on Intelligent Technologies for Interactive Entertainment; 2020. Springer.
28. Kolbe D. Experiential learning. *New Jersey, Eaglewood Cliffs* 1984
29. Gagne R. The conditions of learning and theory of instruction Robert Gagné. *New York, NY: Holt, Rinehart ja Winston* 1985
30. Donovan MS, Bransford JD, Pellegrino JW. How people learn. *Retrieved March* 1999;8:2006.
31. Novak JD. Concept mapping. International Guide to Student Achievement: Routledge 2013:362-65.
32. Bieber C, Müller KG, Blumenstiel K, et al. A shared decision-making communication training program for physicians treating fibromyalgia patients: effects of a randomized controlled trial. *Journal of psychosomatic research* 2008;64(1):13-20.
33. Kaper MS, Sixsmith J, Koot JA, et al. Developing and pilot testing a comprehensive health literacy communication training for health professionals in three European countries. *Patient education and counseling* 2018;101(1):152-58.
34. Back AL, Arnold RM, Baile WF, et al. Efficacy of communication skills training for giving bad news and discussing transitions to palliative care. *Archives of internal medicine* 2007;167(5):453-60.
35. Bylund CL, Brown RF, Bialer PA, et al. Developing and implementing an advanced communication training program in oncology at a comprehensive cancer center. *Journal of Cancer Education* 2011;26:604-11.
36. Labs A. Serious Illness Conversation Guide Training [Available from: https://www.ariadnelabs.org/serious-illness-conversation-guide-training/ accessed 23-27 2023.
37. Zion SR, Crum AJ. Mindsets matter: a new framework for harnessing the placebo effect in modern medicine. *International review of neurobiology* 2018;138:137-60.
38. Smith KA, Vennik J, Morrison L, et al. Harnessing placebo effects in primary care: using the person-based approach to develop an online intervention to enhance practitioners' communication of clinical empathy and realistic optimism during consultations. *Frontiers in Pain Research* 2021:49.

39. Howick J, Gray Muir, . The Oxford Empathy Programme 2015 [Available from: https://www.philosophy.ox.ac.uk/oxford-empathy-programme.
40. Shorey S, Ang E, Yap J, et al. A virtual counseling application using artificial intelligence for communication skills training in nursing education: development study. *Journal of medical Internet research* 2019;21(10):e14658.
41. Lee J, Kim H, Kim KH, et al. Effective virtual patient simulators for medical communication training: a systematic review. *Medical education* 2020;54(9):786-95.
42. Petrie KJ, Rief W. Psychobiological mechanisms of placebo and nocebo effects: pathways to improve treatments and reduce side effects. *Annual review of psychology* 2019;70:599-625.
43. Uitterhoeve R, Bensing J, Dilven E, et al. Nurse–patient communication in cancer care: does responding to patient's cues predict patient satisfaction with communication. *Psycho-oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 2009;18(10):1060-68.
44. van Osch M, Sep M, van Vliet LM, et al. Reducing patients' anxiety and uncertainty, and improving recall in bad news consultations. *Health Psychology* 2014;33(11):1382.
45. Elliot AJ, Chirkov VI, Kim Y, Sheldon KM. A cross-cultural analysis of avoidance (relative to approach) personal goals. *Psychological Science* 2001;12(6):505-10.
46. Lockwood P, Marshall TC, Sadler P. Promoting success or preventing failure: Cultural differences in motivation by positive and negative role models. *Personality and Social Psychology Bulletin* 2005;31(3):379-92.



7

English summary



THE POWER OF HELPFUL AND HARMFUL COMMUNICATION IN HEALTHCARE

This dissertation aimed to shed light on how healthcare providers' communication could help and harm patients. We have illuminated the critical role of healthcare providers' communication in providing information, expressing empathy, and managing expectations. In chapter 1, we presented a historical overview of the medical communication and placebo research line and delineated the gaps in the literature upon which this dissertation focused. In chapter 2 we explored how expectations and empathy were used in communication with patients with advanced cancer. In chapter 3, the impact of empathy on the information recall of patients with advanced cancer was examined, considering the mediating role of anxiety. The next two chapters focused on exploring the patient perspective (chapter 4) and previous literature perspective (chapter 5) on potentially harmful communication behaviors in cancer care. In chapter 6 the development and evaluation of a communication training (using an e-learning and virtual reality) for healthcare providers in general was described. In this chapter, an initial summary of the findings from each chapter will be presented.

CHAPTER 2

In chapter 2, we examined how empathy and expectations are currently utilized in the clinical setting of advanced breast cancer. We collected audio-recordings of 45 consultations between oncologists and advanced breast cancer patients. The nature of the conversation (good news, uncertain news, or bad news), and the occurrence of expectancy- and empathy-expressions provided by the oncologists were determined. The majority of the consultations (58%) contained 'good news' (i.e. good scan results). We found that when discussing positive or uncertain medical outcomes, oncologists predominantly made use of uncertain expectancy-expressions. When providing positive expectations, oncologists highlighted the importance of the doctor-patient relationship, whereas negative expectations centered around the severity of the illness. In situations of uncertainty, a 'hope for the best, prepare for the worst' approach was used. Empathy-expressions varied between generic and specific expressions, with oncologists dominantly showing understanding towards patients' emotions. Instances of a lack of empathy were uncommon, and mainly included oncologists not picking up on patients' emotional cues. This chapter indicated that empathy-expressions were already applied regularly, particularly in showing understanding for patients' emotions and complimenting patients on how they handle their disease. Expectancy-expressions were mostly uncertain, suggesting that there might be an underused potential for emphasizing positive aspects when communicating with patients with advanced cancer.

CHAPTER 3

In chapter 3, we used the same audio-taped consultations as in chapter 2, to determine the relationship between clinician-expressed empathy and patients' information recall in clinical advanced cancer consultations. We also tested whether the relationship between clinician-expressed empathy and recall was mediated by a decrease in patients' anxiety. Our results showed that in general patients' remembered 61% of the discussed information and recall was best for information about treatment options (77%) followed by treatment aims/positive effects information (63%) and least for information about side effects (40%). In addition, patients' anxiety significantly decreased after the consultation. Clinician-expressed empathy significantly increased patients' total information recall and recall of treatment aims and positive effects. These effects, however, could not be explained by a decrease in patients´ anxiety level. Although the underlying mechanism remains unclear, our results highlight the impact of empathy expressed by clinicians in consultations with seriously ill patients. The findings of this chapter indicated that clinician-expressed empathy can address patients' cognitive needs, enhancing recall of provided medical information.

CHAPTER 4

In chapter 4, we explored the perspectives of patients with advanced cancer about potentially harmful communication behaviors by oncologists, and helpful alternatives. We developed an online questionnaire including questions about nineteen situations that could potentially entail unnecessarily harmful communication. These situations were accompanied by an example of potentially harmful communication and an alternative of potentially helpful communication. We included 71 patients who completed the questionnaire. The results revealed that communication may be potentially harmful regarding the themes of information provision, prognosis discussion, decision-making, and empathy. Specific harmful examples were discussing the end of anti-cancer therapy without mentioning what is still possible, not listening to the patient, and making vague promises. Patients' views varied on the potential harmfulness of providing general information about test results (60% perceived too much as harmful; 65% perceived too little as harmful) and prognostic information (68% perceived prognostic information as harmful; 50% perceived no prognostic information as harmful). Focusing on prognosis, qualitative results showed that some found it harmful if specific prognostic information was provided, as this sort of information is inherently uncertain. Others found it harmful if no or vague prognostic information was provided. In the cases where patients varied on what they perceived as harmful communication, inquiring about their preferences (tailoring) might be helpful. The findings of this chapter revealed that there are specific communication topics that most patients perceive as harmful, but there are also communication topics where opinions among patients differ on whether it is harmful or not. In this chapter, we offer insights into both easily preventable pitfalls and delicate challenges that demand an individualized approach, where exploration might be beneficial.

CHAPTER 5

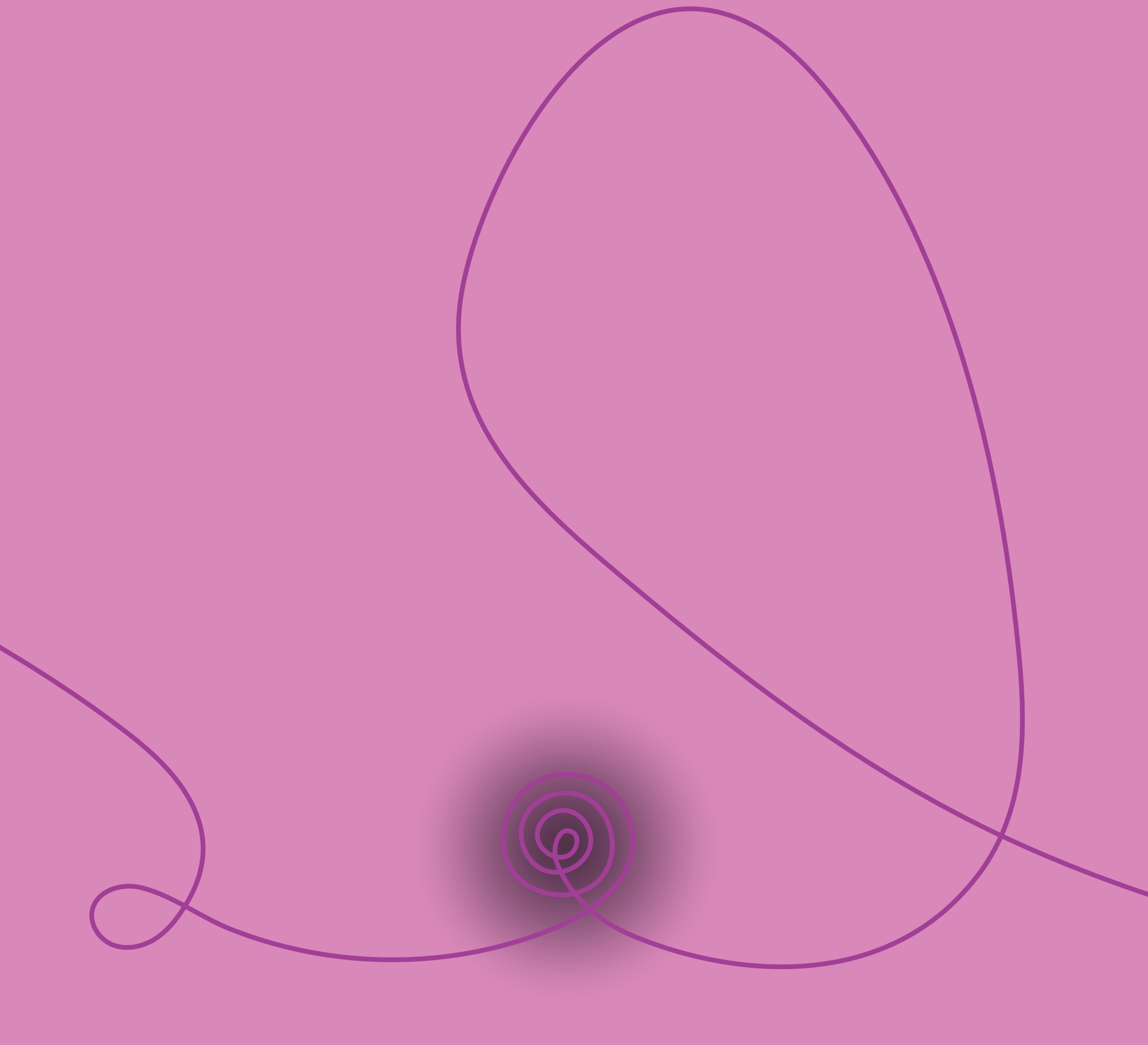
In chapter 5, we advanced the investigation of harmful communication in oncology through a systematic analysis of the existing literature in this domain. This chapter synthesized existing studies on cancer patients' and family caregivers' views on which clinicians' communication behaviors can harm. We searched for all types of peer-reviewed studies that determined adult cancer patients' and/or family caregivers' perspectives on which clinicians' communication behaviors can harm in several databases, supplemented by expert-consultation. We included 47 studies in this systematic review. Seventeen themes of harmful communication were identified, categorized under four main themes: 1) Lack of tailored information provision (e.g. giving too little or too much/specific information) 2) Lack of tailored decision making (ranging from: patient exclusion, to the patients' responsibility, and/or haste) 3) Lack of feeling seen and heard (seen as a disease, not as a human being; not listened to concerns and emotions) 4) Lack of feeling held and remembered (forgotten agreements; lack of care continuity). The results of this chapter revealed that unintended harm could be prevented when information and decision involvement are tailored and patients' and family caregivers' needs to feel seen, heard, held and remembered are met.

CHAPTER 6

In chapter 6, we described the development and evaluation of an innovative communication training, consisting of an e-learning and virtual reality (VR) training, for healthcare providers across all disciplines, to optimize placebo and minimize nocebo effects through healthcare provider-patient communication. The aim of the communication training was threefold: 1) to familiarize healthcare providers with state-of-the art knowledge on placebo and nocebo effects, 2) to raise awareness about the role of placebo and nocebo effects in everyday clinical practice, and 3) to teach communication techniques that can optimize placebo effects and minimize nocebo effects in clinical practice. The content of the communication training was based on the most recent scientific insights and published expert consensus on placebo and nocebo effects. The e-learning provided theoretical knowledge and practical handles distributed across five modules: 1) Optimizing the provider-patient relationship, 2) Asking about patients' expectations, 3) Discussing treatment rationale, 4) Discussing risks and side effects, 5) Explaining placebo and nocebo effects to the patient. In the VR training, healthcare providers interact with simulated patients in two different scenarios (Case 1 prescribing medication; Case 2 administering a local anesthetic injection) while using VR headsets. Results of the evaluation studies showed that both healthcare providers and communication/placebo researchers were mostly positive about the communication training. The e-learning was experienced as user-friendly and the content was perceived as accessible, interesting, and easily applicable in clinical practice. The VR training was experienced as user-friendly as well, and as offering a safe learning environment. Instances where the VR avatar did not understand the participant or gave inappropriate responses remain a focus point for improvement in the future.

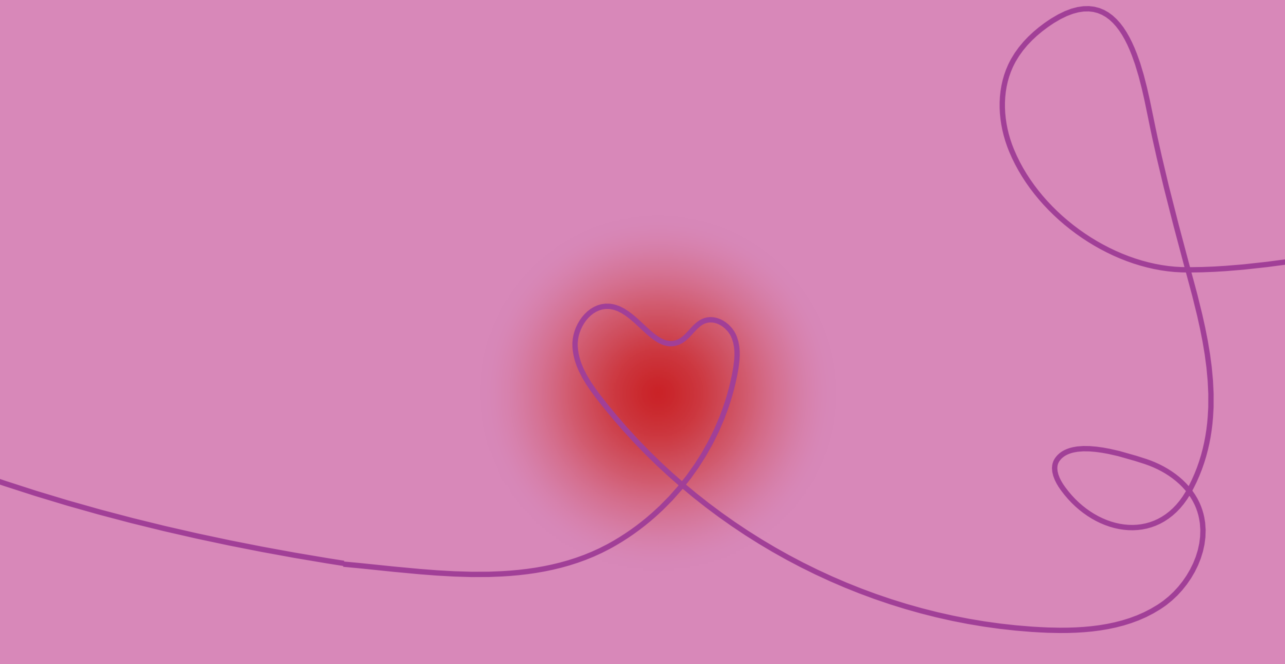
CONCLUSION

Taken together, this dissertation highlighted the pivotal role of healthcare providers' communication in providing information, expressing empathy, and managing expectations. We have explored how communication can either help or harm patients. Our results indicated that empathy not only contributes to addressing patients' emotional needs but also plays a role in meeting their cognitive needs, specifically in recalling medical information. We also introduced a new, more existential need: *to feel held and remembered*. Our results have also enhanced the understanding of communication that might harm patients and have provided guidance on how to prevent such harm. We have further bridged the gap to clinical practice by developing and evaluating a communication training on placebo and nocebo effects, which received positive evaluations. While communicating with patients and addressing their individual needs remains a challenging responsibility for healthcare providers, we aspire for this dissertation to offer support and guidance on which communication can have positive effects and which may potentially harm for individual patients. Increasing this awareness among healthcare providers has the potential to contribute to enhanced communication, greater effectiveness of treatments, and improved patients outcomes in the future.



8

General discussion



FROM UNKNOWNS TO INSIGHTS

In this dissertation, we propose that healthcare providers' communication has three functions that can contribute to enhancing patient care: 1) providing information, 2) expressing empathy and 3) managing expectations. In the forthcoming discussion, we embark on a comprehensive exploration of these three functions of communication. This discussion seeks to illuminate the theoretical contribution of this dissertation, providing an understanding of how communication can both help and harm patients. Following this, we delve into the limitations and strengths, offer suggestions for future directions, provide implications for clinical practice, and end with an overall conclusion.

1 PROVIDING INFORMATION

In medical consultations, patients have a dual need: to *know and understand* and *to feel known and understood.*[1-3] These coexisting needs can be roughly seen as a need for information and for empathy.[2] We recognized the necessity for patients to receive comprehensive information in order to understand their illness and its implications, allowing them to make well-informed decision.[4] This dissertation reveals that patients agree that the need for information can be met by providing information about the disease, explanations of test results, treatment options, treatment consequences, and prognosis (chapter 4 and 5). In these chapters it also emerged that patients generally agreed on identifying several potentially harmful behaviors that could be relatively easy to prevent. For example, not keeping promises/appointments. In line with other studies, patients noted that waiting for crucial and potentially impactful information is inherently stressful.[5] However, as the agreed-upon time passed, patients reported that their anxiety increased. Studies on the effectiveness of providing information through online patient portals are promising in terms of reducing waiting times, providing better patient information, and improving decision-making.[6-8] However, communication through these online portals also poses risks[7 9 10]: the possibility of misinterpreting information and receiving bad news without emotional support of a healthcare provider.[10 11]

As described in chapters 4 and 5, patients noted that the use of vague information, such as medical jargon, was also perceived as harmful. This may lead to patients not comprehending the full extent of their illness, and potentially hindering the ability to make informed decisions.[12] This risk is even greater among patients with low health literacy.[13] Patients also agree that having to make hasty decisions can be harmful. This outcome aligns with the *attentional narrowing theory*, which indicates that simultaneously handling stress and information processing in a dual task results in decreased retention of information.[14 15] Emotions that follow after receiving bad news or hearing about treatment options first need to sink in, before treatment decisions can be made.[16] Chapter 3 indicated that only 61% of the provided information was recalled by patients. Additionally, we observed that clinician-expressed empathy can enhance patients' recall of information. Consistent with the results of chapter 4 and previous studies, these findings underscore the importance of expressing empathy, not providing too much information at once and checking patients' understanding.[12 17]

This dissertation demonstrated that patients' perspectives on what they perceive as helpful and harmful information varied. We identified individual patient's needs and preferences as a prerequisite for optimal information. Overall, in chapter 4 and 5, the differences among patients primarily revolve around the need for general medical information, prognostic information, and involvement in decision-making. We found that both inadequately tailored information provision (such as providing too little or too much) and inadequately tailored decision-making (for instance, excluding patients or making them feel responsible) were deemed as harmful. However, we do not yet know which specific patients prefer more or less information and involvement. We observed that patients' reasons for desiring comprehensive information and the wish to be actively involved in decision-making, seem to overlap. In line with previous studies, patients reported a need for autonomy and control as reasons for preferring extensive information (e.g. about prognosis) and active participation in decision-making.[18-21] Patients who preferred less information and a more paternalistic decision making approach often do not feel capable enough to comprehend such crucial information and decisions.[19 22] We can further connect this to literature suggesting that patients' coping styles may impact their communication needs. In this literature a common distinction is made between patients who adopt an approach strategy (also referred to as monitors) and those who prefer an avoidance strategy (also referred to as blunters).[23-25] Patients desiring more information and greater autonomy in the decision making process might employ an approach coping strategy, while patients seeking less information and preferring less influence in the decision making process might adopt an avoidant coping strategy. These theory suggests that individuals seeking comprehensive information also tend to prefer active involvement in all decision-making, and vice versa. Nonetheless, substantiating this suggestion requires more robust evidence. This dissertation reveals that until exploring patients' needs on information, decision-making, and prognostic information can help patients and prevent potential harm.

2 EXPRESSING EMPATHY

The importance of empathy reoccurs as a common thread throughout all chapters of this dissertation. Chapter 2 revealed that expressing empathy is common in clinical settings for patients with advanced cancer. Healthcare providers demonstrated generic and specific empathic behaviors, such as responding to patient cues or emotions using the NURSE acronym (Naming, Understanding, Respecting, Supporting, Exploring) and expressing interest in the patient.[2 26] Healthcare providers commonly express understanding for patients' emotions and compliment them on how they handle their disease. However, in chapter 4, we found a noteworthy result that compliments, even when well-intended, are not always appreciated by patients. For example, patients expressed discomfort with the well-intended compliment "*You're looking good*". They mentioned hearing this frequently in their daily lives, and it made them feel that they could no longer express that they were not feeling well. Chapters 4 and 5 illustrated that a lack of empathy was perceived as harmful. Examples included overlooking patient cues (also described in Chapter 2), leading to a failure to respond to emotions, or not recognizing the patient as an individual, such as by not using someone's name.[26 27] In chapter 5 we incorporated the family caregivers perspective for the first time. They identified a lack of empathy, demonstrated by a failure to acknowledge the role and emotions of the family caregiver, as harmful too. The perspective of family caregivers is often overlooked, despite the understanding that the impact of an illness extends to the entire system around the patient.[28 29]

Previous research has highlighted that empathy contributes to the patient's need *to feel known and understood*.[1-3] Chapter 3, demonstrated that empathy can also positively contribute to the patient's cognitive *need to know and understand*, specifically in patients recall of medical information. Interestingly, we previously found that the impact of empathy on recall was limited to conversations conveying positive news.[30] In conversations delivering bad or uncertain news, empathy alone might not be sufficient. This is understandable, particularly when bad news implies a shifted life perspective, which can be emotionally burdensome. In chapter 5, we uncovered a deeper layer of empathy that may contribute to a more profound existential need: *the need to feel held and remembered*. This implies that patients want to feel a sense of ongoing care and significance, and desire time for their concerns to be properly heard, especially when patients can no longer be cured.[31] With this dissertation, we suggest expanding the commonly discussed dual need *to know and understand*, and *feel known and understood*, with the addition of a third, more existential need, *to feel held and remembered*.

3 MANAGING EXPECTATIONS

Chapter 2 revealed that in an advanced care setting, healthcare providers predominantly expressed uncertain expectations. Specifically, expectations regarding treatment outcomes and prognosis were often formulated with uncertainty. We observed that uncertain expectations were characterized by an emphasis on what an oncologist hopes for but cannot guarantee, often referred to as 'hope for the best, prepare for the worst'.[32 33] This approach is comprehensible given the unpredictable nature of advanced cancer. Healthcare providers place significant value on avoiding false hope[34], as treatment effects in an oncological setting are often overestimated by patients.[35 36] On the other hand, patients also appreciate it when healthcare providers are optimistic in their communication (e.g. highlighting possible positive expectations, or mentioning positive success stories), and some require this sense of 'hope' to cope with their illness.[37 38] In light of the evidence supporting the helpful effect of provided positive expectations, the use of managing patients' expectations in the realm of serious illness, may be underutilized. In advanced cancer care, it may not be feasible or ethical to provide overly optimistic information about prognosis and treatment outcomes. It remains essential to provide realistic expectations, as overly optimistic expectations could undermine trust, lead to overtreatment and may decrease patients' quality of life.[35 39-42] Nonetheless, there is an opportunity in this context to effectively emphasize positive expectations about achievable aspects, such as pain management and the ongoing care and involvement of healthcare providers. Literature also illustrates that focusing on what is still possible positively contributes to feelings of hope and helps patients.[38 43 44] We observed this need among patients also reflected in chapters 4 and 5. In advanced cancer care, there is an opportunity for greater implementation of this focus on positive expectations of continuity of care. This allows treatment and prognosis expectations to remain realistic while concurrently fostering trust in the continuity of care.

Healthcare providers not only encounter the challenge of communicating uncertain expectations in advanced cancer, but also in other healthcare contexts with high uncertainty. Especially in medical procedures in which perceived pain can vary, healthcare providers might struggle with the right communication strategy. A recent experimental study demonstrated that when the level of pain is uncertain, direct expression of uncertainty (e.g. "*I do not know how painful this is*") was related to more perceived pain compared to a more indirect expression of uncertainty (e.g. "*I have seen it varies widely among people how painful they experience this*").[45] These findings constitute an initial step in improving healthcare providers' verbal suggestions when managing uncertain expectations. In situations where expectations are more certain or negative consequences are less invasive, we have a comprehensive understanding of how verbal suggestions can enhance treatment outcomes.[46] In chapter 6, we have developed a communication training program (utilizing e-learning and Virtual Reality) in which healthcare providers are instructed in these and other strategies to optimize patient expectations and strengthen the healthcare provider-patient relationship. To enhance placebo effects, the healthcare provider is taught to emphasize why the chosen treatment is offered and its short- and long-term positive benefits, without overstating treatment efficacy. To minimize nocebo effects, the healthcare provider learns techniques, such as identifying patients at risk through negative expectancy patterns and introducing the potential side effects of a treatment with care.[47-49] This is the first training that also provides guidance on how healthcare providers can best explain placebo and nocebo mechanisms to patients, which can also contribute to positive treatment effects.[50 51] Healthcare providers evaluated the communication training as user-friendly, and the content was perceived as accessible, interesting, and easily applicable in clinical practice.

LIMITATIONS AND STRENGHTS

Limitations

This dissertation has limitations that we will address. Firstly, we would like to reflect on the observational and exploratory designs used in this dissertation. Chapters 2 and 3, both components of the same study, used an observational design to measure the dynamics of healthcare provider-patient interactions within an advanced cancer care setting. While observational designs hold significance as they provide researchers the capability to investigate behavior and interactions within their natural context, it is also important to realize that generalizing these findings to the entire healthcare system remains challenging, and no causal relations can be established. The data from chapters 2 and 3 capture only a small part of the overall care a patient receives. This dataset comprises just one conversation, and we are unaware of the conversations that took place both before and after. For example, focusing on recall, we conducted an examination of just a snapshot of recall. Some studies suggest that the retention of information diminishes over time. [52 53] Therefore, it would have been valuable to measure longitudinal recall as well. Examining empathy and expectations, we have only illuminated the researcher's perspective. We did not include the patient's perspective of how empathic they rated the healthcare provider, and neither their own expectations before and after the consultation. A previous publication from the same study however demonstrated that patients' opinions about the healthcare providers empathy differed from how healthcare providers perceived it. Patients tended to be more positive.[54]

Chapters 4, 5 and 6 had a more exploratory focus. In chapters 4 and 5, we explored what patients perceive as harmful communication. However, we did not measure the extent of harm associated with these themes and the potential impact of such harmful communication on patient outcomes (immediate, intermediate and long-term). The next step toward quantifying the communication behaviors of chapter 4 and 5, poses a set of ethical challenges, as we cannot design a RCT exposing patients to potentially harmful communication.[55 56] Chapter 6 is also more descriptive in nature and does not measure the extent to which the communication training is effective on healthcare providers communication skills. This chapter can be considered an essential stepping stone, but to study effectiveness for improving healthcare provider communication, a RCT design is necessary.

Secondly, it is necessary to reflect on the questionnaires and coding schemes used. The research questions in this dissertation occasionally posed challenges in aligning with existing questionnaires or coding schemes. This necessitated the self-creation of several instruments, lacking in validation. We consistently made efforts to align the self-created instruments with existing instruments, previous research, or submitted them for review by research experts and/or patients. In chapters 2 and 3, we utilized existing literature and previous research to develop the coding schemas (e.g. for empathy, expectations, and recall). In chapters 4 and 6, the questionnaires were based on existing literature, and we sought input from experts in the field (e.g. healthcare providers, patients and educational specialists) to develop the used questionnaires.

Thirdly, the studies in this dissertation demonstrate an overarching methodological limitation, namely, predominantly small sample sizes, specifically involving samples characterized by a limited representation of cultural variation. This is noteworthy, particularly in light of the realization that patient communication needs are culturally sensitive. In chapters 3 and 4, the majority of the participants had Dutch ethnicity. The literature included in chapter 5 predominantly originate from studies in the global north (i.e. Northern America, Europe, Australia and New Zealand). Although the origins of the healthcare providers evaluating the training in chapter 6 were not measured, we know that the theories conveyed in the training are rooted in literature with a Western perspective.[48 49] It is acknowledged that individuals within Dutch culture are commonly characterized by their need for autonomy, direct communication, and assertiveness.[57] While recognizing internal variations among the Dutch, there is a clear distinction in preferences compared to, for example, Asian cultures. Particularly concerning the disclosure of prognostic information, these cultures exhibit significant differences. In Asian cultures, it is more customary to refrain from providing information about life expectancy to protect patients from stress.[58 59] Moreover, cultures where religious beliefs play a crucial role perceive that the determination of life expectancy is not within the purview of the physician but rather influenced by their deity.[60 61] Within this dissertation, we did shed light on the individual differences in patients' preferences. However, the specific preferences of non-Western cultures were not investigated. This indicates that the results of this dissertation are limited in their generalizability to non-Western cultures.

Strengths

A strength of this dissertation lies in the bridge we build from empirical evidence to clinical practice. In each chapter of this dissertation, practical guidance was provided to healthcare providers on how their communication can help patients and how they can prevent potential unnecessary harm. In chapter 6, the bridge to clinical practice becomes even more clear as we have developed a communication training for healthcare providers. Existing placebo and medical communication literature were utilized as theoretical foundation for this training. Concrete techniques that optimize the effects of expectations and empathy were taught. Through an e-learning platform, we gave a theoretical overview of directly applicable techniques to enhance communication, and we took it a step further into clinical practice by also developing a virtual reality tool. With this tool, healthcare providers can actively practice with two virtual patients. Recognizing the logistical challenges associated with virtual reality, particularly due to the absence of VR headsets for everyone at home, we also have developed a 2D version of the training that can be conveniently downloaded on a phone or tablet. Throughout this dissertation, considerable attention has also been given to disseminating the results to clinical practice, for instance, through collaboration with a graphic designer. This collaboration facilitated the creation of visually appealing infographics, summarizing the results of chapters 4 and 5 for easy distribution among healthcare providers (see Appendix 1). These infographics were included in the guidelines of Palliative Care in the Netherlands (PZNL).[62]

Despite the discussed limitations of our design, we have approached the research questions of this dissertation from various perspectives and using different methods. In many studies, there was room for qualitative data, allowing us to better grasp underlying themes and generate examples of both helpful and harmful communication at a detailed level. Throughout this dissertation, there was consistent collaboration with experts from clinical practice, including both healthcare providers and patients themselves. This has ensured that this dissertation provides practical insights directly applicable to clinical practice, aligning with the practical needs of the field.

FUTURE DIRECTIONS AND CLINICAL IMPLICATIONS

Future directions

This dissertation offers directions for future research. Firstly, it is crucial to extend the findings of this dissertation through randomized controlled trials (RCTs) that can investigate hypothesized effects. It is important to comprehend how harmful certain communication behaviors can be and specifically identify the negative effects they may have (e.g. decreased patient satisfaction, increased anxiety, or pain). Non-clinical RCTs, utilizing video vignettes (role-played consultations in which communication can be manipulated), can be employed for this purpose.[63 64] By using video vignettes, direct harm to the patient is prevented, while enhancing the comprehensibility of the impact of harmful communication. The development of the training (chapter 6) also requires further exploration with RCTs. Future studies should investigate whether the training is indeed effective: improving healthcare providers' communication and subsequently patient outcomes (e.g. better treatment results). The VR tool that we have developed can be used to investigate the effectiveness of the training. By conducting a pre-measurement using the VR headset (where healthcare providers experience the VR case before undergoing the training) and a post-measurement (going through the VR case after the training), it can be investigated whether the training genuinely enhances healthcare providers their communication skills. Subsequently, through an observational study or RCT in clinical practice, it can be examined whether healthcare providers who have undergone the training communicate better with patients and whether these patients also report better outcomes. Additionally, future research could focus on further enhancing expectation management in oncological setting (characterized by its uncertainty). Research could involve examining the impact of positive verbal suggestions ensuring continuity of care on patient expectations and outcomes.

Secondly, being culturally inclusive will become a crucial avenue for future research. An important aspect to reflect upon in future research is the bias healthcare providers have in displaying empathy. Literature suggest that it is more easy to show empathy towards individuals within our own social group: persons who share similarities with us, we perceive as attractive, or young children.[65 66] Studies have shown that ethnic minorities and patients with a lower socioeconomic status (SES) receive significantly less empathy.[67-69] Meanwhile, non-Western ethnicities appear to benefit more from empathy, expressing greater satisfaction upon receiving it compared to Western patients in an experimental video-vignette study.[70] From literature we know that raising awareness of racial bias among healthcare providers is beneficial for improving their empathetic communication skills.[71] Therefore, future training programs should focus on facilitating this awareness among healthcare providers. Additionally, as aforementioned, the results of this dissertation have a limited representation of cultural variation, which diminishes generalizability of our results. Specifically, future studies should focus on identifying harmful communication behaviors in non-Western cultures. Moreover, intercultural medical consultations report more miscommunications and dissatisfaction compared to intra-cultural medical consultations.[72-74] Furthermore, for the dissemination of the developed training to other countries and languages, it is crucial to provide a clear understanding of the preferred communication in those contexts. The potential discriminatory aspects of empathy pursue also further research.

A third future direction arises when we take into account the emergence of artificial intelligence (AI) in healthcare. The importance of authenticity in empathy is often mentioned in literature, emphasizing that it should not be used as a mere ‘tick-box exercise’.[75 76] It is interesting to note however that studies primarily focused on the patient’s perspective[77], investigating their opinion on whether empathy should be authentic or not. Studies stating that empathy should be ‘genuine’ is quite understandable from the patient’s perspective, as we could presume that no one wants empathy that is ‘fake’. As communication through online patient portals and the use of artificial intelligence (AI) continue to increase, a research question comes up about whether it is truly necessary for empathy to be authentic or if it can also be computer-driven. A study by Ayers et al.[78] demonstrated that an AI tool was perceived as more empathetic, and the provided information was of better quality than that from a real physician. Potential collaboration between researchers, healthcare providers and AI may enhance communication in healthcare. This will be a compelling direction for future research.

Clinical implications

Recommendations for clinical practice run like a common thread throughout this entire dissertation. In chapter 3, we demonstrated that displaying empathetic behaviors can indeed improve cancer patients' recall. Healthcare providers can use more empathy behaviors in their conversations with patients. For instance, by delving into the NURSE acronym (described in chapter 2 and 3) and incorporating simple sentences such as "*What are your most pressing concerns?".* Chapter 2 presented examples of emotional cues that were missed by healthcare providers. These examples can assist healthcare providers in enhancing awareness of potential pitfalls and preventing them in the future. In chapter 4, specific communication behaviors to be avoided are explicitly mentioned, such as making vague promises (e.g. "*I will call you..*" – without an indication when the doctor will call), not seeing the patient as a person (e.g. "*The tumor doesn't seem to be growing so that's going well - great! So we'll continue treatment.*") and not involving the patient in decision making (e.g. "*you must start chemo within a specific time*"). These are some examples of communication behaviors that can be relatively easily avoided, and therefore may prevent harm. However, this dissertation also shed light on several topics where patients differed in their information and decision needs, and treatment expectations, which poses a significant challenge for healthcare providers.

This dissertation provides several strategies that can be used to support a tailored approach and explore patients' needs. In chapter 4 and 5, sentences were provided that can contribute to tailoring information and decision needs, for example "*Some people, but not all, want information about their life expectancy. It's different for everyone. What are your needs here?*" and "*Some people want to make the final decision together; others want to do it themselves. What would you prefer?*". In the developed communication training, described in chapter 6, questions are offered to examine the individual expectations of the patient (e.g. "*Have you ever read or heard anything about the treatment?*"), and how to respond to these expectations (e.g. reinforcing positive expectations and adjusting negative expectations where possible and realistic).

The results of this dissertation largely align with the previously described cognitive (need to know and understand) and emotional (need to feel known and understood) needs of patients. The findings from chapter 5 introduced an additional need on a more existential level: *the need to feel held and remembered*. This need becomes more significant when patients are seriously ill, especially if they are no longer able to be cured. Patients feel abandoned and left alone when they were explicitly told that "there is nothing more we can do for you”. This statement should be avoided, and a better alternative could be, for example: “*We cannot cure the cancer, but there is still plenty we can do and will do to help you* “. The integration of palliative care (i.e. specialized care that focuses on patients’ holistic needs and continues until the end of life) can play a crucial role in meeting this existential need for patients.

An overarching conclusion of this dissertation aligns with the notion that one size does not fit all, and clinicians need to continuously adapt their communication to each unique patient. This conclusion highlights the challenge healthcare providers face in effectively communicating with patients. Especially in communication with patients with serious illnesses, the complexity rises due to heightened emotions in the conversation. Healthcare providers face difficulties in engaging in these conversations, however express a sincere desire to learn and improve.[79] Therefore, it is important to emphasize that this dissertation is not intended to reprimand healthcare providers for their shortcomings but rather to support them in this challenging aspect of their profession. It requires quite an effort from healthcare providers to continuously tailor what is best for each patient. Consistently customizing communication on an individual basis is a considerable proficiency communication skill. Each patient is unique, requiring individual tailoring, which demands ongoing creativity from the healthcare provider. Each healthcare provider is unique too. Some providers are more communicatively skilled even before they start studying, while others may require more training. From a behavioral science perspective, communication is a learnable skill that might call for a touch of creativity. Perhaps, after all, every communication needs a hint of art.

CONCLUSION

This dissertation highlighted the pivotal role of healthcare providers’ communication in providing information, expressing empathy, and managing expectations. Within these three functions, communication can have both positive (helpful) and negative (harmful) impacts on patients. This dissertation provides evidence and tools to healthcare providers to optimize their communication with patients and their family caregivers. Recognizing the importance that one size does not fit all, individual preferences should be preferably aligned with the patient. Through the development of the communication training for healthcare providers, we hope to efficiently disseminate this knowledge and tools to healthcare providers.

REFERENCES

1. Engel GL. How much longer must medicine's science be bound by a seventeenth century world view? *Psychotherapy and psychosomatics* 1992;57(1-2):3-16.
2. van Vliet LM, Epstein AS. Current state of the art and science of patient-clinician communication in progressive disease: patients' need to know and need to feel known. *Journal of Clinical Oncology* 2014;32(31):3474.
3. Bensing J, Schreurs K, Rijk AD. The role of the general practitioner's affective behaviour in medical encounters. *Psychology and Health* 1996;11(6):825-38.
4. Bensing JM, Dronkers J. Instrumental and affective aspects of physician behavior. *Medical care* 1992:283-98.
5. Schag C, Heinrich RL. Anxiety in medical situations: adult cancer patients. *Journal of clinical psychology* 1989;45(1)
6. Johnson AM, Brimhall AS, Johnson ET, et al. A systematic review of the effectiveness of patient education through patient portals. *JAMIA open* 2023;6(1):ooac085.
7. Wiljer D, Leonard KJ, Urowitz S, et al. The anxious wait: assessing the impact of patient accessible EHRs for breast cancer patients. *BMC Med Inform Decis Mak* 2010;10(1):1-10.
8. Smallwood A, Schapira M, Fedders M, Neuner J. A pilot randomized controlled trial of a decision aid with tailored fracture risk tool delivered via a patient portal. *Osteoporosis International* 2017;28:567-76.
9. Barriers, facilitators, and solutions to optimal patient portal and personal health record use: a systematic review of the literature. AMIA annual symposium proceedings; 2017. American Medical Informatics Association.
10. Wiljer D, Bogomilsky S, Catton P, et al. Getting results for hematology patients through access to the electronic health record. *Can Oncol Nurs J* 2006;16(3):154-64. doi: 10.5737/1181912x163154158. [published Online First: 2007/05/26]
11. Wiljer D, Urowitz S, Apatu E, et al. Understanding the support needs of patients accessing test results online. *The Journal of Healthcare Information Management* 2010;24(1):57-63.
12. Back AL. Patient-clinician communication issues in palliative care for patients with advanced cancer. *Journal of Clinical Oncology* 2020;38(9):866-76.
13. Murugesu L, Heijmans M, Rademakers J, Fransen MP. Challenges and solutions in communication with patients with low health literacy: Perspectives of healthcare providers. *PLoS One* 2022;17(5):e0267782.
14. Kessels RP. Patients' memory for medical information. *Journal of the Royal Society of Medicine* 2003;96(5):219-22.
15. Schwabe L, Wolf OT. Learning under stress impairs memory formation. *Neurobiology of learning and memory* 2010;93(2):183-88.
16. Thorne S, Oliffe JL, Stajduhar KI, et al. Poor communication in cancer care: patient perspectives on what it is and what to do about it. *Cancer Nurs* 2013;36(6):445-53. doi: 10.1097/NCC.0b013e31827eeda4. [published Online First: 2013/01/26]
17. Gilligan T, Coyle N, Frankel RM, et al. Patient-clinician communication: American Society of Clinical Oncology consensus guideline. *Obstetrical & Gynecological Survey* 2018;73(2):96-97.
18. van der Velden NC, van Laarhoven HW, Burgers SA, et al. Characteristics of patients with advanced cancer preferring not to know prognosis: a multicenter survey study. *BMC cancer* 2022;22(1):1-12.
19. Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. *Soc Sci Med* 2005;61(10):2252-64.

20. Hagerty R, Butow PN, Ellis P, et al. Communicating prognosis in cancer care: a systematic review of the literature. *Annals of oncology* 2005;16(7):1005-53.
21. ter Hoeven CL, Zandbelt LC, Fransen S, et al. Measuring cancer patients' reasons for their information preference: construction of the Considerations Concerning Cancer Information (CCCI) questionnaire. *Psycho-Oncology* 2011;20(11):1228-35.
22. Brom L, Pasman HRW, Widdershoven GA, et al. Patients' preferences for participation in treatment decision-making at the end of life: qualitative interviews with advanced cancer patients. *PloS one* 2014;9(6):e100435.
23. Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. *Cancer* 1995;76(2):167-77.
24. Ong LM, Visser MR, Van Zuuren FJ, et al. Cancer patients' coping styles and doctor–patient communication. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer* 1999;8(2):155-66.
25. Van Vliet LM, Van Der Wall E, Plum NM, Bensing JM. Explicit prognostic information and reassurance about nonabandonment when entering palliative breast cancer care: findings from a scripted video-vignette study. *Journal of Clinical Oncology* 2013;31(26):3242-49.
26. Back AL, Arnold RM, Baile WF, et al. Approaching difficult communication tasks in oncology. *CA Cancer J Clin* 2005;55(3):164-77. doi: 10.3322/canjclin.55.3.164 [published Online First: 2005/05/14]
27. Mobbs N, Williams C, Weeks AD. Humanising birth: does the language we use matter? 2018
28. Götze H, Brähler E, Gansera L, et al. Anxiety, depression and quality of life in family caregivers of palliative cancer patients during home care and after the patient's death. *European journal of cancer care* 2018;27(2):e12606.
29. Friðriksdóttir N, Sævarsdóttir Þ, Halfdánardóttir SÍ, et al. Family members of cancer patients: Needs, quality of life and symptoms of anxiety and depression. *Acta Oncologica* 2011;50(2):252-58.
30. van Vliet LM, Leeuwenburgh ML, Westendorp J, et al. Good versus bad news consultations in advanced breast cancer: the role of empathy in information recall–an observational study. *BMJ Support Palliat Care* 2023
31. Friedrichsen MJ, Strang PM, Carlsson ME. Cancer patients' interpretations of verbal expressions when given information about ending cancer treatment. *Palliat Med* 2002;16(4):323-30. doi:10.1191/0269216302pm543oa. [published Online First: 2002/07/23]
32. Back AL, Arnold RM, Quill TE. Hope for the best, and prepare for the worst: American College of Physicians, 2003.
33. van der Velden N. Hope for the best, prepare for the worst: Prognostic communication in palliative cancer care. 2023
34. Clayton JM, Butow PN, Arnold RM, Tattersall MH. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer* 2005;103(9):1965-75.
35. Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *New England Journal of Medicine* 2012;367(17):1616-25.
36. Chen AB, Cronin A, Weeks JC, et al. Expectations about the effectiveness of radiation therapy among patients with incurable lung cancer. *Journal of Clinical Oncology* 2013;31(21):2730.
37. Little P, Everitt H, Williamson I, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. *Bmj* 2001;323(7318):908-11.

38. Hagerty RG, Butow PN, Ellis PM, et al. Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. *Journal of clinical oncology* 2005;23(6):1278-88.
39. Bingel U. Placebo 2.0: the impact of expectations on analgesic treatment outcome. *Pain* 2020;161:S48-S56.
40. Temel JS, Greer JA, Admane S, et al. Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non–small-cell lung cancer: Results of a randomized study of early palliative care. *Journal of clinical oncology* 2011;29(17):2319-26.
41. Tang ST, Chang WC, Chen JS, et al. Associations of prognostic awareness/acceptance with psychological distress, existential suffering, and quality of life in terminally ill cancer patients' last year of life. *Psycho-Oncology* 2016;25(4):455-62.
42. Peerdeman KJ, Geers AL, Della Porta D, et al. Underpredicting pain: an experimental investigation into the benefits and risks. *Pain* 2021;162(7):2024-35.
43. van Vliet L, Francke A, Tomson S, et al. When cure is no option: how explicit and hopeful can information be given? A qualitative study in breast cancer. *Patient education and counseling* 2013;90(3):315-22.
44. Kirk P, Kirk I, Kristjanson LJ. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *Bmj* 2004;328(7452):1343.
45. Myronenko A, van der Velde P, Derksen SM, Peerdeman KJ. How should uncertainty about upcoming painful procedures be communicated? An experimental study into highly uncertain pain predictions. *Patient Education and Counseling* 2024;118:108008.
46. Benedetti F, Lanotte M, Lopiano L, Colloca L. When words are painful: unraveling the mechanisms of the nocebo effect. *Neuroscience* 2007;147(2):260-71.
47. Hecht v. Kaplan. *N Y Suppl Second Ser* 1996;645:51-4. [published Online First: 1996/06/17]
48. Evers AW, Colloca L, Blease C, et al. Implications of placebo and nocebo effects for clinical practice: expert consensus. *Psychotherapy and psychosomatics* 2018;87(4):204-10.
49. Evers AW, Colloca L, Blease C, et al. What should clinicians tell patients about placebo and nocebo effects? Practical considerations based on expert consensus. *Psychotherapy and psychosomatics* 2021;90(1):49-56.
50. Locher C, Nascimento AF, Kirsch I, et al. Is the rationale more important than deception? A randomized controlled trial of open-label placebo analgesia. *Pain* 2017;158(12):2320-28.
51. Crichton F, Petrie KJ. Health complaints and wind turbines: The efficacy of explaining the nocebo response to reduce symptom reporting. *Environmental Research* 2015;140:449-55.
52. Mcguire LC. Remembering what the doctor said: organization and adults' memory for medical information. *Experimental aging research* 1996;22(4):403-28.
53. Ong L, Visser M, Lammes Fv, et al. Effect of providing cancer patients with the audiotaped initial consultation on satisfaction, recall, and quality of life: a randomized, double-blind study. *Journal of Clinical Oncology* 2000;18(16):3052-60.
54. Hoffstädt H, Stouthard J, Meijers MC, et al. Patients' and clinicians' perceptions of clinician-expressed empathy in advanced cancer consultations and associations with patient outcomes. *Palliative Medicine Reports* 2020;1(1):76-83.
55. Wasserman RC, Inui TS. Systematic analysis of clinician-patient interactions: a critique of recent approaches with suggestions for future research. *Medical Care* 1983;21(3):279-93.
56. De Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. *Patient education and counseling* 2009;74(3):287-94.

57. Schouten BC, Meeuwesen L, Tromp F, Harmsen HA. Cultural diversity in patient participation: the influence of patients' characteristics and doctors' communicative behaviour. *Patient education and counseling* 2007;67(1-2):214-23.
58. Tang ST, Liu T-W, Lai M-S, et al. Congruence of knowledge, experiences, and preferences for disclosure of diagnosis and prognosis between terminally-ill cancer patients and their family caregivers in Taiwan. *Cancer investigation* 2006;24(4):360-66.
59. Ozdemir S, Ng S, Wong W, et al. Advanced Cancer Patients' Prognostic Awareness and Its Association With Anxiety, Depression and Spiritual Well-Being: A Multi-Country Study in Asia. *Clinical Oncology* 2022;34(6):368-75.
60. Kagawa-Singer M, Blackhall LJ. Negotiating cross-cultural issues at the end of life: You got to go where he lives. *Jama* 2001;286(23):2993-3001.
61. Koenig BA, Gates-Williams J. Understanding cultural difference in caring for dying patients. *Western journal of medicine* 1995;163(3):244.
62. Palliaweb. Richtlijn Angst in de palliatieve fase 2022 [Available from: https://palliaweb.nl/richtlijnen-palliatieve-zorg/richtlijn/angst.
63. Hillen MA, van Vliet LM, de Haes HC, Smets EM. Developing and administering scripted video vignettes for experimental research of patient–provider communication. *Patient education and counseling* 2013;91(3):295-309.
64. Van Vliet LM, Hillen MA, van der Wall E, et al. How to create and administer scripted video-vignettes in an experimental study on disclosure of a palliative breast cancer diagnosis. *Patient education and counseling* 2013;91(1):56-64.
65. Bloom P. Empathy and its discontents. *Trends in cognitive sciences* 2017;21(1):24-31.
66. Bloom P. Against empathy: The case for rational compassion: Random House 2017.
67. Roberts BW, Puri NK, Trzeciak CJ, et al. Socioeconomic, racial and ethnic differences in patient experience of clinician empathy: Results of a systematic review and meta-analysis. *PloS one* 2021;16(3):e0247259.
68. Sim W, Lim WH, Ng CH, et al. The perspectives of health professionals and patients on racism in healthcare: A qualitative systematic review. *PLoS One* 2021;16(8):e0255936.
69. Hamed S, Bradby H, Ahlberg BM, Thapar-Björkert S. Racism in healthcare: a scoping review. *BMC Public Health* 2022;22(1):988.
70. van Vliet LM, Stouthard J, Gröschel LC, Meijers MC. Effect of Clinician-Expressed Empathy in Advanced Cancer on Different Ethnic Groups: Results from an Experimental Video-Vignette Study. *Journal of Palliative Medicine* 2023
71. Hirsh AT, Miller MM, Hollingshead NA, et al. A randomized controlled trial testing a virtual perspective-taking intervention to reduce race and SES disparities in pain care. *Pain* 2019;160(10):2229.
72. Harmsen H, Meeuwesen L, Van Wieringen J, et al. When cultures meet in general practice: intercultural differences between GPs and parents of child patients. *Patient education and counseling* 2003;51(2):99-106.
73. LaVeist TA, Nuru-Jeter A. Is doctor-patient race concordance associated with greater satisfaction with care? *Journal of health and social behavior* 2002:296-306.
74. Saha S, Komaromy M, Koepsell TD, Bindman AB. Patient-physician racial concordance and the perceived quality and use of health care. *Archives of internal medicine* 1999;159(9):997-1004.
75. Wild HB. There's no algorithm for empathy. *Health Affairs* 2020;39(2):339-42.
76. van Vliet LM, Back AL. The different faces of empathy in cancer care: from a desired virtue to an evidence-based communication process: Wiley Online Library, 2021:4137-39.

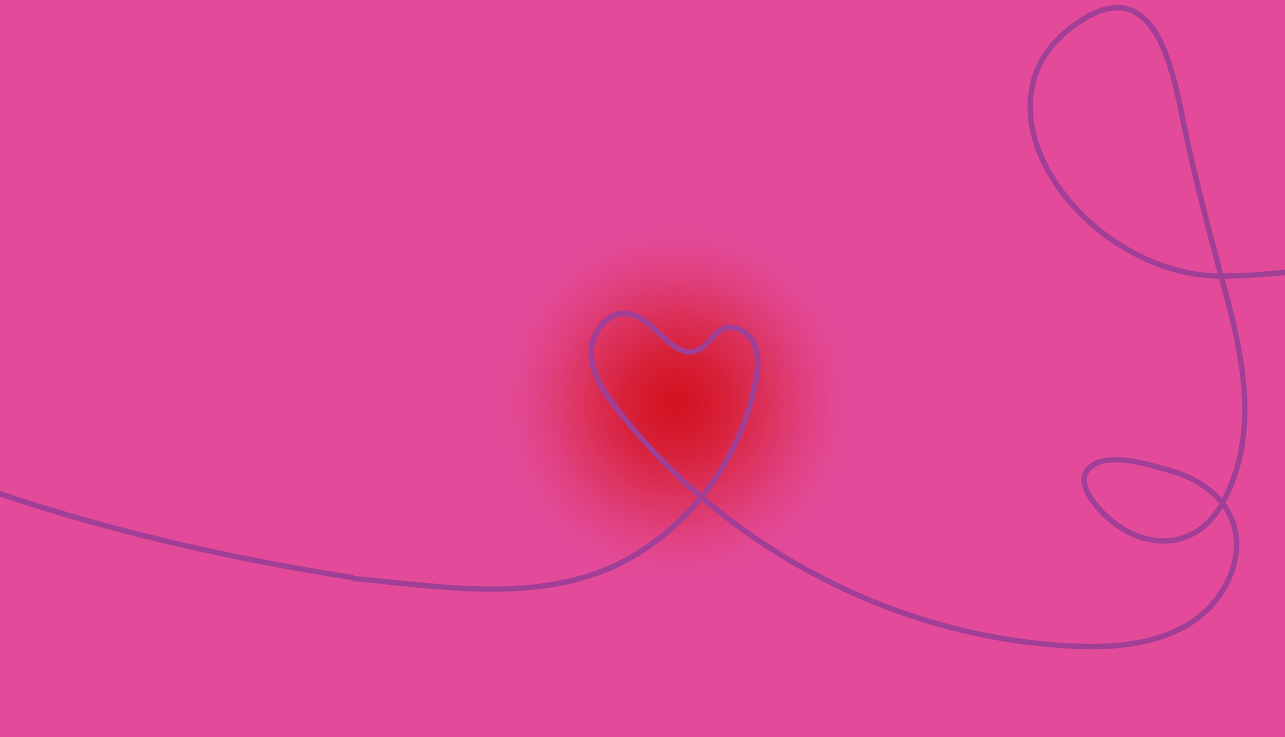
77. Randall TC, Wearn AM. Receiving bad news: patients with haematological cancer reflect upon their experience. *Palliative medicine* 2005;19(8):594-601.

78. Ayers JW, Poliak A, Dredze M, et al. Comparing physician and artificial intelligence chatbot responses to patient questions posted to a public social media forum. *JAMA Intern Med* 2023

79. Holley JL, Carmody SS, Moss AH, et al. The need for end-of-life care training in nephrology: national survey results of nephrology fellows. *American Journal of Kidney Diseases* 2003;42(4):813-20.

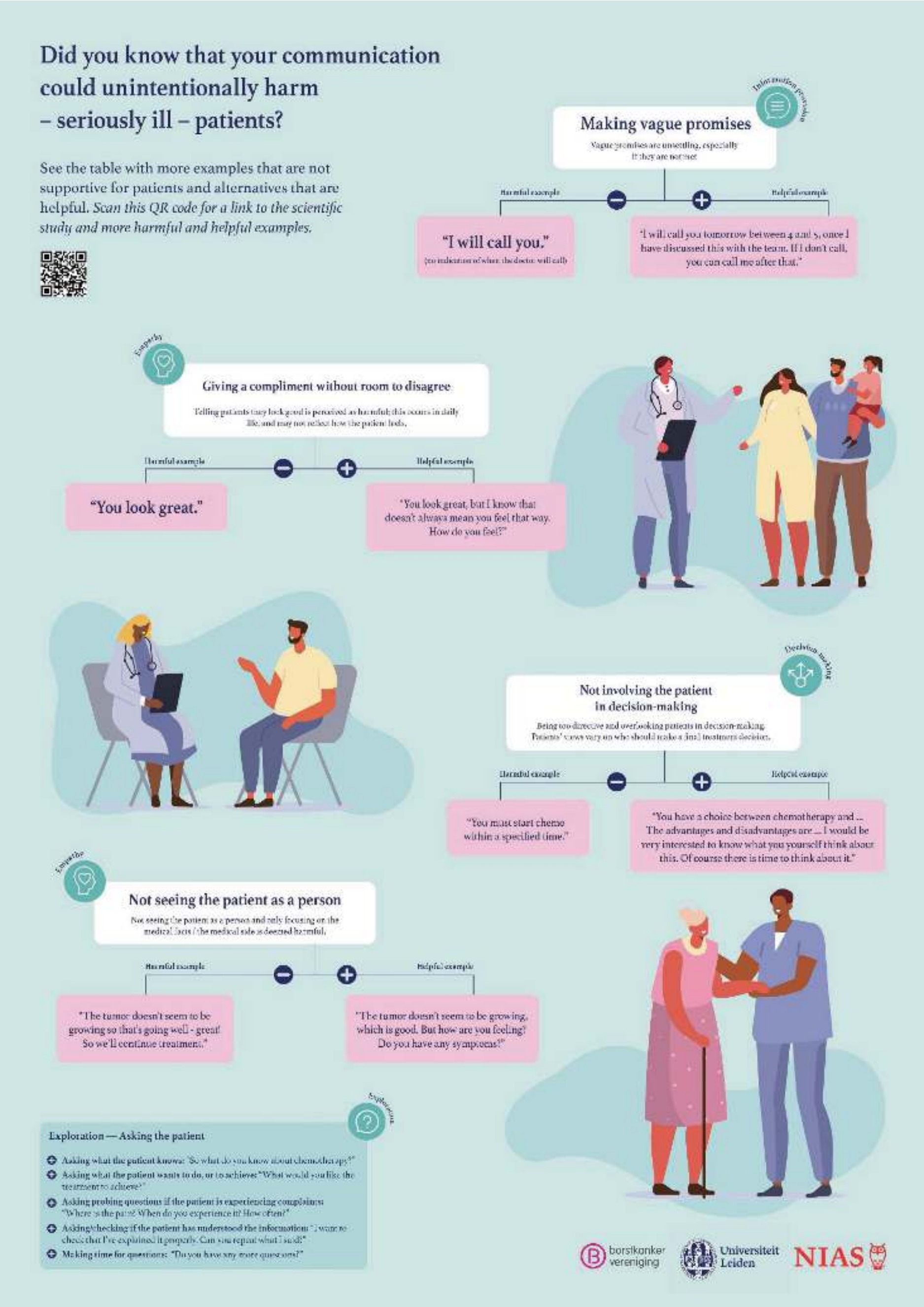
APPENDIX 1

Dissemination



A1. DISSEMINATION

Poster 1: Dissemination of chapter 4



Did you know that your communication could unintentionally harm – seriously ill – patients?

See the table with more examples that are not supportive for patients and alternatives that are helpful. *Scan this QR code for a link to the scientific study and more harmful and helpful examples.*

Making vague promises

Vague promises are unsettling, especially if they are not met

Harmful example

"I will call you."
(no indication of when the doctor will call)

Helpful example

"I will call you tomorrow between 4 and 5, once I have discussed this with the team. If I don't call, you can call me after that."

Giving a compliment without room to disagree

Telling patients they look good is perceived as harmful; this occurs in daily life, and may not reflect how the patient feels.

Harmful example

"You look great."

Helpful example

"You look great, but I know that doesn't always mean you feel that way. How do you feel?"

Not involving the patient in decision-making

Being too directive and overlooking patients in decision-making. Patients' views vary on who should make a final treatment decision.

Harmful example

"You must start chemo within a specified time."

Helpful example

"You have a choice between chemotherapy and ... The advantages and disadvantages are ... I would be very interested to know what you yourself think about this. Of course there is time to think about it."

Not seeing the patient as a person

Not seeing the patient as a person and only focusing on the medical facts / the medical side is deemed harmful.

Harmful example

"The tumor doesn't seem to be growing so that's going well - great! So we'll continue treatment."

Helpful example

"The tumor doesn't seem to be growing, which is good. But how are you feeling? Do you have any symptoms?"

Exploration — Asking the patient

- Asking what the patient knows: "So what do you know about chemotherapy?"
- Asking what the patient wants to do, or to achieve: "What would you like the treatment to achieve?"
- Asking probing questions if the patient is experiencing complaints: "Where is the pain? When do you experience it? How often?"
- Asking/checking if the patient has understood the information: "I want to check that I've explained it properly. Can you repeat what I said?"
- Making time for questions: "Do you have any more questions?"

borstkanker vereniging
Universiteit Leiden
NIAS

Poster 2: Dissemination of chapter 5

Did you know that your communication could unintentionally harm – seriously ill – patients and their family caregivers?

Results of a systematic review on harmful communication in oncology. Poster series 'Harmful communication in oncology' version 2.0. *See QR-CODE for version 1.0 (survey study).*

Analysis of the literature revealed themes of harmful communication behavior according to cancer patients and their informal caregivers:

1. Lack of tailored information provision

Information provision can harm from too little to too much information, poorly timed, contradictions and jargon.

examples

- Lack of information about treatment consequences (e.g. fertility consequences).
- Inconsistent information (e.g. different clinicians providing different information).

2. Lack of tailored decision making

The decision-making process can harm from patient exclusion, to sole patient responsibility, and haste.

examples

- Excluding patients from the decision making process (e.g. pushing towards treatment).
- Leaving the treatment decision completely to the patient (e.g. lack of advice).

3. Lack of feeling seen and heard

A lack of feeling seen as a human being, and feeling heard regarding concerns and emotions can harm.

examples

- Lack of feeling seen: A rushed attitude, no interest in someone's life besides the disease and not taking into account the role of family caregivers.
- Lack of feeling heard: A lack of validation of, or not responding to, patients' concerns and emotions (e.g. "*Luckily you have the 'good' cancer*").

4. Lack of feeling held and remembered

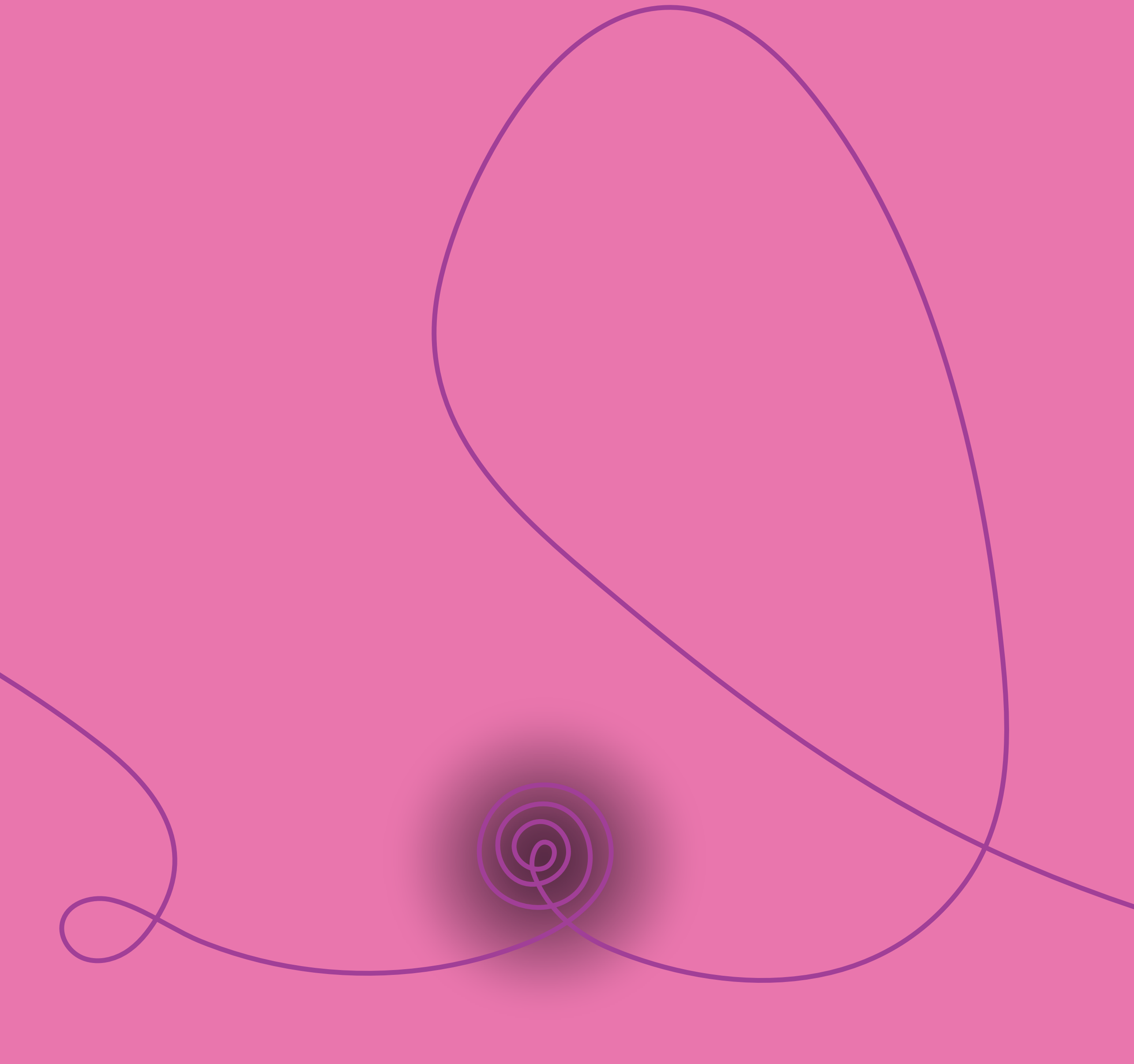
A lack of feeling held (lack of care continuity and time) and remembered (forgotten agreements) can harm.

examples

- Lack of feeling held: Insufficient continuity of care and (existential) support (e.g. "*there is nothing more we can do for you.*").
- Lack of feeling remembered: Excessive waiting (e.g. for important test results beyond the agreed time).

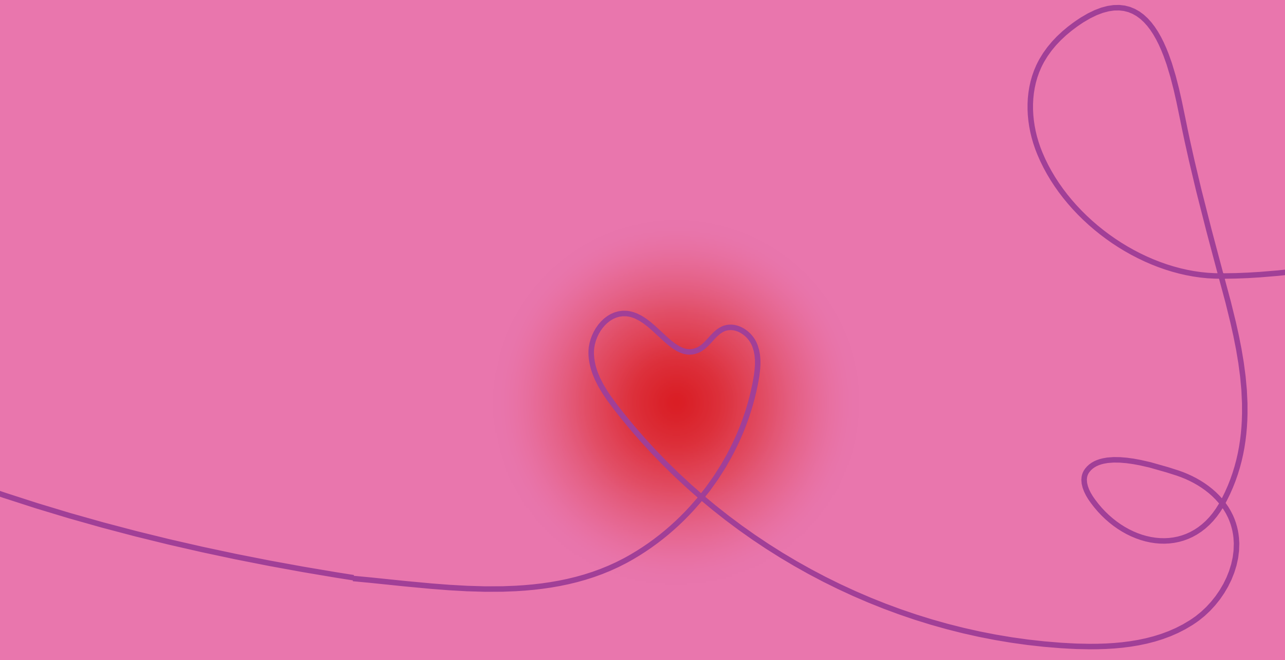
Scan this QR code for a link to the scientific study.

Westendorp J, Geerse OP, van der Lee ML, et al. Harmful communication behaviors in cancer care: a systematic review of patients and family caregivers perspectives. Psychooncology. 2023;1-12.



APPENDIX 2

Dutch summary



A2. DUTCH SUMMARY

DE KRACHT VAN HELPENDE EN SCHADELIJKE COMMUNICATIE IN DE GEZONDHEIDSZORG

Dit proefschrift heeft als doel inzicht te geven in hoe de communicatie van zorgverleners patiënten zowel kan helpen als schaden. We belichten de cruciale rol van de communicatie van zorgverleners bij het verstrekken van informatie, het tonen van empathie en het managen van verwachtingen. In de introductie van dit proefschrift (hoofdstuk 1) gaven we een historisch overzicht van de onderzoekslijnen naar medische communicatie en placebo-effecten. Terwijl de onderzoekslijn van medische communicatie zich richtte op de functies van communicatie en de impact daarvan op patiëntuitkomsten, concentreerde de onderzoekslijn naar placebo-effecten zich op het verklaren van gezondheidseffecten die niet het gevolg waren van voorgeschreven behandelingen, maar die bekend staan als placebo-effecten. In dit proefschrift beschrijven we placebo- en nocebo-effecten als de veranderingen in patiëntuitkomsten die kunnen worden verklaard door de verwachtingen die iemand heeft over de behandeling. In hoofdstuk 2 beschreven we hoe het geven van verwachtingen en het tonen van empathie momenteel wordt gedaan in communicatie met patiënten met gevorderde kanker. In hoofdstuk 3 werd de impact van empathie van artsen op het herinneren van informatie door patiënten met gevorderde kanker beschreven, waarbij de mediërende rol van angst werd meegenomen. De daaropvolgende twee hoofdstukken richtten zich op het begrijpen van de visie van de patiënt (hoofdstuk 4) en eerdere studies (hoofdstuk 5) op mogelijk schadelijke communicatie in de zorg voor patiënten met kanker. In hoofdstuk 6 werd de ontwikkeling en evaluatie van een communicatietraining (e-learning en virtual reality training) voor zorgverleners beschreven. Het proefschrift werd afgesloten met een kritische reflectie op de resultaten en de mogelijke impact voor de klinische praktijk.

HOOFDSTUK 2

In hoofdstuk 2 onderzochten we hoe het tonen van empathie en het geven van verwachtingen momenteel wordt gedaan in de klinische setting van gevorderde borstkanker. We verzamelden audio-opnames van 45 gesprekken tussen oncologen en patiënten met gevorderde borstkanker. De aard van het gesprek (goed nieuws, onzeker nieuws of slecht nieuws), en de verwachtings- en empathie-uitingen door de oncologen werden gecodeerd. De meerderheid van de gesprekken (58%) bevatte ‘goed nieuws’ (bijvoorbeeld goede scanresultaten). We ontdekten dat bij het bespreken van positieve of onzekere medische uitkomsten, oncologen voornamelijk gebruik maakten van onzekere verwachtingsuitingen. Bij het uiten van positieve verwachtingen benadrukten oncologen het belang van de arts-patiënt relatie, terwijl negatieve verwachtingen gericht waren op de ernst van de ziekte. In situaties van onzekerheid werd een benadering van ‘hoop op het beste, bereid je voor op het ergste’ gebruikt. Empathie-uitingen varieerden van algemene tot specifieke uitdrukkingen, waarbij oncologen voornamelijk begrip toonden voor de emoties van patiënten. Gevallen van een gebrek aan empathie waren zeldzaam en betroffen voornamelijk gevallen waarin oncologen de emotionele signalen van patiënten niet opmerkten. Dit hoofdstuk liet zien dat empathie-uitingen al regelmatig werden toegepast, vooral door begrip te tonen voor de emoties van patiënten en patiënten te complimenteren met hoe ze omgaan met hun ziekte. Verwachtingsuitingen waren voornamelijk onzeker, wat suggereert dat er mogelijk een onderbenut potentieel is om potentiële positieve verwachtingen te benadrukken bij communicatie met patiënten met gevorderde kanker.

HOOFDSTUK 3

In hoofdstuk 3 hebben we de relatie onderzocht tussen de mate van empathie van artsen tijdens een gesprek en wat patiënten onthouden, en of een afname van angst bij patiënten hierbij een rol speelt. We hebben hiervoor dezelfde audio-opnames van 45 gesprekken tussen oncologen en patiënten met gevorderde borstkanker gebruikt als in hoofdstuk 2. We vonden dat patiënten over het algemeen 61% van de besproken informatie onthielden en dat de herinnering het beste was voor informatie over behandelopties (77%), gevolgd door informatie over behandelingsdoelen/positieve effecten (63%) en het minst voor informatie over bijwerkingen (40%). Onze resultaten toonden aan dat in gesprekken waarin de arts meer empathie toonde, patiënten zich beter herinnerden wat er besproken was. Vooral de behandeldoelen en positieve effecten werden beter onthouden. Deze relatie kon echter niet worden verklaard door de gemiddelde afname in het angstniveau van patiënten. Hoewel het onderliggende mechanismen dus nog onduidelijk blijft, benadrukken onze resultaten het belang van empathie in gesprekken met ernstig zieke patiënten. Deze studie laat zien dat empathie kan helpen om patiënten medische informatie tijdens een consult beter te laten onthouden.

HOOFDSTUK 4

In hoofdstuk 4 hebben we onderzocht wat patiënten met gevorderde kanker als mogelijk schadelijke communicatie ervaren door hun oncologen, en wat mogelijke behulpzame alternatieven kunnen zijn. We hebben een online vragenlijst ontwikkeld met vragen over negentien situaties die mogelijk schadelijke communicatie zouden kunnen inhouden. Deze situaties werden geschetst met daarbij een concreet voorbeeld van mogelijk schadelijke communicatie en een alternatief van mogelijk behulpzame communicatie. We hebben 71 patiënten geïncludeerd die de vragenlijst hebben ingevuld. De resultaten toonden aan dat communicatie over de volgende thema’s mogelijk schadelijk kan zijn: informatieverstrekking, prognosebespreking, besluitvorming en empathie. Specifieke voorbeelden waren onder andere het bespreken van het stoppen van antikankertherapie zonder te vermelden wat nog wel mogelijk is, het niet luisteren naar de patiënt, en het doen van vage beloften. Patiënten waren verdeeld over de mogelijke schadelijkheid van zowel de hoeveelheid algemene informatie (60% vond te veel schadelijk; 65% vond te weinig schadelijk) als prognostische informatie (68% vond het krijgen van prognostische informatie schadelijk; 50% vond geen prognostische informatie krijgen schadelijk) die werd verstrekt. Met betrekking tot prognostische informatie toonden kwalitatieve resultaten aan dat sommige patiënten het schadelijk vonden als hele concrete prognostische informatie werd verstrekt, omdat dergelijke informatie inherent onzeker is. Anderen vonden het schadelijk als er geen of vage prognostische informatie werd verstrekt. Gezien de grote heterogeniteit in welke en hoeveel informatie patiënten als schadelijk ervaren, zou het nuttig kunnen zijn om patiënten te vragen naar hun voorkeuren. De bevindingen van dit hoofdstuk laten zien dat er specifieke communicatieonderwerpen zijn die de meeste patiënten als schadelijk ervaren, maar ook onderwerpen waarbij de meningen van patiënten verschillen over de schadelijkheid ervan. In dit hoofdstuk bieden we inzichten in zowel eenvoudig te vermijden valkuilen als delicate uitdagingen die vragen om een individuele benadering, waarbij exploratie door de zorgverlener over de informatiebehoefte van de patiënt mogelijk nuttig is.

HOOFDSTUK 5

In hoofdstuk 5 hebben we het onderzoek naar schadelijke communicatie in de oncologie verder uitgebreid door middel van een systematische analyse van de bestaande literatuur op dit gebied. In de systematische review hebben we onderzocht wat volwassen patiënten met kanker en/of hun familieleden als schadelijke communicatiegedragingen van artsen ervaren. Voor het verkrijgen van de juiste studies hebben we diverse databases doorzocht en aanvullend ook experts geraadpleegd. We hebben 47 studies geïncludeerd in deze systematische review. Zeventien thema's van schadelijke communicatie zijn geïdentificeerd en gegroepeerd onder vier hoofdthema's: 1) Gebrek aan persoonsgerichte informatie (bijvoorbeeld: te weinig of te veel/specifieke informatie geven) 2) Gebrek aan persoonsgerichte besluitvorming (variërend van: uitsluiting van de patiënt, tot de verantwoordelijkheid geheel bij de patiënten leggen en/of haast) 3) Gebrek aan zich gezien en gehoord voelen (gezien worden als een ziekte, niet als een mens; niet luisteren naar zorgen en emoties) 4) Gebrek aan zich geborgen en herinnerd voelen (vergeten afspraken; gebrek aan continuïteit van zorg). De resultaten van dit hoofdstuk lieten zien dat onbedoelde schade kan worden voorkomen wanneer informatie en besluitvorming worden gepersonaliseerd en wanneer wordt voldaan aan de behoeften van patiënten en familieleden om zich gezien, gehoord, en geborgen en herinnerd te voelen.

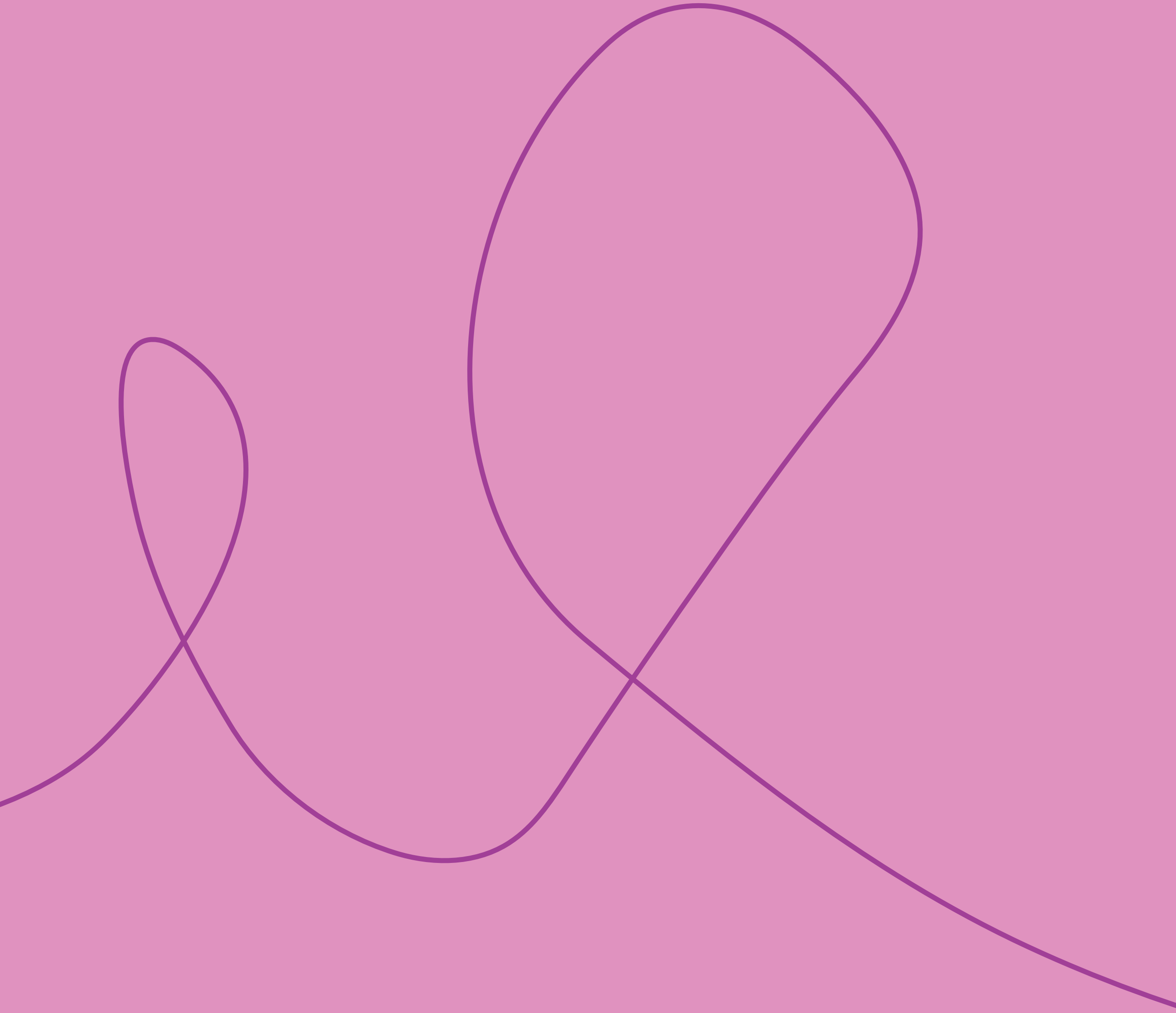
HOOFDSTUK 6

In hoofdstuk 6 beschreven we de ontwikkeling en evaluatie van een innovatieve communicatietraining, bestaande uit een e-learning en virtual reality (VR) training, voor zorgverleners in alle disciplines. Het doel van deze training was om placebo-effecten te optimaliseren en nocebo-effecten te minimaliseren door middel van communicatie tussen zorgverlener en patiënt. De communicatietraining had drie hoofddoelen: 1) zorgverleners vertrouwd maken met actuele kennis over placebo- en nocebo-effecten, 2) bewustwording creëren over de rol van placebo- en nocebo-effecten in de dagelijkse klinische praktijk, en 3) communicatietechnieken aanleren die placebo-effecten kunnen optimaliseren en nocebo-effecten kunnen minimaliseren in de klinische praktijk. De inhoud van de communicatietraining was gebaseerd op de meest recente wetenschappelijke inzichten en gepubliceerde expertconsensus over placebo- en nocebo-effecten. De e-learning bood theoretische kennis en praktische handvatten verdeeld over vijf modules: 1) Optimaliseren van de zorgverlener-patiënt relatie, 2) Vragen naar de verwachtingen van patiënten, 3) Bespreken van de behandelrationale, 4) Bespreken van risico's en bijwerkingen, 5) Uitleggen van placebo- en nocebo-effecten aan de patiënt. In de VR-training konden zorgverleners een gesprek voeren met gesimuleerde patiënten in twee verschillende scenario's (Casus 1: voorschrijven van medicatie; Casus 2: toedienen van een plaatselijke verdoving) met behulp van VR-brillen. Resultaten van de evaluatiestudies toonden aan dat zowel zorgverleners als communicatie-/placebo-onderzoekers overwegend positief waren over de communicatietraining. De e-learning werd ervaren als gebruiksvriendelijk en de inhoud werd beschouwd als toegankelijk, interessant en makkelijk toepasbaar in de klinische praktijk. De VR-training werd ook als gebruiksvriendelijk ervaren en bood een veilige leeromgeving. Het ontwikkelen van een volledig werkzaam AI-model waarbij de VR-avatar de deelnemer in elke situatie begrijpt en adequaat reageert, blijft een aandachtspunt voor verbetering in de toekomst.

CONCLUSIE

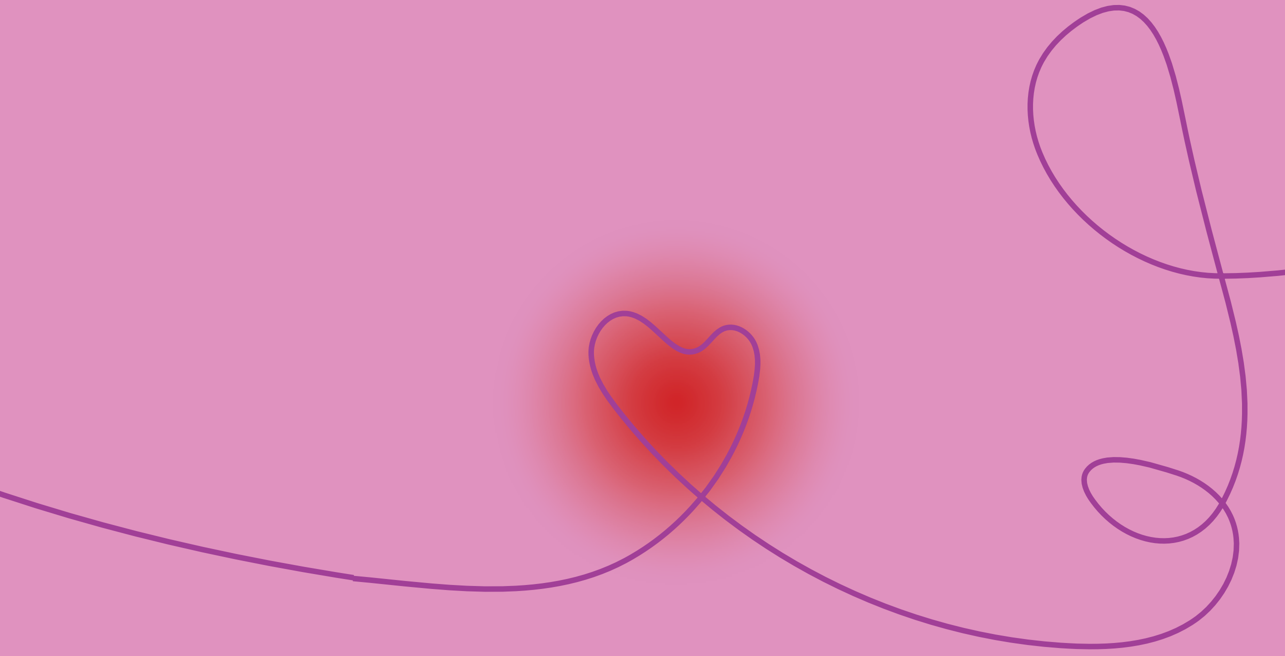
Samengevat benadrukt dit proefschrift de cruciale rol van communicatie door zorgverleners bij het verstrekken van informatie, het tonen van empathie en het managen van verwachtingen. We hebben onderzocht hoe communicatie zowel kan helpen als schaden. Onze resultaten laten zien dat empathie vanuit een zorgverlener niet alleen bijdraagt aan het adresseren van de emotionele behoeften van patiënten, maar ook een rol speelt bij het voldoen aan hun cognitieve behoeften, met name bij het onthouden van medische informatie. We hebben ook een nieuw, meer existentieel aspect geïntroduceerd: de behoefte om geborgen en herinnerd te worden. Onze resultaten hebben nieuwe inzichten gegenereerd van communicatie die schadelijk kan zijn voor patiënten en hebben handvatten geboden om dergelijke schade te voorkomen. Daarnaast hebben we een bijdrage aan de klinische praktijk geleverd door een placebo/

nocebo communicatietraining te ontwikkelen en vervolgens uit te testen bij professionals die de training positief hebben geëvalueerd. Hoewel het communiceren met patiënten en het inspelen op hun specifieke behoeften een complexe verantwoordelijkheid blijft voor zorgverleners, beoogt dit proefschrift duidelijkheid te bieden over welke vormen van communicatie positieve effecten kunnen hebben en welke mogelijk schadelijk zijn voor individuele patiënten. Met dit proefschrift willen we zorgverleners meer bewust maken van de essentiële rol van goede communicatie. We hopen hiermee bij te dragen aan verbeterde zorgverlener-patiënt communicatie, verhoogde effectiviteit van behandelingen, en betere uitkomsten voor patiënten in de toekomst.



APPENDIX 3

Curriculum Vitae

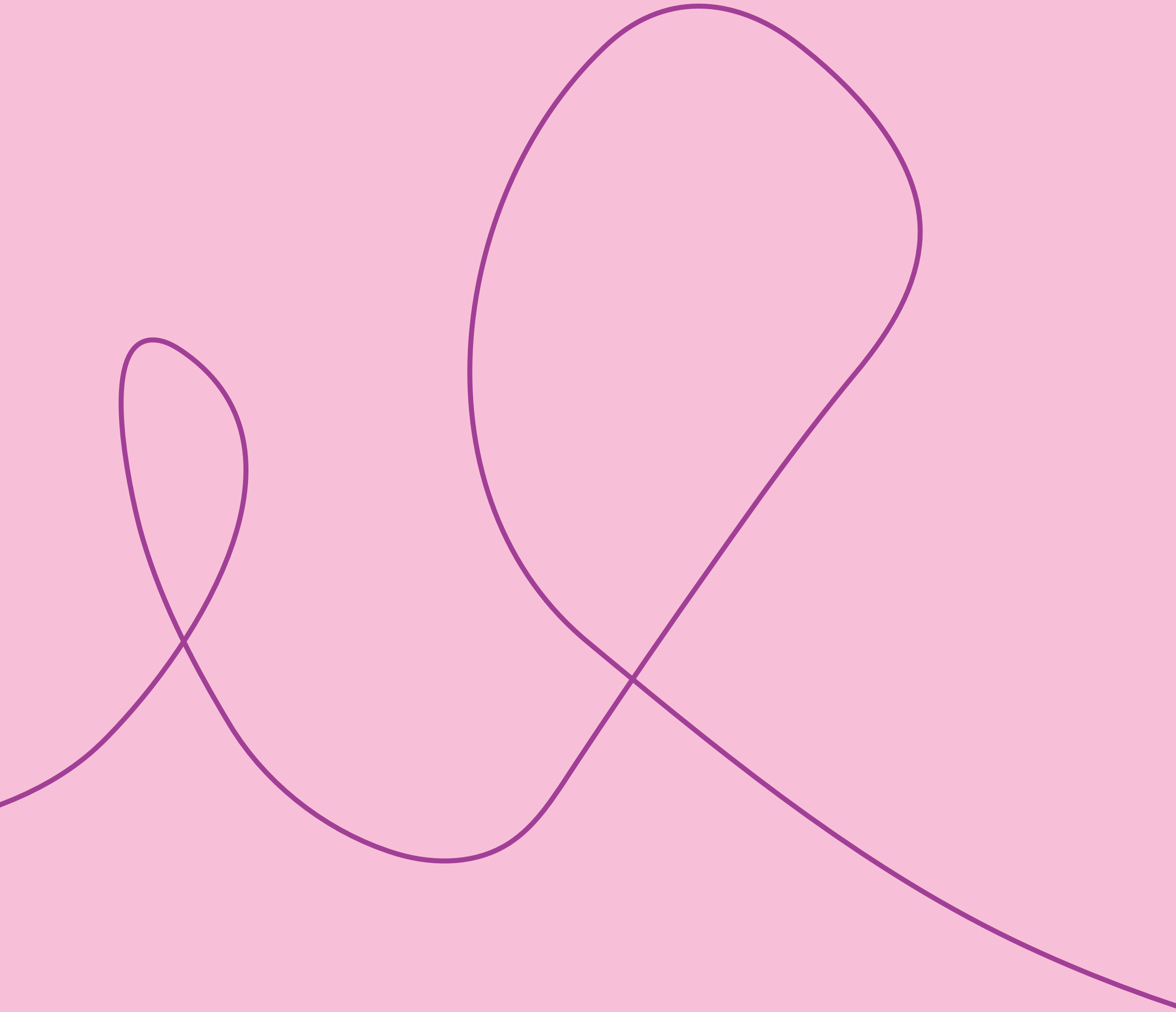


A3. CURRICULUM VITAE

Janine Westendorp was born on March 15, 1997 in Doetinchem, the Netherlands. In 2015, she started her Bachelor in Psychology at Utrecht University, for which she earned her degree in 2018 in the differentiation Clinical Psychology. In 2018, she started her Master's degree in Clinical Psychology at Utrecht University. During this master, she completed two internships. First, a one-year research internship at Nivel (Netherlands institute for health services research), where she wrote her Master thesis on the relationship between clinician-expressed empathy and patients' information recall. Second, she completed a six-month clinical internship at St. Antonius Hospital in Utrecht, where she provided psychological care for patients with medically unexplained symptoms (MUS). After receiving her Master's degree in 2020, Janine immediately started her career as a scientist-practitioner by combining research work and clinical practice as a psychologist.

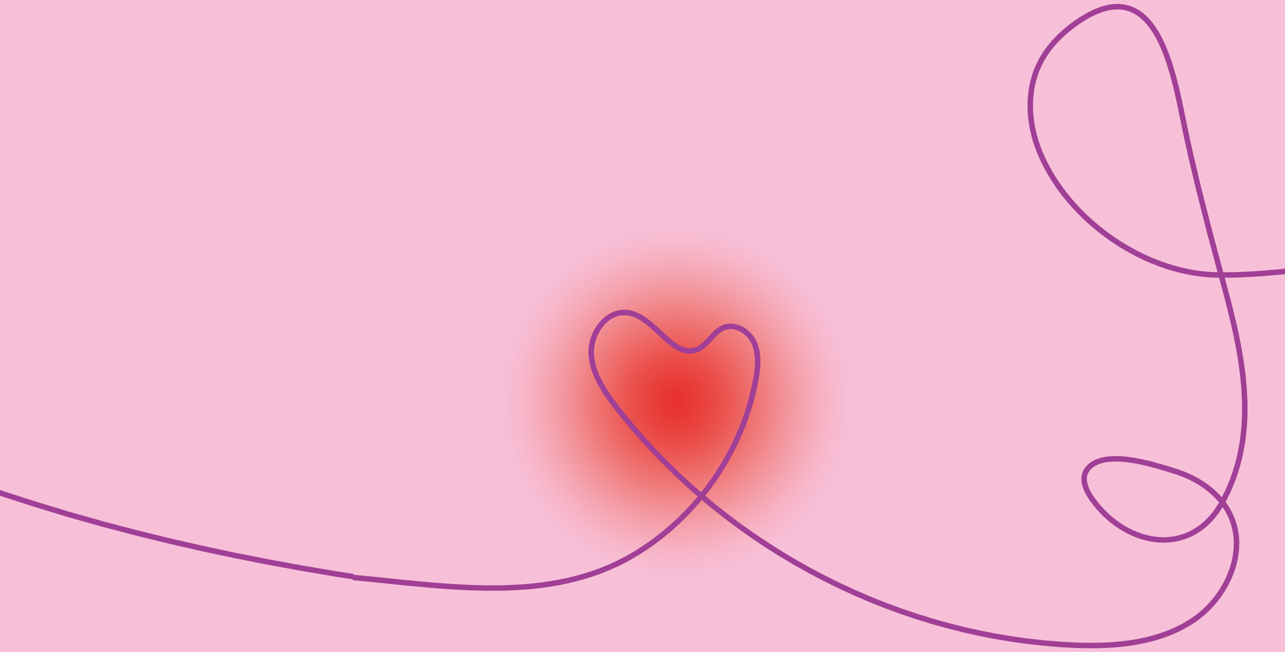
She started as PhD candidate at the Health, Medical and Neuropsychology Unit of Leiden University. Under the supervision of prof. dr. Andrea Evers and dr. Liesbeth van Vliet, she completed various studies about communication in healthcare. Her research was supported by grants of the Dutch Cancer Society, Leids University Funds/Schild-de Groen Funds, the European Research Council, and the Leids University Funds. Janine presented her work at several international conferences and conducted a professional visit to Harvard Medical School in Boston (MA, USA), in July 2022.

Alongside her PhD research, Janine worked as a psychologist at the Helen Dowling Institute, where she provides psychological treatment to cancer patients and their loved ones. Between 2020 and 2022, she completed various clinical training programs: Cognitive Behavioral Therapy (CBT), Acceptance and Commitment Therapy (ACT), and Eye Movement Desensitization and Reprocessing (EMDR). In 2024, she started the post-master training to become a healthcare psychologist (GZ-psycholoog).



APPENDIX 4

List of publications



A4. LIST OF PUBLICATIONS

Articles in international peer reviewed journals

Westendorp, J., van Vliet, L. M., Meeuwis, S. H., olde Hartman, T. C., Sanders, A. R., Jutten, E., ... & Evers, A. W. (2024). Optimizing placebo and minimizing nocebo effects through communication: e-learning and virtual reality training development. *BMC Medical Education*, 24(1), 707.

van Vliet, L. M., Leeuwenburgh, M. L., **Westendorp, J.**, van Dulmen, S., de Jong, P. C., & Stouthard, J. M. (2024). Good versus bad news consultations in advanced breast cancer: the role of empathy in information recall–an observational study. *BMJ Supportive & Palliative Care*, 14(e1), e528-e532.

Westendorp, J., Geerse, O. P., van der Lee, M. L., Schoones, J. W., van Vliet, M. H., Wit, T., ... & van Vliet, L. M. (2023). Harmful communication behaviors in cancer care: A systematic review of patients and family caregivers perspectives. *Psycho-Oncology*, 32(12), 1827-1838.

Westendorp, J., Evers, A. W., Stouthard, J. M., Budding, J., van der Wall, E., Plum, N. M., ... & Van Vliet, L. M. (2022). Mind your words: oncologists' communication that potentially harms patients with advanced cancer: a survey on patient perspectives. *Cancer*, 128(5), 1133-1140.

Westendorp, J., Stouthard, J., Meijers, M. C., Neyrinck, B. A., de Jong, P., van Dulmen, S., & van Vliet, L. M. (2021). The power of clinician-expressed empathy to increase information recall in advanced breast cancer care: an observational study in clinical care, exploring the mediating role of anxiety. *Patient Education and Counseling*, 104(5), 1109-1115.

Hoffstädt, H., Stouthard, J., Meijers, M. C., **Westendorp, J.**, Henselmans, I., Spreeuwenberg, P., ... & van Vliet, L. M. (2020). Patients' and Clinicians' Perceptions of Clinician-Expressed Empathy in Advanced Cancer Consultations and Associations with Patient Outcomes. *Palliative Medicine Reports*, 1(1), 76-83.

Van Vliet, L. M., Francke, A. L., Meijers, M. C., **Westendorp, J.**, Hoffstädt, H., Evers, A. W., ... & van Dulmen, S. (2019). The Use of Expectancy and Empathy When Communicating With Patients With Advanced Breast Cancer; an Observational Study of Clinician–Patient Consultations. *Frontiers in psychiatry*, 10, 464.

OTHER

Westendorp, J., van Vliet, L. M. (2024). ‘We kunnen niets meer voor u doen mevrouw’: nieuwe publicatie over schadelijke communicatie in de oncologie. *Peiler tijdschrift over palliatieve zorg en het levenseinde.*

Westendorp, J., Geerse, O. P., van der Lee, M. L., Schoones, J. W., van Vliet, M. H., Wit, T., ... & van Vliet, L. M. (2024). Schadelijke communicatie in de oncologie. *Huisarts en Wetenschap.*

Wang, Y., Massalee, R., Beebe, K., Latham, W., Putnam, L., **Westendorp, J**., ... & Colloca, L. (2023). A glimpse of the multiple applications of virtual reality. *Placebo Effects Through the Lens of Translational Research*, 351.

Westendorp, J., van Vliet, L. M. (2022). Weet jij of je het juiste zegt tegen je patiënten? (gesprekswijzer). *Palliaweb.nl.*

Westendorp, J., van Vliet, L. M. (2022). ‘Wat ziet u er goed uit mevrouw’, zei de oncoloog, maar zo voelde ze zich helemaal niet. *Carend.nl.*

Westendorp, J., van Vliet, L. M. (2022). “Wat ziet u er goed uit mevrouw”. *Nederlandse Vereniging Psychosociale Oncologie.*

Westendorp, J., van Vliet, L. M. (2022). Communicatie met patiënten verdient structurele aandacht. *Medischeoncologie.nl.*

Westendorp, J., van Vliet, L. M. (2021). Wat een arts zegt tegen mensen met uitgezaaide borstkanker, kan schadelijk zijn. *Borstkanker.nl.*

Westendorp, J. (2021). Overlevingscijfers bij kanker: laat je goed voorlichten. *Kanker.nl.*