Balancing explicit with general information and realism with hope

Communication at the transition to palliative breast cancer care

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De balans tussen expliciete versus algemene informatie en realisme versus hoop
Communicatie tijdens de overgang naar de palliatieve fase van borstkanker

(met een samenvatting in het Nederlands)

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If you live each day as if it was your last, someday you'll most certainly be right (Steve Jobbs)

Voor papa

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1

Introduction

Introduction

Breast cancer is the most common cancer for women [1]. In the Netherlands, 1 out of 8 women will develop breast cancer in her life [2]. This corresponds to around 13.500 women that are annually diagnosed with this disease. Despite increasing cure rates, breast cancer is still the most fatal form of cancer in women [3], with 3.283 deaths in the Netherlands in 2011 [4]. The 10-year survival rate exceeds 75%, leaving a roughly 25% of patients that have died of metastatic disease within this time-frame [2]. At some point in their disease – at diagnosis or after recurrence – these patient have entered the palliative phase of their disease. In this phase, cure is no longer possible and care is primarily aimed at quality of life instead of prolongation of life [5]. When confronted with the message that curative options are impossible, patients may feel bereaved of their future and experience the threat of death [6]. Of all phases in cancer treatment, the palliative phase may well be the phase where good communication of health care professionals is most adamant.

The stressful nature of the transition to palliative care

Discussing the transition from curative to palliative care is in itself a stressful event. Hearing such a bad news message can have a profound influence on patients' subsequent psychological distress [7]; evoking feelings as uncertainty [6,8-10] and anxiety [6,9] about the future. But discussing this transition is also a daunting task for medical oncologists. High levels of psychological [11] and physiological [12] stress are common when breaking bad news. Oncologists are often afraid of both their own emotions when providing such news [13] and of responding to patients' emotions [14].

Guidelines are based on expert perspective

To ease this transition and improve patients' outcomes, several guidelines have been developed on how to break bad news [15-20]. Despite an increase in attention on the patient perspective on communication, most of these guidelines are still solely based on expert-opinion [16,21,22]. This is potentially problematic, as cancer patients might have different priorities than their care providers [23]. For example, Girgis et al [22] compared patients' and doctors' views on guidelines on breaking bad news, revealing some notably differences; e.g. patients endorsed more than doctors the importance of ensuring that patients understand treatment options and to provide the information in a private, quiet place. It seems therefore necessary to provide oncologists with lay people's recommendations and needs to ease the transition to palliative breast cancer care. This may improve medical oncologists' communicative behaviour [11] and consequently, patients' psychological functioning.

Patients' double need: the need to know and the need to feel known

When focussing on patients' needs in medical consultations, an often used theoretical framework divides the needs of patients in two distinctive ones; *the need to know and understand*, and *the need to feel known and understood* [24-26]. The *need to know and understand* is a cognitive need for medical technical information to know what is physically wrong and what can be done to treat the disease. This need can be satisfied by care providers' instrumental communication (e.g. the provision of information). The *need to feel known and understood* is a more emotional need for support and to be seen as a person behind the disease. This need can be satisfied by care providers' affective communication (e.g. displaying empathy).

As previously described, entering palliative care evokes – among other emotions – both feelings of uncertainty and anxiety about the future. Medical oncologists can provide information about the disease status and future developments to handle this uncertainty. Indeed, the use of clear information is appreciated by patients [21,27]. On the other hand, affective communication can help patients to handle the anxiety about the future. This is reflected in patients' appreciation of empathy [27,28]. That being said, when discussing the transition to palliative care medical oncologists face two main dilemmas.

The need to know: explicit versus general information

A first dilemma oncologists encounter is that they have to balance between providing more explicit and more general – prognostic – information. When being confronted with a life-limiting diagnosis, patients want to receive information. They need information about the palliative – life-limiting – nature of their disease [29,30], about treatment options that are still available [31-33], and about how the disease will develop [30,31] and affect day to day life [34]. So far, studies have been inconsistent as to *how explicit* information should be provided about these and related topics. Most patients state that they want as much information as possible [32,35,36]. But it is also common to hear patients state that they wish to receive not too much information [29,37,38] or hear them complain that they are overwhelmed by the information provided [39].

Balancing explicit with general prognostic information

When exploring this apparent paradox, the difficulty might be most apparent regarding the explicitness of prognostic information. Not all patients want to receive complete information about their life expectancy [33,40-42]. Studies differ in the percentage of patients this holds for. For example, in one study over 85% of patients with incurable cancer wanted to receive 5-year, longest, and average survival rates [33] while another study found that only half of cancer patients wanted to receive a quantitative estimate of their prognosis [40]. It is also unclear in what way prognostic information should be discussed. For example, the subset of patients who wanted to discuss a time frame in one qualitative study varied whether they preferred to hear how long an average person would live or whether they would prefer to hear the longest possible time to live [29] while another quantitative study found inconsistent results as to whether precise numerical data were preferred or more qualitative words when discussing prognosis [33]. What is clear is that when too vague prognostic [39] or harsh [43] information is given, patients are distraught. Based on these and other studies it is often suggested that an individualized approach to discuss prognosis is necessary [15,30,44]. Unfortunately, there is a lack of studies on the level of patients' preferred explicitness of prognostic information and recommendations for medical oncologists how to tread the fine line between providing information while not overwhelming patients.

Oncologists' attitudes towards balancing explicit with general prognostic information

The importance of creating insight into this dilemma does not only follow from patients' ambivalent attitudes but also from the attitudes and communication styles of oncologists. In surveys, oncologists report that they would not always provide a full prognostic disclosure [45,46]. Oncologists may have a wish to provide open information, they are especially reticent about discussing time-frames [47,48]. They seem to be afraid of destroying patients' hopes [49] and believe that patients do not wish to receive and are not able to understand such information [48]. Consequently, when conveying bad news medical oncologists are prone to use implicit language [50]. One study found that while in 100% of the conversations with adults who had incurable cancer oncologists used implicit words to discuss prognosis and death, only in 52% of the conversations explicit wordings were used [51].

Tailoring communication

As the need for information, and especially prognostic information, seems to vary between patients it seems important to tailor communication. When tailoring, information is adjusted to the individual patient's preference [52]; both in content and presentation style [53]. To provide more handles for how to tailor communication, studies have focused on whether information needs depend on cancer patients' demographic and personality characteristics. Most studies found that younger [32,54-56], higher educated [56], and female [32,32,54,55] patients want to receive more information. Next, patients with high trait anxiety might be the ones wanting the least prognostic information [40] while more optimistic patients might have a higher need for information [57]. But most studies have focused on patients’ coping styles, more specifically on ‘monitoring’ versus ‘blunting’.

Monitoring versus blunting

Miller [58] proposed two – independent – coping styles that influence preferences for information and communication; ‘monitoring’ and ‘blunting’. The most apparent difference between the two coping styles seems to be that (high) monitors generally want to know more and (high) blunters want to know less and that they benefit from receiving their preferred level of information [59-62]. Indeed, the literature shows that people scoring high on monitoring (i.e. ‘high monitors’) have great needs for information [21,63,64]. Moreover, they experience high levels of distress surrounding medical procedures, such as genetic testing [65-68] and (colpo/gastro) scopies [69,70], exaggerate the significance of their problems more than (high) blunters [61], and perceive situations easily as threatening [71,72]. On top of that they are generally less satisfied with provided information compared to low monitors [73,74]. Still, it is often concluded that high monitors do benefit the most from specific information [60,70,75,76]. Meanwhile, people scoring high on ‘blunting’ (i.e. ‘high blunters’) seem to prefer to avoid threatening information [58-60]. They seem less distressed compared to (high) monitors [70] or low blunters [66] in the face of threat and more satisfied with information provided than low blunters [66,73]. In line with their preferences, they also benefit the most from general information surrounding medical procedures [70,75]. However, high monitors’ and high blunters’ reactions at the transition to palliative care have not yet been studied.

Uncertainty management theory

While entering palliative care evokes uncertainty, and patients vary in the degree they prefer – prognostic – information to decrease this uncertainty, uncertainty management theory aims to provide a theoretical insight into these preferences [77,78]. According to this theory, when confronted with a specific uncertainty people appraise its significance and an emotional response (which can either be positive or negative) is elicited, resulting in a final reaction [77]. In every situation people have an optimal state of uncertainty which they will be motivated to find [78]. So, for most patients the uncertainty evoked by entering palliative care seems to instil feelings of threat, while others might value this uncertainty. These reactions lead to either an increased or decreased desire for explicit information; it may be that the first reaction holds especially for high monitors, the latter for high blunters.

The need to feel known: hope versus realism

A second dilemma oncologists encounter is how to provide hope while remaining realistic at the same time. Many studies emphasize that patients in such situations need hope [6,30,79,80] while the importance of receiving realistic information is also stressed [6,30,80,81]. It is often stated that oncologists have to tread the fine line between being hopeful and realistic [11,30,82]. However, concrete advice on how to do so is largely lacking.

Balancing hope with realism

This might be because when focusing on hope versus realism, the association with cure and related prognosis is often made [79]. Indeed, even in the palliative phase cure is an important hope for patients [8,39]. Moreover, a systematic review showed that for a minority of patients the avoidance of – prognostic – information nurtures hope [79]. These patients seem to regard hope and realism as two disconnected elements by which realism destroys hope [83]. At the same time there is literature showing that most patients appreciate an honest – prognostic – discussion [79] and think that realism in this regard might actually foster feelings of hope [81]. Overall patients need honesty [34,41,84]; they thus need to know that they can rely on the information their oncologist is providing. That they simultaneously express a need for hope for a cure, even against all odds [8,39], still creates the impression that oncologists have to choose between being either hopeful or realistic in their communication.

Oncologists' attitudes towards balancing hope with realism

This is illustrated in oncologists' perceptions of balancing hope and realism. Oncologists perceive the provision of hope to cancer patients as a vital [48,85,86] yet challenging [48,87,88] component of their work. One particular concern is how to react when hope and realism are – too – disconnected and patients hold unrealistic hopes. Most oncologists feel they should discourage these hopes [48,87]. In one study, many oncologists stressed the importance not to collude which such hopes to give patients the chance to prepare for death. Contrary, others felt that you cannot force the truth to people [87]. Indeed, 'being honest without taking away hope' was the most complicated aspect of discussing bad news according to participants of an American Society of Oncology meeting [15].

Hope in a wider context

However, hope actually does not seem to be limited to hope for a cure or a longer life expectancy, but seems to be a more multidimensional and flexible construct [89]. When focussing on the literature in more detail, the term 'hope' is very ambiguous; its content is subject to change [89,90] and an uniformly accepted definition of this term is lacking [79]. Indeed, hope can both be used as a noun ('there is hope') or as a verb ('I hope') by patients [91]. Two systematic reviews already concluded that hope can be framed in a wider context than purely survival [6,79]. There is evidence that patients treated with curative versus palliative intentions feel equally hopeful [92,93]. Patients in the palliative phase not only hope for a cure, but also hope for more realistic goals such as a comfortable time to live and eventually a good death [8,94].

When taken these findings into account, there might actually be various manners in which oncologists can balance realism with hope at the transition to palliative care, exceeding the hope for a cure. One particular promising way to provide hope at this point in time may be by using affective communication, serving patients' *need to feel known*. More specifically, a systematic review found that an empathic doctor, who sees the patient as a person and who provides emotional support, might offer hope [79]. An empirical base for this claim is however still lacking.

Tailoring communication

While all patients seem to have a need for both realism and hope, tailoring seems less obvious in this regard. However, personality characteristics might influence reactions to hopeful and realistic information. Most importantly, high monitors seem to require more emotional support compared to low monitors [21,63,95,96]. Next, optimism can play a beneficial role in the psychological adaptation to cancer and other life-threatening diseases [97-100]. So, optimism might be beneficial following all types of communication, i.e. following more realistic versus hopeful information (and also following explicit and general information, although they seem to prefer more detailed information).

Questions based on dilemmas

Based on the aforementioned literature, two main dilemmas and questions stand out regarding how oncologists can communicate when discussing the transition from curative to palliative breast cancer care. First, how can oncologists balance between providing more general and more explicit – prognostic – information? Second, how can oncologists balance between being hopeful and realistic at the same time? In the current project we will try to answer these two questions from a patient perspective.

An experimental study design

Clinical versus experimental studies

When focusing on the patient perspective on communication most studies have used an observational design, which has the benefit of ecological validity but is not without drawbacks [101]. Practical, ethical and methodological limitations are pressing. First of all, standardization of communication cannot be accomplished in clinical interactions, creating much ‘noise’ in the research design and preventing causal relations between communication and outcomes to be drawn [101,102]. Next, systematically varying communication is often difficult as it would be unethical to expose half of the patients to possible harmful communication. Last, communication is often used as a container-concept, with little interest in the specific elements it consists of [102]. So, when positive effects of an intervention are found little can be said about which communication element(s) influenced patient outcomes.

To overcome these limitations, and to draw causal conclusions about the effects of communication on patient outcomes, experimental studies are needed. In these studies specific elements of communication are manipulated in laboratory-like settings, while all other communication is held constant. By linking the effect of specific communication to specific outcomes, this approach builds further upon recently developed models proposing that communication serves different functions influencing different outcomes [102,103]. Derived from the model proposed by de Haes and Bensing [102] central functions of communication during bad news consultations include ‘providing information’, which can influence outcomes like understanding and recall, and ‘fostering the relationship’, which can influence outcomes like satisfaction and trust. Such propositions lend themselves to be tested in an experimental design.

Scripted video-vignette studies including analogue patients

An example of such an experimental design is a scripted video-vignette study. In scripted video-vignette studies, researchers create a (basic) script of a (hypothetical) consultation between a practitioner and patient. Various versions of this script are then created. The medical content is equal in all versions, but specific types of communication are varied while all other communication is held constant across the conditions. This allows determining the isolated effects of specific communication. For example, Fogarty et al [104] created two versions of a script of a consultation in palliative breast cancer care. These were identical, except that in one script 40 seconds of empathic statements were added. This way, the isolated influence of empathic remarks could be determined. After researchers have created the written scripts, they are role-played by professional actors or real doctors/patients, videotaped and shown to participants (called 'analogue patients') in an experiment. Analogue patients are healthy people or (former) patients, who are asked to watch one or multiple videos while placing themselves in the shoes of the video-patient and judge the communication of the practitioner from this patient-perspective.

A fundamental, yet unanswered question is how valid the use of analogue patients is. According to simulation theory, we can infer the mental states of others by adopting their perspective through embodying their states with resonant states of one's own mental state [105,106]. Indeed, we seem to have certain mirror-neuron systems that are active when a particular action (e.g. hand movement) is carried out and also when this particular action is observed in others [107] and such systems have been shown to be involved in experiencing and observing emotions in others [108]. The study of Fogarty et al [104] supports this line of reasoning in cancer communication; both healthy subjects and cancer survivors were less anxious after watching the empathic consultation. From these and other studies we are inclined to conclude that the use of analogue patients appears to be valid, but more evidence is needed.

Additional advantages and limitations of scripted video-vignette studies

A scripted video-vignette design has two additional advantages; namely that videos can be viewed by multiple people and that ceiling effects may be overcome. First, showing one video to multiple analogue patients provides the opportunity of assessing the influence of background characteristics – e.g. age or coping style – on the evaluations of communication. Moreover, this leads to a higher number of observations for one video-vignette, increasing the reliability of outcomes [109,110]. Second, clinical patients in observational studies are often extremely satisfied with their practitioner [111,112], perhaps because they feel dependent of their doctor [113,114]. When people watch videos of unfamiliar practitioners these ceiling effects might be overcome.

Still, scripted video-vignette studies might suffer from validity problems. As the use of this design is still in its infancy, insight into both internal and external validity of these studies is largely missing. Studies using scripted video-vignettes have often made no detailed reference to or description of their study's validity [e.g. 115,116], which might suggest that they have taken the validity of this approach for granted. Focusing on internal validity, the success of the manipulations is central when determining the effect of communication with this design and should thus be tested (i.e. variations in empathy should be perceived as such). Moreover, the use of a scripted video-vignette remains an approximation of clinical care, instead of a real clinical consultation. External validity can thus not be assumed without caution. More specifically, analogue patients have to consider the videos as realistic and be able to identify themselves with the video-patient.

Aims and outlines of this thesis

Aims of the current project

The primary aim of this project is to determine optimal communication strategies for discussing the transition from curative to palliative care in breast cancer. To do so we focus on two dilemmas, which might be handled by communication in the functions of ‘providing information’ and ‘fostering the relationship’ [102]. First, we focus on how medical oncologists can balance between giving explicit – prognostic – information and more general – prognostic – information. Second, we focus on how oncologists can balance between being hopeful and realistic at the same time. For this second dilemma, we will mainly focus on the potential of the use of affective communication to provide hope. Our project regards these two dilemmas from a patient perspective, exploring the influence of background characteristics. Based on the presented theoretical background we developed a conceptual model to guide our project (see Figure 1.1). This model is derived from the ‘doctor-patient communication from a stress coping perspective’, developed by Bensing [117] and integrates uncertainty management theory [77,78]. Ultimately, the effect of communication on uncertainty, anxiety and related measures (i.e. satisfaction and self-efficacy) is determined. In addition to this primary aim, our secondary aim is to provide more insight into and evidence for the validity of using scripted video-vignette studies including analogue patients to study the patient perspective on communication systematically.

Outline of the thesis

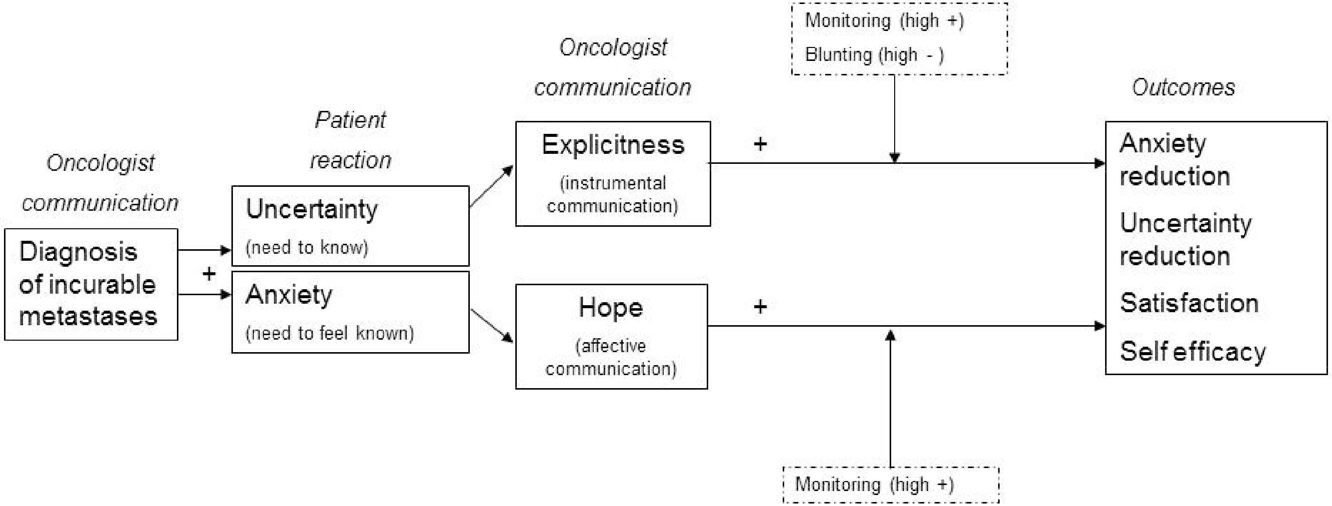
The project comprised of three parts: i) the qualitative study, ii) the methodological phase, iii) the experimental study.

In the first part of this thesis we focus on the qualitative study. A qualitative study was performed on how oncologists can balance between giving i) explicit and general, and ii) realistic and hopeful information when discussing various topics at the transition from curative to palliative breast cancer care. **Chapter 2** describes the results of this study. Focus groups were held among breast cancer survivors and healthy women who imagined themselves in the situation of hearing life-limiting information. We decided to include no participants in the active phase of their disease because we hypothesized that this might be too emotionally distressing for them. After receiving negative reactions of patients we successfully granted the Ethics Committee for permission to include patients in all phases of their disease in the subsequent experimental study.

In the second part of this thesis we focus on the methodological phase. First, we conducted a systematic review on the validity of conducting (scripted) video-vignette studies including analogue patients. Results are described in **Chapter 3.** We describe studies' rationales to conduct video-vignette studies including analogue patients, studies' attempts to increase and test internal and external validity, analogue patients' perceptions on studied communication elements and whether analogue patients' evaluations overcome ceiling effects. We expected to find further support for the applicability of (scripted) video-vignette studies including analogue patients to study the patient perspective on communication. Second, we used the outcomes from the qualitative study to create valid scripted video-vignettes of a consultation in which the transition to palliative care is being discussed with a female breast cancer patient. In these video-vignettes both the level of 'explicitness of prognostic information' and 'reassurance about non-abandonment' (an operationalization of the term 'hope') were systematically varied (either high or low). The process of the different steps in creating and validating both the written and role-played scripts is described in **Chapter 4.**

In the third part of this thesis the results of the experimental study are being described. In the experimental study, the aforementioned scripted video-vignettes were used. Analogue patients (both breast cancer patients/survivors and healthy women) viewed all four possible videos, in which 'explicitness of prognostic information' and 'reassurance about non-abandonment' (an operationalization of the term ‘hope’) could either be high or low. Main outcome measures were uncertainty and anxiety; secondary measures were satisfaction and self-efficacy. Analogue patients’ monitoring and blunting coping styles were assessed. We expected that more explicit prognostic information would lead to more favorable outcomes, especially for high monitors, but not for high blunters. Moreover, we expected that reassurance about non-abandonment would be appreciated, while this effect would be strongest for high monitors. In **Chapter 5** the main outcomes of this study are presented, exploring the moderating influences of monitoring and blunting. Last, in **Chapter 6** the concept of monitoring was studied in greater detail. The relation of monitoring scores with background characteristics including communication preferences and with responses to receiving an incurable cancer diagnosis, and more specifically the highly and lowly explicit prognostic and reassuring information, were studied in greater detail.

Figure 1.1 Conceptual model



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Part 1: The qualitative study

2

When cure is no option: How explicit and hopeful can information be given?

A qualitative study in breast cancer

van Vliet L, Francke A, Tomson S, Plum N, van der Wall E,
Bensing J. 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. Copyright (2011), reprinted with permission from Elsevier

Abstract

Objective
To investigate how oncologists can balance explicit with general and realistic with hopeful information when discussing various topics at the transition from curative to palliative care in breast cancer.

Method
Qualitative analysis of focus groups consisting of female breast cancer survivors and healthy women.

Results
Perceptions of survivors and healthy women largely overlapped. Participants thought that oncologists can help patients regain a future perspective during this consultation. To achieve this, four themes seemed important: honest medical information, availability of continued support, hope has many faces, and space to choose. Moreover, participants stressed they would need time to let the message sink in before any further information was provided.

Conclusion
Participants thought that when confronted with this type of consultation they would need – more or less explicit – medical information and information regarding support. In order to maintain hope, knowledge about (treatment) possibilities is important, but also the certainty not to be abandoned by the hospital at a later stage of the disease and the confidence to remain able to make one's own decisions.

Practice implications
A life-limiting diagnosis may shatter patients’ future perspective; however, this study provides suggestions for oncologists to create a new perspective.

Introduction

Consultations in which a life-limiting diagnosis is discussed often cause distress to both patients [1-3] and oncologists [4-6]. Therefore, guidelines have been developed for breaking bad news [7-15]. Although there is an increasing focus on patients' perceived needs, these guidelines are usually created by experts [16-19]. Providing oncologists with lay people's recommendations for easing the transition from curative to palliative care may improve oncologists' communicative behavior and patients' psychological functioning [20].

Explicit versus general information

Studies focusing on the kind of information patients in the palliative phase prefer indicate that patients need to be aware of the incurable nature of their disease [18,21-24], to handle [25,26] and plan their future [27]. Additionally, they require an overview of available palliative treatment options [18,21,23,28-30] and information on how the cancer will affect their daily life [28,30,31]. However, patients might differ in the preferred time of discussing various topics [32].

Research findings are inconsistent as to how this diagnosis should be discussed and accompanied by information about future expectations [24,27,32-34]. Most patients want to receive as much information as possible [24,30,31,35-37]. However, it is also common to hear patients say they do not wish to receive too much information [38-43] or that they are overwhelmed by the information provided [39,44]. When exploring this apparent paradox, it seems a substantial minority of cancer patients prefer to remain partly ignorant about their life expectancy [21,35,45-47]. It is unclear whether numerical data or qualitative words are preferred when discussing future expectations [21,27,38,45]. Some studies concluded that oncologists should provide patients with as much detailed information as patients prefer but did not specify how much [3,38,48]. Accordingly, recommendations are lacking for oncologists on the level of preferred explicitness when discussing future expectations [49]; so far, no research has explored whether explicit (detailed/specific) information is more often preferred for some topics than for others.

Hope versus realism

Most patients [30,37,47,48] (and guidelines [19,24]) favor ending a bad news conversation with hopeful statements. Patients often express an ongoing need for hope, even against all odds [24,33,39,47,50-53]. At the same time patients often hope for realistic goals such as optimal comfort in the remaining time [51,53,54]. Still, a clear definition of hope is lacking [53] and the content of hope may be subject to change [55].

In a seemingly contradictory fashion, patients (and guidelines) also stress the importance of receiving realistic information [9,16,22,28,30]. For some, realistic information may nurture hope [30,56] while others argue that realistic information destroys hope [57]. One study found that optimistic statements did not distort patients' prognostic awareness, provided realistic information was also given [52]. Interestingly, patients sometimes simultaneously ask for ambigious, hopeful information and realistic, honest information [39,58]. So, while the literature stresses that oncologists should balance realism with hope [32,59,60], how this can be done is a dilemma not yet resolved [27,61].

Besides the content of information, the manner in which bad news is communicated is very important. Patients need an empathic doctor [3,5,62-65] but some studies indicate that during bad news consultations technical expertise is more important [18,66,67]. It is important to know how oncologists can balance this need for both affective and task-oriented communication [68].

Aim of the study

So far, we do not know whether patients prefer more explicit or general information on the one hand and hopeful or realistic information on the other hand about the diagnosis and for which topics. The aim of this qualitative study is to explore how oncologists can balance these preferences when discussing the transition to palliative care.

Methods

Recruitment and sample characteristics

For this qualitative study we focused on breast cancer because this disease affects almost only women and gender influences communication preferences [69]. We decided not to include incurable patients but female survivors and healthy women instead (age 18-65, with sufficient command of the Dutch language), because of ethical constraints. Similar approaches have been applied before, resulting in valid outcomes [17,70,71]. Survivors were recruited through websites and in publications of the Dutch Breast Cancer Patient Advocacy Organization and a sister organization. Healthy women were recruited through selected health-related websites, message-boards at health service organizations and via snowball procedures.

Ethical approval

The study was approved by the Medical Ethics Committee of the University Medical Centre of Utrecht.

Focus groups

Ten focus groups (five with healthy women and five with survivors) of three to seven persons were set up. Prior to the focus group the participants' demographic characteristics were assessed. At the start of the focus group permission was asked to audiotape and videotape the discussion. The participants were asked to read a hypothetical case about a woman who hears from the oncologist that her recurrent breast cancer has spread and that she cannot be cured. They were asked to identify with this woman and then the discussion started, guided by the first author (LV) using a list with semi-structured questions (see Appendix 2.1). The women were asked which topics they would wish to discuss in such a consultation, and whether they would prefer oncologists to be more explicit or general and more realistic or hopeful. Focus group sessions took about 3.5 hours.

Analysis

Data analysis started after the initial focus groups were held, and was part of a cyclical process of data collection – data analysis – data collection etc. All focus group discussions were transcribed verbatim. Two researchers (LV and AF or ST) read all transcripts and independently wrote a memo for each interview in which they described the most important or remarkable outcomes. These memos were subsequently compared and discussed. Moreover, the first author (LV) and one co-author (ST) systematically coded the transcripts. Initial 'open coding' (initial codes given to fragments of text) was gradually replaced by 'axial coding' (describing codes and intergration in broader related concepts). In the last phase of 'selective coding' core concepts were determined and the relationships between concepts were interpreted [72,73]. Answers to the research questions were formulated by constant comparison between and within interview transcripts of the coded material. The coding, sorting and comparing of the interview fragments was facilitated by MAXQda software [74]. To improve the quality of the analyses, at different points interim analyses were discussed among the co-authors, who have a background in medicine, psychology, sociology or nursing. This 'peer debriefing' [75] prevents one-sided interpretations of the data. Since the last two focus group sessions provided no new themes related to the research questions, data saturation appears to have been reached as far as Caucasian Dutch women are concerned.

Results

52 women participated in the study; 23 breast cancer survivors and 29 healthy women. Demographic variables are shown in Table 2.1.

Table 2.1 Demographic variables of focus group participants

Variable	Breast cancer survivors (n=23)	Healthy women (n=29)
Age (range)	57 (37-66)	49 (22-65)
Marital status		
Maried	14	15
Never married	2	9
Other (divorced, widowed)	7	5
Occupation		
Paid job	10	12
Unemployed	2	1
Disabled	4	5
Housewife / retired	9	7
Student	0	4
Highest education		
Lower secondary school	3	5
Higher secondary school	3	5
Post secondary school	17	19

From a lost future to a new future perspective

The women agreed that hearing that their disease is incurable would destroy their future perspective in a split second. They thought that during the consultation, the oncologists' main task is to restore this perspective, by discussing different themes, resulting in the patients' feeling that they will be able to live full lives until the end.

I would want to leave with the feeling "I will go on with my life, despite the fact that I've had terrible news, and there's no cure, I'm going to try to make something of my life." (healthy woman, age 59)

Time to let the message sink in
Before feeling able to engage in any discussion they would appreciate some time to let the news sink in.

I would say 'Let two patients go ahead, because I first have to think about it (the diagnosis)' (survivor, age 59).

After this pause they would want – more or less explicit – medical information and information about continued support.

Honest medical information
Above all, the women thought that oncologists should give honest medical information to make them understand their disease. They stressed that they only needed information personalized to their specific situation. Information would be needed concerning the characteristics of the disease (where the disease is located, how it would develop, and predicted life expectancy). Additionally, information was required regarding available treatments.

I'd like to know, is it in my liver, bones or all over… Yes, just some kind of test results. (survivor, age 56)

The first thing that crosses my mind is what the course of the disease will be like. What will it look like? (healthy woman, age 58)

Level of preferred explicitness
Although everyone stressed the importance of honest medical information, the women's preferred level of explicitness varied. All regarded it as fundamental to receive fairly explicit information concerning their medical diagnosis.

The medical situation now, that's a fact. They know exactly where it's located. So that's what I'd like to know, that's a starting point. (healthy woman, age 62)

However, focusing on prognosis, preferences varied widely. Some women explained that they would need very specific information, including statistics, to understand their situation. Others preferred general information (i.e. whether the oncologist expects them to live for some time) because when confronted with a time limit they would focus on that date. For examples see Box 2.1.

Box 2.1 Quotes from women preferring explicit or general prognostic information

If a physician says: “Madam, in your situation, with your cancer cells and your metastases – and they can infer much from that – we know that…” It would be useless to hear that I will die between 1 and 10 years from now. That’s not concrete enough, so they'd better say nothing then. If they say: “It's 3 years, give or take a year or two”, yes. I do understand that they cannot say: “It will last 2 years and 4 months.” They cannot say that. But at least I have some kind of indication that they have taken a look at it. That would be specific enough, but not between 1 and 10 years. (survivor, age 55)

I would like to know very explicitly. Not too vague in terms like ‘some years’ or ‘some months’. (healthy women, age 59)

A kind of minimum - maximum perspective. Like, if it progresses very rapidly and invasively, how long do I have then? And if I'm lucky, how long might I have? If it's 3 weeks or 3 years, well, give me some idea. (survivor, age 60)

They don’t know what will happen. So, they cannot say, because they don’t know. They can give a general indication: “Often when the disease has progressed like this so far, then it will be approximately so many years”; but more than that they cannot say. (healthy woman, age 26)

Perhaps some estimate. There will be degrees varying from ‘this will be over next week’ to ‘it will take months or years’. (healthy woman, age 23)

This variation applied to a lesser extent to information regarding palliative treatments. It would be sufficient for many to hear that there are still options. During follow-up consultations they would gradually need more explicit information concerning the treatments and their side effects to make well-informed decisions. This would be too much to comprehend during the first consultation.

I would appreciate it if they would tell me: "There are several options available for treatment which we can consider. And I think it would be wise to talk about that during another appointment." (survivor, age 56)

Availability of continued support

Besides medical information, the interviewees found it important to discuss the availability of continued support. Women wanted to know how they are guided by health care professionals during their disease. Most often, participants mentioned the need for specific telephone numbers to contact the hospital directly if necessary. They envisaged a central role for a specialist breast cancer nurse who would function as a contact person. Emotional guidance could be offered both for patients and their families. Even women who indicated not to need such guidance would appreciate the gesture. Interestingly, there was a preference for early discussion of the support available during later stages of the disease.

And the specialist nurse, basically, provides more support, because nurses see much more of a patient in the hospital department. (survivor, age 63)

I would really appreciate if a physician would say: "Well, if you have any questions or you are scared or whatever, you can always call." (healthy woman, age 50)

Hope has many faces: there's always something that can be done

When introducing the topic of 'hope', a few women associated 'hope' purely with cure and preferred terms such as 'positive information'. Irrespective of how it was labeled, all participants found it extremely important for patients never to feel that 'nothing can be done'.

Because if the physician were to say: "Well madam, there is no hope left", then someone might as well punch you in the face, because that's what just happened. (healthy woman, age 58)

The feeling that something is being done, ranging from treatments aimed at prolonging life to pain medication to improve quality of life, was perceived as hopeful. Oncologists could focus on the possibilities to extend life through treatments and on good quality of life.

For me it's just the fact that something is being done, that gives hope. It doesn't have to be put like: "This can save your life", but the person feels that there are things that can be done. (healthy woman, age 26)

Women often said that they would be scared 'to be left alone'. They wanted an oncologist to reassure them that they will be taken care of and not be abandoned throughout the disease.

Before you leave, they might say: "We will take good care of you, we'll make sure that you don't have pain, that you will die peacefully and we'll be standing by you to the very end." (survivor, age 50)

Last, hope was also something that comes from within, such as hope for a miracle. According to the participants, oncologists ought not to feed this hope but they can tell patients they would be pleased if they beat the odds.

Space to choose

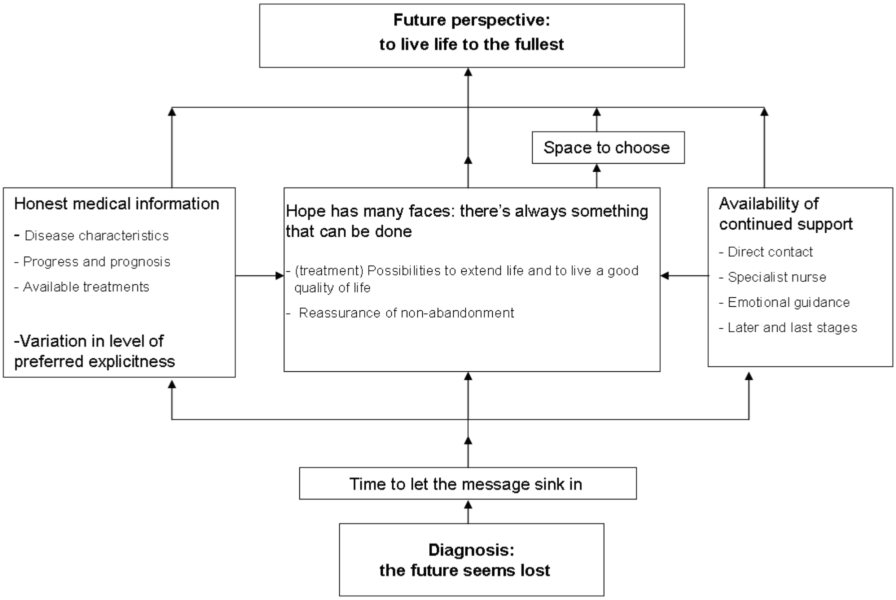
A last element that would be important for women – and defined as hopeful - was knowing that they can make their own decisions in the future. Reassurance of non-abandonment was a prerequisite for this; women could only feel able to make own decisions when they were sure that they would be taken care of unconditionally. Some wanted to make decisions on their own while others preferred to follow an oncologist's expertise and decide together.

Hopeful doesn't mean to me 'live longer'. It's more the confidence that I can manage my own life: "We won't abandon you. We will be standing by you." (survivor, age 58)

Graphic representation

The potential relationships among the described themes are displayed in Figure 2.1. This figure illustrates a patient perspective on discussing the transition to palliative care by providing information on various topics and balancing explicit with general and hopeful with realistic information, in order to create a new future perspective.

Figure 2.1 potential relationships among described themes



Differences in information preferences

As the presented figure was based on participants' views, there were variations in how the agreed needs were preferred to be discussed.

Differences associated with participant characteristics

Women who expressed a greater need to be in control and make their own decisions preferred more explicit information. Also, experiences women had with cancer influenced preferences; good and bad experiences of loved ones were often given as reasons for preferences. This was most apparent for not wanting to hear an explicit time-frame when loved ones had outlived poor prognoses.

Too often I've seen people get a bad prognosis and then they are still alive after 5 or 10 years. So that's why I wouldn't want to know. (healthy woman, age 61)

Additionally, the women recognized that preferences vary and they put forward variables that may influence these: older generations may prefer general information – which they based on examples of their own parents – and non-western immigrants may have other needs as well.

I presume that if it were a typical non-western woman, a completely different approach will be needed. Discussing the disease is 'not done' in their culture. (healthy woman, age 58)

Handling differences

The interviewees thought that oncologists need to tailor their communication. They suggested that oncologists go by their intuition and sense what kind of woman they are talking to. However, this may require too much interpersonal sensitivity for some oncologists. An alternative suggestion was to ask the patients how explicit the information should be; possibly right at the start of the consultation. Preferably, oncologists should provide general information per topic and ask whether this is enough.

If someone asks: "What about the pain?", then you explain about pain medication and you ask: "Is this enough information for the moment?" So you adjust your information. (healthy woman, age 53)

Differences between survivors and healthy women

Overall, there appeared to be little difference in survivors' and healthy women's perceptions, with two exceptions. First, survivors more often expressed a strong desire to manage their own life and, consequently, they preferred more explicit information.

I don't want him to tell me: "Go take these pills." (...) No, I want to participate in decisions. I want to hear all the 'ins and outs'. (survivor, age 63)

Second, survivors sometimes expressed – contrary to healthy women – that they had low expectations of oncologists' communication skills.

But my expectations are so low. He will only think: "Do you need a referral for a psychologist?" (survivor, age 49)

Preferences for communication

Last, women brought up two overarching expectations regarding oncologists' communication.

Getting a feeling of sufficient time

Participants agreed that oncologists have to create the impression of sufficient time (e.g. by avoiding interruptions). They also expected oncologists to be well prepared and to advise patients to bring a companion when test results are discussed.

He has to give me the feeling that he's there for me and has all the time in the world. Even if he hasn't, just create that feeling. (survivor, age 42)

Empathy with a professional distance

Women expected oncologists to show empathy (e.g. by maintaining eye contact) and they wanted to be taken seriously and listened to. Simultaneously, they expected oncologists to keep a professional distance; oncologists cannot become too emotionally involved.

When someone cries with you, that doesn't help. But he can make it feel like 'how do you feel now'. (survivor, age 57)

Discussion and conclusion

Discussion

This study focused on how – from a perspective of survivors and healthy women – oncologists can balance explicit with general and hopeful with realistic information when discussing the transition to palliative care in breast cancer. Women thought that oncologists ought to help patients regain a sense of future perspective, which can be achieved by providing relevant, realistic medical information – while tailoring the level of explicitness – and information about support. The needed hope has many faces and can be given by stressing (treatment) possibilities and non-abandonment while respecting patients' choices. Meanwhile, oncologists have to take into account variations in preferences.

We found, in line with recent reviews, that information about the disease’s characteristics, prognosis and treatment options is needed during this consultation [28,33,76] as well as information regarding the hospital’s support throughout the illness. Some guidelines have suggested introducing palliative care services – covering continued support – early [16,24,77]. Patients indeed appreciate regular consultations [48,63] or direct contact numbers [48]. However, until now, continued guidance has not received a prominent role in the literature on breaking bad news.

While it has been suggested to negotiate the timing of discussing these topics [78], our study found that oncologists may have to focus on the explicitness of medical information instead. Most women preferred information regarding the disease and treatment options (immediately or later) to be discussed explicitly. Previous studies showed that patients indeed require much information on these topics [23,42,76,79]. The crux seems to be the level of explicitness in prognostic information, as both the interviewed women’s and clinical patients’ preferences [21,30,35,39,42,46,80] vary widely. Marwit and Datson [81] suggested that the distinction often made between full versus non-disclosure is not sensitive enough as many patients need partial and paced disclosure.

Our analysis indicated that factors predicting these preferences may include the need for control and previous experiences with cancer. Interestingly, one study found that positive experiences with death increased cancer patients’ preferences for detailed prognostic information [81]. These experiences could be important for oncologists to explore when discussing life expectancy.

Although the tailoring of information seems important, oncologists tend to give information routinely [82]. Tailoring information implies that oncologists adapt to patients’ preferences [64]. Physicians sometimes rely on their intuition when providing information but their predictions are often incorrect [83-85]. Alternatively, oncologists can ask patients about their preferences [24,86,87], which is often overlooked [88]. These two approaches were also suggested in the current study. One interesting study found that patients' initial response was to say they wished to receive all information, while in further questioning some preferred general prognostic information instead [89]. So, it may be better to start by giving general information per topic and then ask whether patients prefer more explicit information, as suggested by our results.

Our analysis indicated that providing personally relevant information is another important aspect of tailoring, which highlights a discrepancy in clinical practice. While oncologists are inclined to give primarily technical information ('type of treatment') patients need to know how this information applies to them instead ('will I get chemo and go bald?') [90]. As patients are known to recall little (technical [44]) information when receiving bad news [91,92], the need for relevant information becomes even more apparent.

Regarding hope versus realism, our study found that this may not be such a contradiction as suggested in the literature [37,60,93]. Still, the first association with hope was cure, which is unrealistic in this situation and should thus not be given by oncologists. That incurable patients still hope for a miracle [37,39] may stem from other sources [94]. Our results seem to indicate that oncologists fundamentally ought to provide realistic information, meanwhile generating (realistic) hope by different means. The quotation that best reflects this is: "There is always something that can be done" which covers hopeful information regarding (treatment) options, some time left and non-abandonment. While (treatment) options have previously been labeled as hope [37,53,67], also the hope for longer survival is important to patients [54,55]. Knowing that one will not be abandoned by the hospital becomes more important for patients during disease progression as a source of hope [95,96]. Last, the interviewees needed to know that they can make their own decisions – on the premise of being taken care of unconditionally. Although this element of hope has sometimes been mentioned by patients

[37,48,97] and guidelines [16,77], it has not received much attention in studies on breaking bad news.

Besides providing information, one of the core elements of communication is ‘fostering the relationship’ [98]. Oncologists who are both empathically and medically competent during bad news conversations are the most valued [99,100], indicating that clinical patients rate both qualities highly. This was also found in the present study. Nevertheless, in a recent study only 62% of cancer patients thought their diagnosis was conveyed in an empathic manner [65]. Additionally, survivors in our study had lower expectations of oncologists’ communication than healthy women.

Limitations

As qualitative research requires detailed data collection, sample sizes are often small and might therefore not be representative of the total population. We failed to include women of ethnic minorities, whose perspectives on good communication might differ [101]. Participants were educated and stated that they were assertive, which may be attributable to recruitment through the Patient Advocacy Organization and advertisements. Therefore, quantitative studies should be conducted to assess the generalizability of the findings.

Using proxies for incurable cancer patients rather than incurable patients themselves is a limitation of this study. In clinical care patients may be emotionally overwhelmed after hearing this diagnosis [36,102] and react less rationally than the interviewed women. Yet, the current approach has been applied in previous studies in which lay people [64], curable patients [81] and relatives [34,37,101,103,104] reflected on communication in palliative care. Almost all the healthy women in our study had second-hand experience of this type of consultation. Finally, both the survivors’ and the healthy women’s perceptions largely overlapped, providing additional evidence for the validity of this methodology.

Future research

Future research could try to disentangle the effect of explicit versus general information on various participants. Additionally, the various forms of hopeful information could be further studied, especially reassurance for non-abandonment. Last, the potential relationships among the themes could be investigated. Such studies could test and clarify the potential application of the results of this explorative study in clinical practice.

Conclusion

Women who imagined themselves to be in the situation of hearing life-limiting information thought they would need realistic medical information and information regarding support. The maintenance of hope was not restricted to the (treatment) possibilities left, but was particularly based on the reassurance to always be taken care of and the confidence to remain able to make one's own decisions.

Practice implications

Oncologists should be aware that providing life-limiting information could shatter a patient's future perspective. The results presented provide oncologists with suggestions from a patient viewpoint to create a new future perspective, while tailoring explicitness of information and providing realistic hope. These results may have relevance for other health professionals, particularly oncology nurses.

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Appendix 2.1 Case used in focus groups

Try to imagine yourself in the following position. You are a 45-year old female, married and a mother of two children. Four years ago, you discovered a lump in your left breast. This turned out to be malignant. Fortunately, the tumor was small, 1.5 cm, and was found to be confined to the breast. You were treated with surgery, radiotherapy and adjuvant chemotherapy. One month ago you again felt a small lump in your left breast. Physical examination by the surgeon revealed several lymph nodes in the axilla, suggestive for pathological involvement, i.c. the lymph nodes containing cancer cells. You underwent a bone scan and CT scan of the lungs and liver. These investigations revealed metastases in your bones and liver. There are no treatments available that will cure you. The doctor wants to discuss your future expectations.

Question 1:
Which topics do you think are most important to discuss when a doctor raises the issue of future expectations with a breast cancer patient who is incurable?

Question 2:
About which of these topics would you prefer to receive explicit information and about which topics would you prefer to receive more general information?

Question 3:
Can you give concrete examples of how an oncologist might give specific or general information?

Question 4:
About which of these topics would you prefer realistic information and about which topics would you prefer more hopeful information?

Question 5:
Can you give concrete examples about how an oncologist might give realistic or hopeful information?

Question 6:
We are also interested in your opinion about the manner in which a doctor gives you information; how do you think that a doctor should behave in this situation?

Question 7:
Do you have any other important opinions or remarks about anything that has been discussed today that you would like to share?

Part 2: The methodological phase

3

The validity of using analogue patients in practitioner–patient communication research:

Systematic review and meta-analysis

van Vliet LM, van der Wall E, Albada A, Spreeuwenberg PM, Verheul W, Bensing JM. The validity of using analogue patients in practitioner-patient communication research: Systematic review and meta-analysis. J Gen Intern Med 2012;27:1528-43. (open-access)

Abstract

Background

When studying the patient perspective on communication, some studies rely on analogue patients (patients and healthy subjects) who rate videotaped medical consultations while putting themselves in the shoes of the video-patient.

Objective

To describe the rationales, methodology, and outcomes of studies using video-vignette designs in which videotaped medical consultations are watched and judged by analogue patients.

Data sources

Pubmed, Embase, Psychinfo and CINAHL databases were systematically searched up to February 2012.

Data extraction

Data was extracted on: study characteristics and quality, design, rationales, internal and external validity, limitations and analogue patients' perceptions of studied communication. A meta-analysis was conducted on the distribution of analogue patients' evaluations of communication.

Results

Thirty-four studies were included, comprising both scripted and clinical studies, of average-to-superior quality. Studies provided unspecific, ethical as well as methodological rationales for conducting video-vignette studies with analogue patients. Scripted studies provided the most specific methodological rationales and tried the most to increase and test internal validity (e.g. by performing manipulation checks) and external validity (e.g. by determining identification with video-patient). Analogue patients' perceptions of communication largely overlap with clinical patients' perceptions. The meta-analysis revealed that analogue patients' evaluations of practitioners' communication are not subject to ceiling effects.

Conclusions

Analogue patients’ evaluations of communication equaled clinical patients’ perceptions, while overcoming ceiling effects. This implies that analogue patients can be included as proxies for clinical patients in studies on communication, taken some described precautions into account. Insights from this review may ease decisions about including analogue patients in video-vignette studies, improve the quality of these studies and increase knowledge on communication from the patient perspective.

Introduction

Studies of the patient perspective on communication usually rely on clinical patients (CPs) who rate their practitioner's communication [1,2]. Other studies rely on analogue patients (APs) - patients and/or healthy subjects - who rate videotaped medical consultations while putting themselves in the shoes of the video-patient. These videotapes can be of real encounters (referred to as 'clinical studies') or scripted encounters (referred to as 'scripted studies'). Scripted studies provide researchers the opportunity to vary and study specific elements of communication (e.g. compassionate remarks [3]).

Until now, insight into the reasons warranting the use of video-vignette studies with APs is lacking. Studies might use general, implicit rationales. Alternatively, there may be ethical considerations; not all communication can cautiousness be randomized in clinical care. Methodological advantages may be another reason. As stated above, scripted studies can investigate specific elements of communication. Additionally, CPs are often extremely satisfied with their practitioner [4,5] – perhaps because they feel dependent [6] or because of social desirability [7] – leading to ceiling effects. It has to be established whether APs' evaluations of communication can overcome ceiling effects, and which rationales underlie and strengthen the use of video-vignette studies.

While video-vignette studies are sometimes preferred over empirical studies, the former may have validity problems. With regard to internal validity in scripted studies, the question arises whether manipulations are successful, i.e. variations in empathy should be perceived as such. With regard to external validity, the question arises whether results are generalizable to CPs and clinical care, i.e. are APs able to adopt a video-patient's perspective?

Considerable research has been conducted on how CPs perceive their doctor's communication. CPs appreciate various types of affective communication: verbal empathy [8-10], social talk [10,11], non-verbal eye-contact [8] and listening [8,10]. Appreciated instrumental communication includes information-giving [8-12]. Last, 'patient-centeredness' is an often studied 'general' communication style mostly associated with positive outcomes [8-15]. Whether APs evaluate these communication elements similarly is largely unknown.

To summarize, we lack an understanding of the rationales for conducting video-vignette studies with APs; how both internal and external validity are increased and tested; how APs' perceptions of communication correspond to CPs' perceptions; and whether APs' evaluations of communication overcome ceiling effects. An overview of these elements will provide more insight into when and how APs can be used in future studies. Therefore, a systematic review is conducted with the following research questions:

1. What are the rationales for conducting clinical and scripted video-vignette studies on medical communication with APs?
2. What have video-vignette studies done to increase and test their internal and external validity?
3. How do APs perceive – affective, instrumental and general – communication elements?
4. Do APs' evaluations of communication overcome ceiling effects?

Methods

Identification of studies

Pubmed, Embase, Psycinfo and CINAHL were searched in February 2012. Searches were not restricted to any parameter and focused on two central concepts: 'analogue patients' and 'video' (see Appendix 3.1).

Studies were eligible for inclusion if they were about (verbal/nonverbal) communication between physicians/nurses and patients and: i) used video-vignette designs; ii) included APs (>18 years): healthy subjects, untrained or trained only for this study; patients not judging their own doctor/nurse; standardized patients viewing a videotaped consultation they took part in; and iii) used APs' perceptions of physician's/nurse's communication as outcome measures (e.g., preferences, recall). Studies were excluded if: i) observers were trainers, research assistants, trained/experienced coders, examiners, medical students or faculty members; ii) APs' comments did not include a quality judgment.

Data

The following data were extracted from each study and summarized in Table 3.1: study characteristics and quality, design, rationales for conducting video-vignette studies with APs, attempts to increase and test internal and external validity, limitations, and APs' perceptions of the studied communication elements.

Quality of studies was assessed [16] by applying the Research Appraisal Checklist (RAC) [17]. The RAC consists of 51 items covering the quality of title, abstract, introduction, methodology, data analysis, discussion, and style/form. Each item is scored on a 1-6 scale, so total scores can vary between 0 and 306 points with three quality categories: i) Below Average (0-103 points), ii) Average (103-204 points), iii) Superior (205-306 points).

Meta-analysis to determine ceiling effects

To determine whether APs' evaluations of communication (e.g. satisfaction, preferences) overcome ceiling effects, a random-effects multivariate meta-regression analysis [18] was performed using the statistical package MLWIN 2.02 [19]. The following quantitative data was abstracted for each evaluation: M, SD, range. For each study the number of participants, videos viewed per participant and available videos was abstracted. For each evaluation, using various scales, the mean score was transformed to a 0-100 score [20] using two formulas; for scales starting at 1: ((mean-1)/(range-1))x100, for scales starting at 0: ((mean/range))x100. Authors were contacted to provide relevant data not presented in the articles.

Results

The 2950 references initially found were reviewed on title/abstract (and if necessary on full-text) to determine whether they: a) were about communication, b) used a video-vignette design, c) included APs. A random 10% of the articles were independently checked on these criteria by two authors (LV and JB); interrater agreement exceeded 95%. Thirty-four articles met these criteria and a forward- and backward reference search was performed. Four hundred and fifty-two new articles were reviewed in the aforementioned manner, resulting in 32 additional articles. These 66 articles were explored full-text on the final criteria: a) a focus on doctor/nurse-patient communication, b) inclusion of APs who viewed videos and judged the communication. Thirty-four articles met all criteria. Their references were hand-searched, resulting in 4 extra articles. Accordingly, 38 articles were included (see Figure 3.1) that were based on 34 studies; some studies produced multiple articles [21,22], [23,24], [25,26], [27,28].

Table 3.1 Characteristics and results of included video-vignette studies

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Aruguete & Roberts, 2000, USA, superior	To examine the effectiveness of affiliative and controlling communication styles for male and female physicians.	n = 146 undergraduate psychology students, 91 female, age range: 17-51 years, M=21	Cross-sectional; experimental study structured survey	APs viewed one out of four 5-minute videos in which a physician discussed a diagnosis of a peptic ulcer. This could be done in an affiliative or controlling communication style, either by a female or male physician. Post video measures: satisfaction, trust, motivation to comply, likelihood of recommendation, willingness to self-disclosure, recall	An analogue design is used to examine the causal effects of variables (gender and communication style).	APs perceived the controlling and affiliative physicians as such.	The affiliative style was seen as more believable than the controlling style. Subsequent analyses were controlled for believability. APs were waiting for a medical consultation.	An affiliative style led to higher APs' satisfaction, trust, self disclosure and motivation to comply, independent of physician gender. For male students, recall was lower for the affiliative style.	The behavior or APs might not reflect CPs' behavior. APs were students and thus not representative of the patient population. Likelihood of disclosure etc was measured instead of real behavior.

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Aruguete & Roberts, 2002, USA, superior	To determine the effect of physician race (white vs black) and nonverbal behavior (concerned vs distant).	n = 116 lay people, 84% black, age M=23	Cross-sectional; experimental study structured survey	APs viewed one out of four 7-minute videos of a physician-patient interaction. The race of the physician and nonverbal concernedness were systematically varied. Post video measures: satisfaction, trust, motivation to comply, likelihood of recommendation, willingness to self-disclosure, recall.	The analogue design increases internal validity.	APs could distinguish between a nonverbal distance and concerned communication style.	APs were waiting for a medical consultation. To increase identification with the video-patient the camera depicted the physician while patient appearance and dialogue was minimal. The four videos were seen as believable.	Concerned nonverbal behavior led to higher APs' self disclosure, motivation to comply, likelihood of recommendation, trust, satisfaction and recall, independent of physician race. For non-verbal distant physicians, men were more satisfied and the likelihood of recommendation was higher for same-race	The analogue design increases internal validity at the cost of external validity; whether APs perceptions compare to CPs' perceptions is unsure. APs were young, Afro-American and in good health, thus not representative. Last, likelihood of disclosure etc was measured instead of real behavior.

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Blanch et al., 2009, USA, superior	To determine the effect of medical students' expressions of uncertainty (EOU) in a standardized visit.	n = 244 undergraduatestudents	Cross sectional: non-experimental study with standardized patients (SPs); structured survey	APs watched one out of 72 videos. Post video measures: perceived confidence, competence, compassion, communication, satisfaction and overall performance.	APs have been used to understand patient perceptions when the actual patient population is not available.	Levels of EOU were objectively coded by trained raters (only low scores were included).	None	EOU were related to lower scores of confidence, competence, satisfaction, liking and communication according to APs.	It is not certain whether the same results would be found with real physicians instead of students.

- Table 3.1 continued -

Author, year, country, quality	Aim of the study	Sample	Design	Method	Rationale for design &method	Internal-validity	External-validity	Results	Limitations
Blanch-Hartigan et al., 2010, USA, superior	To determine whether there is a gender bias in patient perceptions of patient-centered (PC) behaviors.	N = 384 undergraduate students, 265 female, 76% Caucasian.	Cross sectional: non-experimental study with SPs; structured survey	Pre video measure: preference for patient-centeredness (PC) (PPOS). Next, APs received a neutral message or a message stressing the importance of either technical competence or PC. Then APs viewed one out of 61 videos. Post video measures: perceived compassion and competence.	This methodology has been used in previous studies focused on patient perceptions when the actual patient population is not available. Moreover, this design controls for patient behavior and other factors that might influence results.	The medical students' PC was objectively coded by applying the Four Habits Coding Scheme and RIAS.	None	AP judged a more PC physician as more compassionate (following each message). A more PC male physician was seen as more competent following each message. A more PC female physician was seen as less competent after the neutral + technical message and more competent after the PC message.	APs were young and may be unrepresentative for the general population. APs had no interaction with the medical students. Research in clinical settings is needed.

Author, year, country, quality	Aim of the study	Sample	Design	Method	Rationale for design &method	Internal-validity	External-validity	Results	Limitations
Bradley et al., 2001, Australia, superior	To determine the effect of consultative versus authoritative communication on APs' perceptions. Moderating effects of age and gender are determined.	N = 492 lay people, 333 female, age range: 17-84, M=39.5	Cross-sectional; experimental study structured survey	APs viewed in groups one 3-minute videotaped scenario in which the communication style of the physician was either consultative or authoritative. Post video measures: satisfaction, likelihood to comply with medial recommendations (adherence) and recall.	An experimental design has the advantage that ratings are made independently of confounding variables (e.g. previous exposures). Found results between female and male physicians can be attributed to gender instead of gender-based patterns of behavior.	Scripts were created with help of focus groups and a medical practitioner. Written scripts were validated by students and lay people/health professionals. APs could distinguish between a consultative and authoritative communication style.	Simulated situations evoke the same reactions as actual settings. APs read an introduction to the scenario to increase identification. The videos were seen as realistic (especially the authoritative style). APs could easily adopt to the patient's	A consultative communication style increased APs' satisfaction, but not adherence or recall. These latter outcomes were moderated by gender and age, i.e. a female consultative style increased adherence the most, while for young APs recall was highest with an authoritative male or consultative female.	More research is needed to replicate the findings in other conditions, other research methods and on more age categories.

Author, year, country, quality	Aim of the study	Sample	Design	Method	Rationale for design &method	Internal-validity	External-validity	Results	Limitations
Cousin & Schmid Mast, 2011, Switzerland, superior	To determine whether correspondence in non-verbal affiliative behavior between physician and patient is related to positive patient outcomes.	n = 58 students, 58% female	Cross sectional; non-experimental study with CPs; structured survey	APs watched from 8 unscripted videos (4 including female doctors, 4 including male doctors) 2-minute silent excerpts and indicated their satisfaction, trust, competence and determined adherence. APs' agreeableness was measured once.	The use of APs is not rare in the field of physician-patient communication. By standardizing the physician (i.e. all APs viewed all physicians), all variances in the dependent variables can be attributed to the APs level.	The physician's affiliative behavior was objectively coded.	None	Higher agreeable APs react to the affiliative physician with higher competence, trust and adherence scores, but not with higher satisfaction scores. The higher competence scores moderated the influence on trust and adherence. Overall, high affiliativeness was related to better outcomes.	The generalizability to real patients is uncertain; APs had no real physical complaints and related distress and they were young.

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Dowsett et al., 2000, Australia, superior	To explore preferences for and satisfaction with patient-centered and doctor-centered communication in a breast cancer consultation (with the segments: diagnosis, treatment, prognosis).	n = 113 women treated for breast cancer and 48 of their relatives/ friends	Cross-sectional; experimental study structured survey	APs watched 6 videos with either a good or bad prognosis. The doctor's communication was systematically varied. After every style in every segment satisfaction was measured and after both styles per segment the preferred doctor was indicated.	Video-vignette studies produce less skewed satisfaction scores; APs can compare and contract different styles directly.	Oncologists and patients were involved in creating scripts. APs rated all doctor styles in every segment as 'worst to best doctor available'; indicating they could discriminate between the two styles.	Both healthy participants and cancer survivors were included.	Perceptions of survivors and relatives/friends overlapped. APs preferred a patient-centered approach. Predictors were: watching a poor prognosis and having a professional occupation.	Whether the results are generalizable to other participants (e.g. lower SES, other cancer types) is uncertain.

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Floyd et al., 1999, USA, superior	To determine the comfort levels with different communication approaches for conducting a HIV risk assessment.	n = 75 lay people: students, people from a senior center. 75% female. Age range: 20-75 years.	Mixed method; experimental study qualitative; structured survey	APs viewed 10 videos of a HIV risk assessment interview, comprised of 5 areas. In every area, 2 different communication styles were created. After every style APs indicated their level of comfort.	None	Videotapes, aimed to display a variety of interview approaches, were evaluated by an independent expert panel.	None	A PC approach and close-ended interviewing techniques were more comforting.	Whether the results are generalizable to CPs is uncertain. Other factors than the varied communication may influence comfort.

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Fogarty et al., 1999, USA, superior	To assess the effect of compassion in a breast cancer consultation, in which palliative treatment options are being discussed.	n= 123 breast cancer survivors, 87 healthy women.	Cross-sectional; experimental study; structured survey	APs viewed either a ‘standard’ video or a video with enhanced compassion. Post video measures: physician compassion, anxiety, recall, treatment decision, perceptions of physician, treatment choice.	None	The scripts were created based on audiotapes of real consultations.	Both healthy participants and cancer survivors were included. Four pilot focus groups were held. Videotapes seemed realistic and appropriate for the intended audience.	Perceptions of survivors and healthy women overlapped. The compassionate physician seen as: more compassionate, warm, sensitive, pleasant, higher on specific attributes. Anxiety and recall decreased.	Whether the results are generalizable to women with breast cancer (at the time they are making treatment decisions) is unknown.

- Table 3.1 continued –

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Gask et al., 1989, UK, average	To examine the effect of an 8-week training for psychiatry trainees on the use of specific communication skills.	n = not reported, SPs	Cross sectional: non-experimental study with SPs; structured survey	Pre- and post-training, trainees had a consultation with a SP. The SPs watched the consultation on video, rated the trainees' communication skills.	None	None	None	APs judged the trainees after the consultation better in explaining the link between somatic complaints and psychological distress.	None

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Gerbert et al., 2003, USA, superior	To determine what kind of physician (race and ethnicity) is preferred.	n = 359 lay people. 61% female.	Cross-sectional: experimental study: structured survey	APs viewed 6 doctors varying in gender and ethnicity. They indicated their favorite doctor after an introduction segment and after a preventive message and rated the doctors on different qualities (e.g. professional)	Through video-method a verisimilar experience is created, in which i) the constraints of availability and access of real life are overcome, ii) variables such as doctor's age may be held constant.	None	None	Same-race and female doctors were preferred initially. After the preventive message APs preferred the PC female doctors even more. The preference for same-race doctors decreased.	None

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Gilbert, 1998, 2004, USA, superior	To investigate which relational themes are communicated by nurses' (verbal/nonverbal) listening behavior during brief interactions and whether these themes reflect positive patient-nurse relationships.	n = 126 female students. Age range: 17- 44 years	Cross sectional: non-experimental study with SPs; structured survey	APs watched six 30-second segments of nurse-patient interactions. After every segment, they rated the extent to which the nurses communicated relational themes and indicated their overall satisfaction.	None	None	None	Participants were more satisfied when a nurse communicated 'trust', 'affection', 'composure', 'little difference', 'little formality'. Nonverbal simultaneous coordination communicates positive patient-nurse relational information.	All other influencing variables were controlled. Only white college women were included. Still unsure: i. whether nurses react the same in the clinical setting, ii. whether CPs would perceive relational themes equally

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Gillotti et al., 2002, USA, superior	To understand which communication moves are associated with perceived competence in the delivery of bad news (disclosing a HIV diagnosis to a female patient)	n = 527 undergraduate students. 53% female. Age range: 20-53.	Cross sectional: non-experimental study with SPs; structured survey	APs watched 3 videos in which a medical student provided the news. Post video measures: empathy and general communication skills.	None	Trained coders objectively coded behavior and this was related to APs ratings.	None	During bad news conversation information-verifying, -giving and -seeking, and small talk was not valued.	The perceptions of APs may not overlap with real patients: APs may focus more on the giver of bad news instead of own anxieties and may be higher educated.

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External -validity**	**Results**	**Limitations**
Hall et al., 2009, 2009, USA, average	To examine the relation between medical students' nonverbal sensitivity / rapport and APs' impressions during a SP visit.	n = 244 students in psychology courses.	Cross sectional: non-experimental study with SP; structured survey	APs viewed a consultation between a medical student and SP. Post video measures: liking, compassion, satisfaction, quality of communication, self-confidence.	APs are used when access to CPs' impressions is impractical or impossible.	Rapport and interpersonal sensitivity were objectively measured.	None	More nonverbal sensitivity led to higher ratings of liking, compassion. APs' ratings of satisfaction, competence, good communication, confidence and calm were positively related with observed rapport.	The generalizability of APs' findings to CPs remains to be discovered.

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Harrigan & Rosenthal, 1983, USA, superior	To determine the effect of physician's nonverbal behavior.	n = 118 psychology students. 60% female. Age ranged between 17-25.	Cross sectional: experimental study: structured survey	APs watched 24 silent video segments in which a physician's trunk position, head nodding and open arm/leg postures were systematically varied. After every segment the behavior was judged on different ratings, measuring rapport.	None	None	Patients could only view the physician.	Physicians who leaned backward, with their arms uncrossed and nodded their head received higher rapport ratings.	None

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal -validity**	**External-validity**	**Results**	**Limitations**
Haskard et al., 2009, USA, superior	To determine the effect of verbal and nonverbal affective and instrumental communication of nurses and patients on their satisfaction with a consultation and each other. This was related to APs' perceptions.	n = 4 female naive raters (trained)	Cross sectional: non-experimental design with CPs; structured survey	Patients and nurses judged the consultation. APs watched silent videos of these consultations. They rated different affective (sensitive/caring) and instrumental (professional and negative/rushed) communication aspects.	None	None	None	When APs judged nurses' nonverbal communication as more caring/sensitive+ less negative/rushed, CPs were more satisfied with the nurse. When APs judge nurses' nonverbal communication as less negative/rushed, nurses were more satisfied with the consultation.	None

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Johnson et al., 1988, USA, average	To determine the effect of physician's expressed uncertainty when prescribing antibiotics on satisfaction.	n = 80 lay people	Cross sectional: experimental study: structured survey	APs watched one out of five videos. Video 1+2: no expression of uncertainty Video 3: uncertainty was expressed but ignored. Video 4+5: uncertainty was expressed and the doctor consulted a textbook (4) or computer (5). Post video measures: satisfaction	By using videotapes, one aspect of the patient-physician interaction can be isolated and manipulated, while the remainder of the encounter is held constant.	APs' ratings of perceived uncertainty were indeed higher when physicians expressed uncertainty.	APs were asked the question in the 'I' form. APs were waiting for a medical consultation, so they were sensitized to judge communication.	When a physician expressed more uncertainty, APs' satisfaction ratings decreased.	The study was not conducted during a genuine medical encounter, which can limit the generalizability of the findings to real patients.

- Table 3.1 continued -

Author, year, country, quality	Aim of the study	Sample	Design	Method	Rationale for design &method	Internal-validity	External-validity	Results	Limitations
Kaaya et al., 1992, UK, average	To examine the effect of an 8-week training for psychiatry trainees on the use of specific communication skills.	n = not reported, SPs	Cross sectional: non-experimental study with SPs; structured survey	Before and after the training, trainees conducted a consultation with a SP. The SPs watched the consultation on video and rated the trainees' communication skills.	None	None	None	APs judged the trainees post-consultation better in: i) explaining the findings from physical examination, ii) explaining the link between somatic complaints and psychological distress.	None
Koss et al., 1997, USA, average	To explore the effect of nonverbal behavior (positivity) on CPs' satisfaction. This was related to APs'	n = 12 students	Cross sectional: non-experimental study with CPs; structured survey	Consultations between patients and doctors were videotaped. CPs gave their satisfaction ratings post-consultation. APs rated 20-seconds silent video excerpts	None	None	None	APs' ratings of positivity were higher for female doctors. There was no relationship with CPs' satisfaction.	None

Author, year, country, quality	Aim of the study	Sample	Design	Method	Rationale for design &method	Internal-validity	External-validity	Results	Limitations
Mazzi et al 2011, Italy/UK/ Netherlands/ Belgium, Superior	To study the quality of physician's responses to patients' negative emotions (i.e. cue/concern) in an OSCE setting.	n = 259	Cross sectional: non-experimental study with SPs; structured survey	APs viewed 4 videos of medical interactions and provided for each video an overall quality judgment. Next, for every video, 4 fragments of a patients' expression of a cue or concern and the medical student's reaction hereon were shown. AP judged the appropriatenes	All APs viewed all videos, while physician's reactions were coded, increasing standardization of quality assessments. This approach enabled the investigation of APs' background characteristics on judgments. Next, the use of APs is a widely used methodology.	The cues/concerns and reactions were coded using VR-CoDES.	None	APs appreciated reactions which provided space the most. Especially explicit empathic reactions were appreciated. Next, individual quality assessments were influenced by the general impression from the consultation. Last, younger, higher educated APs were most critical.	APs were not emotionally engaged in the consultation and only from Western-European countries. Moreover, the validity of APs assessments needs to be determined.

Author, year, country, quality	Aim of the study	Sample	Design	Method	Rationale for design &method	Internal-validity	External-validity	Results	Limitations
Mazor et al., 2005, USA, average	To assess the correspondence between OSCE checklist scores and APs' perceptions of communication, and whether specific behavior is related to APs' satisfaction.	n = 111 lay people. 27% female.	Cross sectional: non-experimental study with SPs: structured survey	APs watched five videotaped consultations. Post video measures: satisfaction with the doctor's communication Next, the importance of the different checklist items was assessed.	It is important to have more raters, to increase reliability of scores.	None	None	APs were more satisfied when the physician: i) presented information clearly, ii) moved through the encounter efficiently. The OSCE checklist scores did not correspond to APs' perceptions of communication.	None.

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Mazor et al., 2007, USA, average	To investigate the processes raters (APs, SPs, doctors) use when judging professionalism of medical students, in an OSCE setting.	n = 3 lay people	Qualitative: non-experimental study with SPs; with think aloud technique	All raters watched 20 videos and expressed all their thoughts about professionalism on the following domains: introduction, respect, verbal and nonverbal communication, physical examination, overall conduct.	None	None	None	There was much variation between and within raters on how behavior is evaluated. APs appreciated information-giving.	None

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
McKinstry, 2002, UK, superior	To determine whether patients prefer a shared or directed approach in the decision making process of general practice consultations.	n = 410 lay people	Cross sectional experimental study; structured interviews /survey	APs watched in groups one out of five scenarios, both styles were viewed. Post video questions: i. which doctor do you prefer, ii. which doctor seems like your own doctor, iii. what is the difference between the two doctors?	None	For every scenario, the two versions were played by two different actor pairs. The 20 videos were shown to APs, revealing that the two styles differed on power, authority, length of time etc.	APs were waiting for a medical consultation	For medical problems, a directed approach was valued, but not for depression and lifestyle. APs preferring a shared style were younger, of a higher social class, smokers.	None

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Mumford et al., 1987, USA, average	To determine whether communication improves after a psychiatry clerkship.	n = 5 naive raters (trained)	Cross sectional: non-experimental study with SPs; structured survey	Medical students conducted a consultation with a SP pre and post a psychiatry clerkship. Videos were rated by APs on process communication.	Consultations with SPs were chosen because real patients vary, influencing students' communication. Real consultations were also more difficult to plan.	None	APs' ratings were compared with different measures, e.g. how much students were satisfied with their own work.	According to APs, students improved in the process area of communication.	None

- Table 3.1 continued -

Author, year, country, quality	Aim of the study	Sample	Design	Method	Rationale for design &method	Internal-validity	External-validity	Results	Limitations
Quilligan & Silverman, 2012, UK, Superior	To study the effect of (different types of) summary in doctor-patient interactions	n = 2 SPs	Case study: non-experimental study with SPs; qualitative analysis	A videotaped interaction between a medical student and SP was analysed for summarizing. Then the student and SP viewed the video, which was stopped at summaries, and commented on the purpose and effect of the summary. These comments were qualitatively	None	None	None	According to SPs, the use of summary increased accuracy and let them know they had been heard. However, consistent incorrect summaries made them feel they were not listened to and made them question whether they have been clear.	SPs played a role, which may not reflect real situations. SPs may be more assertive and have more knowledge about summarizing. Research in clinical care is warranted.

Author, year, country, quality	Aim of the study	Sample	Design	Method	Rationale for design &method	Internal-validity	External-validity	Results	Limitations
Quirk et al., 2008, USA, superior	To define 'caring' from a patient perspective.	n = 46 lay people	Qualitative: non-experimental with SPs; focus groups	APs watched two videos; one with high caring and another one with low caring behavior of a doctor. They discussed the behavior in focus groups.	None	None	None	APs perceived different physicians' themes as caring: i) communicate effectively, ii) arrange to meet healthcare needs, iii) respectful, iv) empathic. Within these themes, specific behaviors perceived as caring varied.	None

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Roberts & Aruguete, 2000, USA, superior	To determine the effect of task- and socioemotional behavior of doctors when discussing a diabetes diagnosis.	n = 93 lay people. 44% female.	Cross sectional: experimental study structured survey	APs watched one out of four videos in which the doctor's behavior was high or low on socioemotional and task behavior. Post video measures: trust, recommendation, satisfaction and recall.	With experimental studies, the isolated effect of physician behavior on patient responses can be studied.	47 APs scored each videotape on socioemotional and task attributes of the doctor. They could recognize both behaviors, although socio-emotional better.	APs only saw the face of the doctor, as if he was directly talking to them. 47 participants also rated the believability of the interaction. The videos were seen as believable. APs were waiting for a medical consultation.	Socio-emotional behaviors led to higher levels of: satisfaction, recommendation, trust and words recalled. Task behavior did not influence outcomes.	The reactions of APs may not reflect how patients would react in actual consultations

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Roter et al., 2008, USA, superior	To assess the effect of nonverbal sensitivity on APs' satisfaction and knowledge after watching a standardized genetic counselling consultation.	n = 559 lay people	Cross sectional: non-experimental study with SPs; structured survey.	Genetic counsellors (GCs) conducted a consultation with a SP. APs watched a video on prenatal screening or breast cancer. Post video measures: knowledge and satisfaction scores.	None	None	The following inclusion criteria for APs applied: Prenatal: under age of 35, having had a pregnancy (or partner had pregnancy). Cancer: Over 18 years of age, a family history of cancer.	GCs' nonverbal sensitivity increased APs' knowledge scores. GCs' nonverbal sensitivity decreased satisfaction scores.	The attitude of APs might be differed from those of CPs; they were all college-educated.

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Saha & Beach, 2011, USA, superior	To test the influence of a PC communication style on APs' evaluation of the physician and acceptance of clinical recommendations.	n = 48 subjects over age 40 with a coronary artery disease (CAS) or risk of CAD	Cross-sectional; experimental study; structured survey	AP viewed one video, with either a high or low PC physician. Post video measures: competence, trust, liking, comfortable and overall evaluation. Next, the necessity of treatment was determined and likelihood to undergo treatment.	By using this design, the effect of specific variables could be studied, independent of other factors such as patient context. Next, while judging an unknown doctor high ceiling effects of CPs' evaluative ratings could be overcome.	Patients, physicians and researchers helped to create the scripts and judged the final scripts on content.	To increase APs empathic involvement, the camera depicted the physician and either a female or male patient voice was used. Moreover, a brief introduction about the patient was given before seeing the video. Only participants at risk of/with CAD were included. APs were recruited at the care clinic. Patients, physicians and researchers found the final scripts realistic.	A PC style was seen as more competent, trustworthy, increased feelings of comfort and global evaluations, mainly by higher educated APs. Next, following a PC style APs felt a higher necessity for treatment and intention to undergo treatment, with less need for a second opinion.	In real interactions, evaluations and decision makings are influenced by many variables not taken into account in this study.

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Shapiro et al., 1992, USA, superior	To determine the effect of communication style when presenting ambiguous mammography results.	n = 40 healthy women	Cross sectional: experimental study: structured survey	APs watched the presentation of mammography results in either a worried or non-worried way. Pre video measure: anxiety. Post video measures: anxiety, recall, perceived severity.	The APs methodology is used when interventions in real consultations are impractical and impossible. Ethical constraints are important in this study.	Experts were involved in creating the scripts. A pilot study with 22 women was done; the videos differed on level of worriedness.	Participants had to have a high risk of cancer themselves. A brief introduction about the patient was given before seeing the video. APs could identify with the video-patient and the videos were perceived as realistic in the pilot study.	The worried presentation of information decreased APs' recall, increased anxiety and the perceived severity of the situation.	The absence of interaction between the doctor and patient (as APs only viewed videos) hampers the generazability to real interactions.

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Schmid Mast et al., 2005, Switzerland, superior	To determine the effects of different communication styles when providing a breast cancer diagnosis.	n = 159 major students	Cross sectional: experimental study; structured survey	APs watched a video in which a doctor used a PC doctor-centered (DC) or emotion-centered (EC) style. Pre video measures: mood. Post video measures: mood, satisfaction and perceptions of communication.	No cancer patients were included as APs because: i) it is not ethical to let them watch videos of a cancer consultation, ii) they may reflect on their own memory instead of communication in the video.	The three conditions were RIAS coded and indeed differed on communication.	APs were asked how well they could identify with the video-patient; no difference were observed between the 3 conditions.	APs were more satisfied with a PC approach and evaluated this doctor better. A PC approach led to lower increases in tension/ depression.	The generalizability to real patients is uncertain. Only young, high educated women were included, while the average breast cancer patient is older.

- Table 3.1 continued -

Author, year, country, quality	Aim of the study	Sample	Design	Method	Rationale for design &method	Internal-validity	External-validity	Results	Limitations
Schmid Mast et al., 2008, 2011, Switzerland, superior	To determine the effect of various nonverbal and verbal behaviors on APs' impressions.	n = 163 major students. 63% female.	Cross sectional; non-experimental study with CPs; structured survey	APs watched from 11 unscripted videos 2-minute excerpts and indicated their satisfaction and perceived dominance (for the analysis on dominance, 8 videos were used; 4 including female doctors, 4 including male doctors)	The APs approach has been effectively applied in several studies to obtain representive measures. Using this methodology has the advantage of standardizing the physician.	None	APs are potential patients.	Concerning non-verbal behavior: APs were more satisfied with female doctors and when a physician displayed gender congruent behavior. Concerning (non)verbal behavior: APs perceived dominant behavior as more dominant for females than for male doctors and interpreted this more negative for females.	APs were young and high educated, which may hamper generalizability.

- Table 3.1 continued -

Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Swenson et al., 2004, 2006, USA, superior	To investigate preferences for a PC or DC approach when discussing complementary and alternative medicine (CAM) use	N = 250 lay people.	Mixed method; experimental study and qualitative; structured survey	APs watched a scenario in which CAM use was discussed, in a PC and DC style. Both styles were scored on: satisfaction and characteristics. For qualitative analysis the following two questions were asked: i) which of the doctors did you prefer, and why, ii) what were the differences between the two doctors?	By including APs less skewed distributions may be found. Using this methodology, all other variables can be controlled.	Expert panels helped to create the different scripts. The videos were shown to interns, which determined face validity.	In video research the same variations in preferences are found as in clinical studies with CPs. APs were waiting for a medical consultation.	A PC approach was valued, mostly by: younger, higher educated APs who were CAM users and had a PC physician. Qualitative analysis showed that APs' evaluated the same behavior in different ways.	It is uncertain whether responses to videos are similar to responses of patients in the real clinical setting.

- Table 3.1 continued -

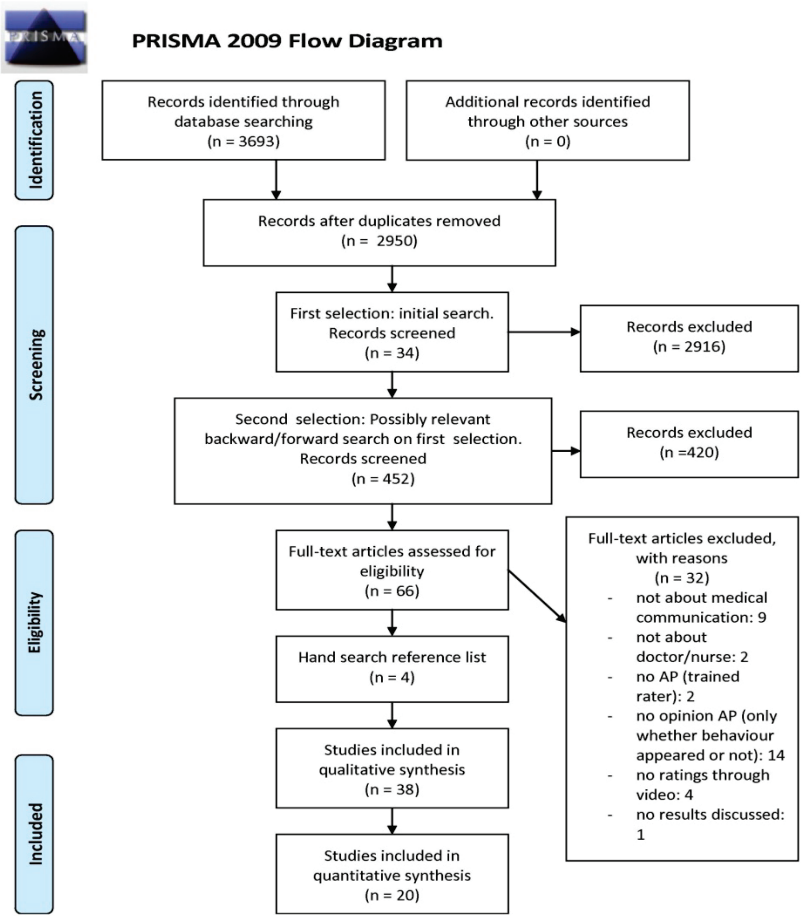
Author, year, country, quality	**Aim of the study**	**Sample**	**Design**	**Method**	**Rationale for design &method**	**Internal-validity**	**External-validity**	**Results**	**Limitations**
Willson & Mcnamara, 1982, USA, superior	To investigate how different levels of courtesy and competence influence APs' perceptions with care.	n = 127 undergraduate students	Cross sectional: experimental study: Structured survey	APs watched one out of four videos in which a nurse discussed a sore throat with a patient. The videos varied on levels of competence and courtesy (high/low). Post video measures: satisfaction, intended compliance perceived courtesy and perceived competence.	Variations in quality of communication cannot be varied and studied in clinical care out of ethical constraints, so this approach offers a solution.	Clinical algorithms were used to create the technical parts of the script. In a pilot study, AP classified 80% of communication fragments correctly. All APs also rated the courtesy/competence behavior, which were two different factors. Competence influenced level of courtesy but not vice versa.	In a pilot study APs thought the videos were credible. APs were given information on the medical condition, and were asked to think back of the last time they had this problem.	Courtesy led to higher satisfaction, but competence both to higher satisfaction and intended compliance.	Whether the results of APs' viewing a videotape are the same as CPs' reactions is unclear.

Description of included studies

Study characteristics and quality

All studies were published in English, between 1982 and 2012, and conducted in the USA [3,21-26,29-48] (n=24), Switzerland [27,28,49,50] (n=3), UK [51-54] (n=4), Australia [55,56] (n=2), and an European setting [57]. Studies were performed in general care [21-31,33-43,48,50,51,54,55,57] (n=25), oncology [3,32,47,49,56] (n=5), psychiatry [46,52,53] (n=3), and genetic counseling [45].

Figure 3.1 PRISMA flowchart of the inclusion procedure



Most studies included lay people [21,22,29,31-36,39,42,45,46,51,55-57] (n=16) – who were trained in two studies [36,46] – or non-medical students [23-28,30,34,37,38,41,43,44,48-50] (n=13). Some studies included cancer survivors [3,47] (n=2) or patients with/at risk of coronary heart disease (CAD) [40]. In three studies standardized patients viewed videotaped consultations they had participated in [52-54].

As determined with the RAC, 8 studies [25,26,31,35,37,39,46,52,53] were of average quality, the remaining of superior quality. Four articles (10%) were independently rated by two authors (LV and AA); the quality category was agreed on. Differences in quality assessment for specific items were resolved by consensus. The studies of average quality mostly lacked quality in the areas of methodology (e.g. design) and introduction (e.g. problem definition).

Study design

Eighteen studies were clinical [23-28,30-32,36,37,39,41,44-46,50,52-54,57]. These included videos with standardized [23-26,30-32,39,41,44-46,52-54,57] (n=14) or clinical [27,28,36,37,50] (n=4) patients. Sixteen studies were scripted [3,21,22,29,33-35,38,40,42,43,47-49,51,55,56]; APs watched one [3,29,35,40,42,43,47-49,55] (n=10) or multiple [21,22,33,34,38,51,56] (n=6) videos. Six studies [21,22,32,34,39,51,54] had a (partially) qualitative approach. Physicians' communication was most often assessed [3,21,22,25-35,37-44,46-57] (n=31), but some studies included nurses [23,24,36] (n=2) or genetic counselors [45].

Rationales for conducting video-vignette studies with APs

Twenty-one studies reported general, ethical or methodological rationales for conducting video-vignette studies with APs [21,22,25-31,33,35,40-43,46-50,54-57]. According to general rationales, APs are representative for CPs [25-28,30,33,41,46,50,57]. Scripted studies pointed out the ethical constraints of standardizing (negative) communication in real consultations [47,48]. When providing methodological rationales authors argued that; ceiling effects may be overcome [21,22,40,56]; reliability increases with multiple raters [31]; scripted studies increase internal validity [42] and investigate communication systematically [21,22,29,33,35,40,43,55,56]; clinical studies can standardize physicians [27,28,33,41,50,57] and assess the influence of background characteristics [50,57]. One study included healthy subjects because including patients would be unethical and patients may be distracted by their own memories [49].

Validity

Internal validity

All but one [38] of the scripted studies tried to achieve internal validity by ensuring that their manipulations were successful. APs [40,55,56] and experts [21,22,40,47,55,56] were involved in creating the scripts, or content from clinical interactions was used [3,48]. Furthermore, APs [29,35,42,43,47,48,51,55,56] or experts [21,22,34] concluded that communication varied between videos (manipulation check), but only three studies provided useful numerical data. [35,47,48]. Other studies objectively coded the studied communication in their videos [25,26,30,41,49,50,57].

External validity

In attempt to ensure external validity several (oncological) scripted studies focused on APs' identification with the video-patient. Three studies measured (and ensured) the level of identification [47,49,55]. Other studies included subjects at risk of developing cancer [47] or CAD [40], included CAD patients [40], or included both healthy participants and cancer survivors [3,56]; their perceptions overlapped and were merged for analyses. Other (non-oncological) scripted studies tried to increase APs' identification in various ways; by depicting only the physician [29,38,40,42]; decreasing patient dialogue [29,42]; introducing the patient (via text or video) [40,47,55]; asking participants to remember the time they visited the doctor with a similar health problem [48]; using personalized questions [35]; and recruiting participants waiting for a doctor's appointment [21,22,29,35,40,42,51].

Furthermore, scripted studies often focused on video credibility to ensure external validity; APs stated that the videos were credible [3,29,42,43,47,48,55], while only five studies provided numerical data. [29,42,47,48,55]. Indirect evidence for external validity was provided by clinical and scripted studies stating that: APs are potential patients [27,28]; differences in APs' preferences equal those of CPs [21,22]; and simulated and clinical situations evoke equal reactions [55]. Last, one clinical study [46] assessed external validity, i.e. medical students who were appreciated by APs reported more satisfying interactions with CPs.

Twenty-three studies mentioned generalizability as limitation [3,21-30,34,35,40-45,47-50,54-57]. It was often questioned whether APs' reactions equal CPs' reactions [3,21-26,29,34,35,42-45,49,50,54,57] and whether findings were generalizable to real – interactive – consultations [23,24,30,40-43,47,54] or other participants (e.g. demographic characteristics) [23,24,27,28,41,45,49,50,55-57]. Research with CPs in real consultations was often recommended [23-26,30,34,41,44,48,49,54,55].

Perceptions of communication

APs' perceptions of communication were studied. Patient-centeredness was preferred overall to doctor-centeredness [21,22,33,34,40,41,49,56], but not for acute physical problems [51]. (Non)verbal affective communication was overall associated with positive effects (on trust [29,43], satisfaction [29,43,48,55,57], anxiety-reduction [3,47], intended self-disclosure [43]), but inconsistent results were found on intended compliance [43,48,55] and recall [3,29,47,55]. Social talk was appreciated in general care [34], but not during bad news conversations [44]. Appreciated nonverbal behaviors included; rapport [25,26], listening [23,24], (non)verbal gender-congruent behavior [27,28], affiliativeness [50], an open body posture combined with nodding [38], concernedness [42], while the effect of nonverbal sensitivity was inconsistent [26,45]. Two studies [36,37] compared APs' perceptions with videotaped patients' satisfaction of nonverbal behavior; one study [36] found a positive relation. Instrumental communication produced mixed results. In general care, information provision [31,39,54] and little expression of uncertainty [30,35] were appreciated, while the effect of competence was inconsistent [29,48]. Conversely, during bad news consultations information-exchange was negatively evaluated [44].

Ceiling effects

A random-effects multivariate meta-regression model compared the transformed means of 64 evaluations for 20 studies [3,21-24,27,28,30,31,35-37,40-43,49,50,55,57]. The overall mean of APs' evaluations was 54.28 on a 0-100 scale, 95% CI: 47.99-60.57. (Single) mean evaluations varied between 24.00 and 82.00 while studies' mean evaluations varied between 39.23 and 69.26, indicating also that no plateau effect occurred.

Discussion

This systematic review focused on the rationales, methodology and outcomes of medical video-vignette studies with APs. Scripted studies provided more specific rationales for using video-vignette designs with APs than clinical studies and directed more efforts at increasing/testing internal and external validity. APs' perceptions of communication overlapped generally with CPs' perceptions. Meanwhile, their evaluations overcame ceiling effects. These results have interesting methodological, theoretical and practical relevance.

Scripted studies paid the most attention to increasing the designs' methodological soundness. Specific methodological rationales for conducting video-vignette studies with APs were provided, such as the opportunity to study communication systematically. This fills a gap in clinical care studies, in which only correlations, but no causality between communication and outcomes can be determined [15,58,59]. Unfortunately, some scripted studies included container-concepts of communication (e.g., patient-centeredness). When positive effects are found, it remains unclear which specific element(s) of communication influenced outcomes [15,58]. Additionally, as argued, when videos are watched by multiple APs, the reliability of assessments increases [60,61].

Another argument for including APs was that their evaluations can overcome ceiling effects. APs' evaluations were indeed not high; averagely 54.28 on a 0-100 scale. By comparison, a meta-analysis of

CPs’ satisfaction ratings showed an average score of 80.00 (0-100 scale) [20]. Moreover, a recent study compared CPs’ satisfaction scores with those of APs viewing these videotaped consultations. Mean score (1-6 scale) for CPs was 5.8, while for APs it was 4.0 ($p<.001$) [62]. APs’ ratings thus seem to overcome this limitation of CPs’ evaluations [4,5]. Accordingly, these and other methodological rationales provide strong foundations for conducting video-vignette studies with APs.

To achieve internal validity, APs reflected on manipulations in scripted consultations. Unexpectedly, ‘experts’ (doctors/researchers) were not often asked to comment on manipulations, although they may have insight into the manipulations’ (theoretical) success. Moreover, little information was provided on how exactly scripts were created, i.e. it often remained unclear what input researchers used to develop scripts and at what point(s) the scripts were validated.

Focusing on external validity, some studies argued that APs’ perceptions overlap with CPs’ perceptions. However, none of these studies determined whether APs watching videotaped consultations and CPs in these consultations overlapped on outcome measures. As stated earlier, such a study has recently been performed [62]. In this study – taking into account CPs’ skewed satisfaction scores – APs’ and CPs’ evaluations were correlated. Additionally, a meta-analysis in psychology [63] showed that lay people can make reliable judgments for (non)verbal communication based on brief (clinical and scripted) videotaped interactions.

Theoretical evidence supporting the external validity of APs can be found in simulation theory and is supported by neuro-cognitive studies on empathy. According to simulation theory, we infer other persons’ mental states by matching their states with resonant states of one’s own mental state [64]. Neuro-cognitive studies show that the brain’s mirror neurons fire when a particular action is carried out or observed [65]. They form the basis for empathy [66-69], as they are involved in experiencing and observing emotions in others [70] and allow people to adopt another person’s perspective [71]. Indeed, some oncological scripted studies included survivors alongside healthy participants. Their perceptions overlapped, indicating that healthy people can put themselves in the shoes of (cancer) patients [72].

However, the methodological and theoretical rationales and advantages of using APs as proxies for CPs are relevant only when APs' perceptions of communication are applicable in clinical practice, which is mainly supported by our results. APs' perceptions of communication overlap mostly with those of CPs. A few – seemingly – contradictory findings were found. APs disliked information-exchange during bad news conversations, while CPs mostly valued this behavior. However, CPs often report receiving too much information during these conversations [73-78]. Besides, while most studies point to the positive effects of patient-centeredness, a study with APs (43) and review on CPs (68) found that for purely physical complaints, a patient-centered style may be suboptimal.

Despite these promising results, various aspects should be taken into account when interpreting APs' perceptions for clinical practice. First, in one study APs' perceptions were unrelated to CPs' satisfaction scores. The considerable age difference (students versus seniors) may be responsible for this finding, as age influences communication preferences [79-81]. Future studies should take background characteristics influencing preferences – e.g. gender [81,82], education [83,84] – into account. Consequently, students should not be included as APs merely for convenience. Second, the diversity in APs' evaluations should be kept in mind. The long-term doctor-patient relationship possibly influencing CPs' evaluations cannot be captured by studies using APs. Thus, as video-vignette studies make it possible to disentangle the effect of various communication elements, these elements should afterwards be tested in clinical care.

Limitations

This review has its limitations. First, the literature is inconsistent in the terms used for "analogue patients". To include all relevant articles, both forward and backward reference searches on possible relevant articles were performed and included studies' references were hand-searched. Future studies should use the term "analogue patients" consistently. Second, we excluded trained observers, but included lay people trained for this specific study. As studies may have used inconsistent labels, we screened for detailed information on observers. Despite these precautions taken, inadequately indexed and little cited relevant studies may have been missed, as we used a top-down search strategy.

Conclusion and future studies

Scripted video-vignette studies increased their methodological soundness by providing specific rationales for conducting video-vignette studies with APs and increasing (internal and external) validity. In keeping with simulation theory and neuro-cognitive studies, APs' perceptions of communication overlapped largely with CPs' perceptions – while overcoming ceiling effects. However, it may be necessary to match participants on variables such as age and gender. Moreover, the effect of a long-term doctor-patient relationship on evaluations cannot be studied with APs. This leads to the conclusion – taking these precautions into account – that APs can provide knowledge on the patient perspective on communication.

Future – scripted – studies may benefit from the described elements to increase their methodological strength and provide more information about the process of ensuring validity. From this review we cannot conclude which communication elements – and outcome measures – can best be studied with APs. Ambady and Rosenthal [63] suggested that communication with an affective component is fastest recognized because its evolutionary importance [85,86]. Future studies could investigate differences between various types of APs. Research could build further on aforementioned work [62], comparing CPs' perceptions with those from APs watching these consultations, taking into account differences in rating dispersion and focussing on background characteristics. This will raise the level of future studies in this promising research field, aimed at systematically unraveling the patient perspective on communication.

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Appendix 3.1 Search strategies used. Date of search: 17-2-2012 (published as online appendix)

Pubmed:
(("Patient Simulation"[Mesh] OR analogue patient* OR actor patient* OR simulated patient* OR placebo patient* OR standardized patient* OR lay person* OR healthy patient* OR healthy person* OR healthy subject* OR healthy participant* OR naïve patient* OR lay subject* OR lay people* OR naïve participant* OR naïve subject*) AND ("Video Recording"[Mesh] OR videotaped encounter OR video OR film OR audiovisual OR webcam)) OR analogue-patient*

Embase (Excluding Medline. Exclude 'map to preferred terminology):
'analogue patient' OR 'analogue patients' OR 'lay people' OR 'actor patient' OR 'actor patients' OR 'simulated patient' OR 'simulated patients' OR 'placebo patient' OR 'placebo patients' OR 'standardized patient' OR 'standardized patients' OR 'lay person' OR 'lay persons' OR 'healthy patient' OR 'healthy patients' OR 'healthy person' OR 'healthy persons' OR 'healthy subject' OR 'healthy subjects' OR 'healthy participant' OR 'healthy participants' OR 'naive patient' OR 'naive patients' OR 'lay subject' OR 'lay subjects' OR 'naive participant' OR 'naive participants' OR 'naive subject' OR 'naive subjects' AND [embase]/lim AND videorecording'/exp OR 'videorecording' OR 'video' OR 'video'/exp OR video OR 'film' OR 'film'/exp OR film OR 'medical encounter' OR audiovisual OR webcam AND [embase]/lim OR 'analogue-patient'

Psychinfo (Advanced search. Exclude: 'map term to subject heading'):
(analogue patient*.mp. or lay people*.mp. or actor patient*.mp. or simulated patient*.mp. or placebo patient*.mp. or standardized patient*.mp. or lay person*.mp. or healthy patient*.mp. or healthy person*.mp. or healthy subject*.mp. or healthy participant*.mp. or naive patient*.mp. or lay subject*.mp. or naive participant*.mp. or naive subject*.mp.) AND (videotapes/ OR video display units/ OR audiovisual communications media/ OR video.mp. OR videotaped encounter OR film.mp. OR audiovisual.mp. OR webcam.mp.) OR analogue-patient

CINAHL (Excluding Medline. Include: 'also search in fulltext')
Up to Februari 2010:
(patient simulation(MH) OR analogue patient* OR actor patient* OR lay people* OR simulated patient* OR placebo patient* OR standardized patient* OR lay person* OR healthy patient* OR healthy person* OR healthy subject* OR healthy participant* OR naïve patient* OR lay subject* OR naïve participant* OR naïve subject*) AND (videorecording+(MH) OR audiovisual(MH) OR video OR film OR audiovisual OR webcam OR medical encounter) OR analogue-patient*

From Februari 2010 to February 2012: 0

(((MH "Patient Simulation") OR TX(analogue patient* OR actor patient* OR lay people* OR simulated patient* OR placebo patient* OR standardized patient* OR lay person* OR healthy patient* OR healthy person* OR healthy subject* OR healthy participant* OR naïve patient* OR lay subject* OR naïve participant* OR naïve subject*)) AND ((MH "Videorecording+") OR (MH "Audiovisuals+") OR TX(video OR film OR audiovisual OR web cam OR medical encounter))) OR TX(analogue-patient*)

4

How to create and administer scripted video-vignettes in an experimental study on disclosure of a palliative breast cancer diagnosis

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van Vliet LM, Hillen MA, van der Wall E, Plum N, Bensing JM. How to create and administer scripted video-vignettes in an experimental study on disclosure of a palliative breast cancer diagnosis. Patient Educ Couns 2012 [Epub ahead of print]. Doi: 10.1016/j.pec.2012.10.017. Copyright (2012) reprinted with permission from Elsevier

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Abstract

Objectives

Scripted consultations provide the opportunity to vary and study the effect of specific elements of medical communication. These scripted consultations are role-played, videotaped and then judged by analogue patients. Most studies applying this methodology have provided little insight into how they created internally and externally valid written and role-played scripts. In this paper we aim to address this gap by providing a detailed description of a scripted video-vignette study's methodology.

Methods

Following the five phases of creating and implementing scripted video-vignettes the current study's methodology is described: 1) deciding if video-vignettes are appropriate, 2) developing a valid script, 3) designing valid manipulations, 4) converting the scripted consultations to video, 5) administering the videos in an experiment.

Results

Following these phases and four validation steps internally and externally valid vignettes were developed.

Conclusions

The detailed description of the current study's methodology produced general recommendations for scripted video-vignette studies, such as the importance of validating both the written as well as the role-played scripts and involving both experts and lay people in validating the scripts. For other choices no golden standard exists.

Practice implications

The presented methodology and recommendations may serve as a source of inspiration for future scripted video-vignette studies.

Introduction

While observational studies on communication provide valuable insight into the practitioner-patient relationship, causal relations between communication and outcomes cannot be determined [1]. Therefore, in the era of evidence-based medicine, communication is increasingly being studied experimentally. Scripted video-vignettes are an example hereof; researchers create multiple role-played scripts of a consultation in which elements of communication (e.g. empathic remarks [2]) are systematically varied. Analogue patients (APs; healthy persons or patients) view these videos and judge the communication from the patient perspective. This methodology allows researchers to assess the impact of isolated variations in communication.

In order to draw causal relations, methodological validity of scripted video-vignettes has to be ensured. First, internal validity has to be warranted by creating scripts and manipulations that reflect the communication under study. Second, external validity is established when APs perceive the scripts as realistic and can identify with the video-patient. In a recent systematic review we concluded that previous scripted video-vignette studies often failed to ensure both types of validity [3]. For example, many studies do not provide detailed information on the creation and validation of their manipulations [2,4-10]. We suggested that researchers provide more insight into these elements, thereby increasing the quality of studies.

In this paper we aim to address this gap by providing a detailed description of the methodology of a specific scripted video-vignette study. We focus mainly on the procedures of creating internally and externally valid scripts as well as the experiment conducted with these role-played scripts.

Methods

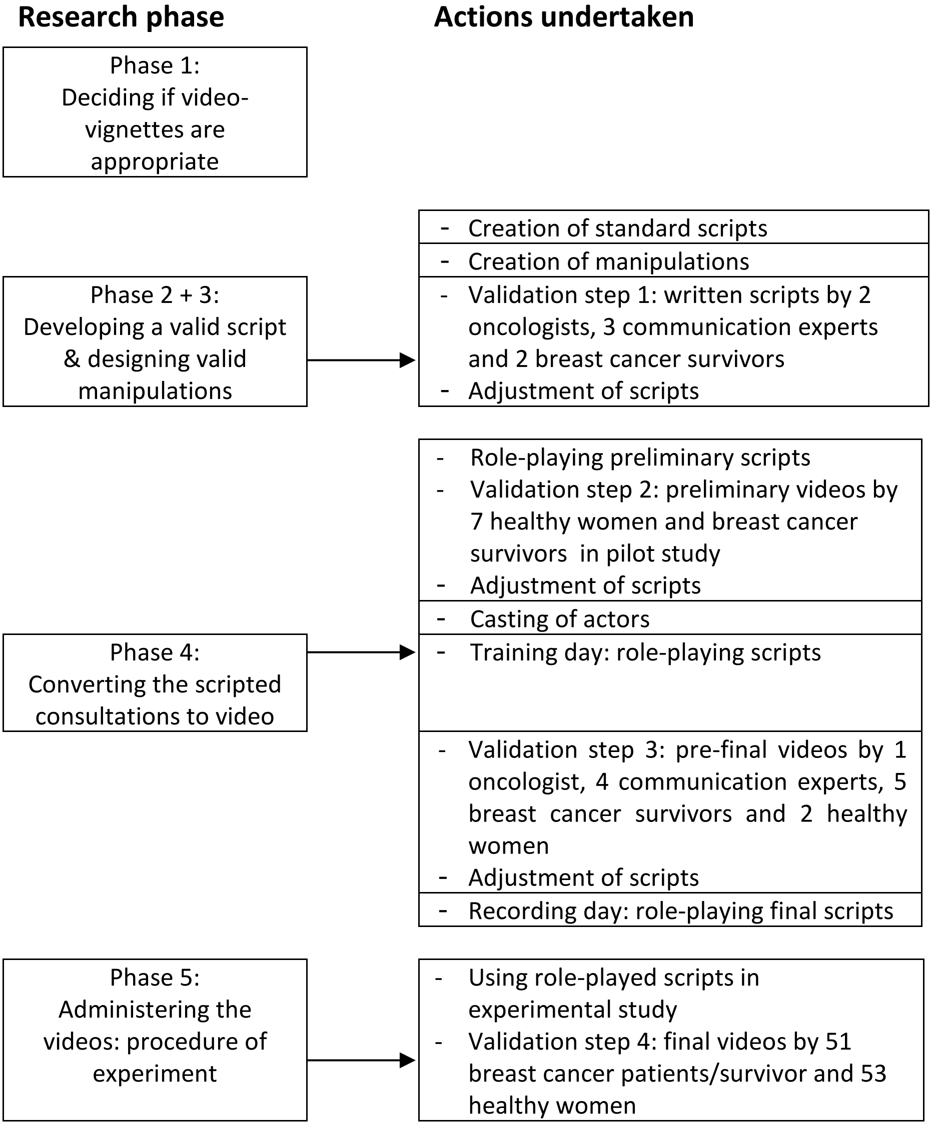
When creating and implementing scripted video-vignettes researchers encounter five phases [11]; 1) deciding if video-vignettes are appropriate, 2) developing a valid script, 3) designing valid manipulations, 4) converting the scripted consultations to video, 5) administering the videos. The current study’s methodology will be described following these phases (see Figure 4.1 for a visual representation). The validity of the written and role-played scripts was tested in four steps by having them rated and commented upon by experts and lay-people: oncologists, communication experts and breast cancer survivors and healthy women (step 1-3). In the final fourth step role-played videos were validated in an experiment with breast cancer patients/survivors and healthy women.

Phase 1: deciding if video-vignettes are appropriate

The current study focused on the transition from curative to palliative breast cancer care. When communicating such information, oncologists encounter several dilemmas. First, patients often want as much information as possible [12-16], while it is also common to hear patients express a wish not to receive too much – prognostic – information [17-22]. Second, many patients stress the importance of receiving realistic information [23-26], while simultaneously asking for hope [23,27-29]. Oncologists have to balance between these seemingly contradictory needs. In a previous qualitative study we found that women who imagined themselves in the situation of hearing life-limiting information varied in their preference for explicit prognostic information, while they believed hope could be provided by reassuring patients that they will not be abandoned by the hospital [30]. Moreover, oncologists often seemed to struggle with providing prognostic information in patients’ preferred manner and did not always offer reassurance about non-abandonment (unpublished study). Therefore, in the current experimental study we aimed to provide more insight into the effect of: i) more versus less explicit prognostic information, and ii) more versus less reassurance about non-abandonment at the transition from curative to palliative breast cancer care.

For this study, using scripted video-vignettes in an experimental design was appropriate for the following reasons. First, it allowed us to standardize communication across consultations, which is

Figure 4.1 Visual representation of the procedure of creating and administrating valid scripted video-vignettes



impossible in clinical care [31] as patients might for example ask for more prognostic information. By standardizing communication, causal conclusions about the manipulated communication could be drawn. Second, it allowed the randomizing of potentially negative communication (e.g. more prognostic information than preferred), which would be unethical to vary in clinical care [32]. This allowed studying the effect of potentially negative communication. Last, by showing one video to multiple APs, the influence of background characteristics (e.g. coping style) on the perception of communication could be assessed. Moreover, as multiple participants rated the same video-vignette, the reliability of outcomes was increased [33,34].

Phases 2 & 3: developing a valid script and designing valid manipulations

A standard script was written of part of a consultation in which the transition from curative to palliative breast cancer care was being discussed. Various sources were used to create the standard script. First, quotes from the aforementioned qualitative study [30] were used. Next, two authors – a practicing medical oncologist (EvdW) and experienced communication researcher (JB) – provided the biomedical/social content and structure. Additionally, videotapes of clinical bad news conversations and prior scripted video-vignette studies [35-37] were viewed for input. The standard script contained a ‘diagnosis’, ‘prognosis’ and ‘treatment’ sequence instead of a whole consultation as we were interested in specific communication instead of a general impression of the consultation. This standard script remained identical, while the manipulated communication varied between the different versions of the script. Last, an introduction sequence was written displaying the video-patient introducing herself and her feelings towards the upcoming consultation, aimed to increase APs’ empathic involvement [38,39].

Next, the manipulations were crafted. During the ‘prognosis’ sequence, the oncologist’s level of prognostic information was varied (high versus low) and during the ‘treatment’ sequence, the reassurance about non-abandonment was varied (high versus low). By combining all variations within the standard script, four different scripts were created (see Table 4.1). Manipulations were based on oncologists’ and lay peoples’ remarks in the qualitative study. The lowly explicit manipulation included qualitative information while the highly explicit manipulation involved statistical information. The lowly reassurance manipulation was the standard script while the highly reassurance manipulation consisted of three added fragments (one or two sentences each) of reassurance about non-abandonment. See Appendix 4.1 for the final scripts including manipulations.

Table 4.1 Conditions of the systematically varied videos

Video 1	Explicit high	Reassurance high
Video 2	Explicit high	Reassurance low
Video 3	Explicit low	Reassurance high
Video 4	Explicit low	Reassurance low

We varied only the verbal content between scripts, to ensure that all effects could be attributed to verbal elements. During the prognosis manipulation non-verbal communication was standardized and during the reassuring comments, non-verbal communication was held equal with the remaining script. A length-difference between the lowly and highly reassuring condition emerged due to the added reassuring fragments. We did not compensate for duration differences, as i) clinical consultations with various levels of empathy also differ in length [40] and, ii) entering 'filler' communication might unintentionally influence perceptions.

Validation step 1: The written scripts were commented upon by both experts and lay people; two oncologists, three communication experts and two survivors. Participants rated each script's realism (external validity) using the response categories 'not at all realistic', 'partially realistic' and 'very realistic'. To determine internal validity, the success of the manipulations – how explicit the prognostic information was perceived and how reassuring (concerning non-abandonment) the oncologist came across – was measured for each script using 1-10 scales ('not at all' to 'very'). Participants were asked to provide additional comments. Results and comments were used to adjust the scripts.

Phase 4: converting the scripted consultations to video
Validation step 2: The adjusted scripts were role-played by a physician and breast cancer survivor (NP) for pilot-testing by seven lay people; both healthy women and survivors. The manipulation success and realism of the videos was determined using the aforementioned measures. Next, the extent to which participants could empathize with the video-patient (external validity) was measured for each video using the response categories ‘not at all’, ‘partially’, and ‘very’. Again, scripts were adjusted following the results.

Meanwhile, professional actors were casted to role-play the oncologist, patient and husband. We chose not to use a clinical oncologist, as it was crucial that the videos would vary only on specific communication. Videotaped castings were shown to oncologists, communication researchers, cancer patients/survivors and healthy women who stated which actors came across most realistically (i.e. as if they were a real oncologist and patient). This was done during presentations (for patients/survivors and oncologists) and individual contacts (for all sorts of participants). For each part the large majority chose the same actor. So, a 50-year old white male played the oncologist, as many oncologists are middle age men. A 45-year old white female played the patient, enabling women of all ages to identify with her. The husband was role-played by a white male of 50 years.

The chosen actors role-played the scripts under supervision of a movie-director. This was first done during a training day. Alternating camera-perspectives were used; during emotional moments close-ups of the patient/husband may increase viewers’ emotional arousal [41,42]. Contrary, during the manipulations APs’ own feelings towards the communication have to be elicited, so the camera was then focused on the oncologist [43].

Validation step 3: Edited pre-final videos were sent by secured email to experts and lay people; one oncologist, four communication experts, five breast cancer survivors and two healthy women participated. Participants judged again the videos’ realism and manipulation successes (external versus internal validity) and provided additional comments. Results were used to adjust the scripts a final time.

During a recording day the final scripts were role-played and videotaped. The explicit prognosis manipulations were comparable in length (low 55; high 60 seconds). The reassuring fragments covered 31 seconds. To put these lengths into perspective, the introduction sequence took 1.53 minutes, the diagnosis sequence had a length of 2.13 minutes, and the standard treatment sequence was 2.25 minutes long. Videos are available from the authors upon request.

Phase 5: administering the videos

Next, the videos were used in an experiment, which was approved by the Medical Ethics Committee of the University Medical Center of Utrecht. Both breast cancer patients/survivors and healthy women were recruited for this outcome study. Participants were 51 breast cancer patients/survivors and 53 healthy women (Table 4.2). They viewed and judged all four videos (Table 4.1). We chose to show participants all videos, which allowed them to compare the different styles while showing only one video would have required a much larger sample size. In the aforementioned pilot study (validation step 2) participants indicated that they were able to concentrate on four videos of 3½-4 minutes in succession, though communication was varied only slightly.

Validation step 4: Manipulation success was determined in the experiment as well, by asking participants how explicit they perceived the prognostic information and how reassuring (concerning non-abandonment) the oncologist came across after each video (using 1-10 scales ‘not at all’ to ‘very’). We analyzed whether the manipulations were perceived as equally successful by the patients/survivors versus healthy women.

Results

Validation step 1: the written scripts. A majority of the participants perceived all scripts as ‘very realistic’. The manipulation of explicitness was successful (low M=3.42, SD=1.96; high M=8.17, SD=.75, possible range 1-10) and the 3 added reassuring fragments were perceived as such (M=6.8, SD=1.92; M=7.0, SD=.82; M=8.5, SD=.58, possible range 1-10). Various comments were provided regarding the script. These concerned, for example, reassurance: ‘*When the doctor says ‘as you understand’ (after a reassuring fragment, red), I would take that as an instruction to keep silent about my fears and doubts, which would make me more anxious’* (quote) and the introduction: *‘To ‘undergo’ a scan is very passive, I think that more often the doctor would use words like ’the scan was made’* (quote). Based on these quantitative and qualitative results the scripts were adjusted.

Table 4.2 Demographic characteristics of participants in the experimental study

	Breast cancer patients/survivors (n=51)		**Healthy women (n=53)**	
	M	(SD)	M	(SD)
Age	52.03	(8.50)	41.35	(14.49)
	N	(%)	N	(%)
Marital status				
Married	28	(55)	25	(47)
Single (includes divorced, widowed)	23	(45)	28	(53)
Highest Education				
Low (< secondary school)	1	(2)	3	(6)
Medium (secondary school + vocational education)	17	(33)	17	(32)
High (higher vocational education or university)	33	(65)	33	(62)

- Table 4.2 continued -

Occupation				
Paid job	32	(63)	32	(60)
Non-paid job (including unemployed, housewife, student)	19	(37)	21	(40)
Ethnicity				
Dutch (including Western immigrants)	45	(88)	42	(83)
Immigrant	6	(12)	11	(17)

Validation step 2: the preliminary role-played videos. In the pilot study almost all participants found the preliminary role-played videos very realistic. Moreover, all could empathize with the video-patient very well. The videos differed in prognostic explicitness (low M=6.43, SD=2.34; high M=8.08, SD=1.55) and reassurance about non-abandonment (low M=4.86, SD=2.44; high M=8.08, SD=1.19). As the distinction in explicitness was less sharp, these manipulations were intensified (e.g. in the lowly explicit condition the remark that the tumour is quite aggressive was deleted).

Validation step 3: the pre-final videos (role-played by the actors). Videos were seen equally as realistic and partially realistic. Videos differed in level of prognostic explicitness (low M=3.83, SD=1.87; high M=7.70, SD=1.55) and reassurance about non-abandonment (low M=3.92, SD=2.02; high M=7.48, SD=1.17). Additional comments were used to shape the final scripts. These concerned, for example, the introduction: *'I got the impression that the physician does not know the patient. However, he does not introduce himself'* (quote), the non-verbal communication: *'I would have expected that a real couple (…) exchanges some glances to share their common loss'* (quote) and the diagnosis *'I think the physician is unclear. Why doesn't he say that you cannot be cured anymore when you have metastases?!'* (quote).

Validation step 4: the success of the manipulations determined in the experiment. Again, in the highly explicit videos the prognosis was perceived as being more explicit than in the lowly explicit videos (low: M=3.68, SD=2.39; high: M=5.96, SD=2.06) while the videos also differed in level of perceived reassurance about non-abandonment (low: M=4.24, SD=2.27; high: M=7.23, SD=1.98). See Table 4.3 for an overview of the manipulation success in all four validation steps. Moreover, in the experiment, the manipulated communication was equally successfully perceived by the breast cancer patients/survivors versus healthy women (for all manipulations p>.21, see Table 4.4).

Table 4.3 Validation of the written and role-played scripts: success of the manipulations

		Explicitness				**Reassurance**			
		Low		**High**		**Low**		**High**	
Step	**N**	M	(SD)	M	(SD)	M	(SD)	M	(SD)
Step 1: Written scripts	**7**	3.42	(1.96)	8.17	(.75)	-			
Fragment 1								6.8	(1.92)
Fragment 2								7.0	(.82)
Fragment 3								8.5	(.58)
Step 2: Preliminary videos	**7**	6.43	(2.34)	8.08	(1.55)	4.86	(2.44)	8.08	(1.19)
Step 3: Pre-final videos	**12**	3.83	(1.87)	7.70	(1.55)	3.92	(2.02)	7.48	(1.17)
Step 4: Videos experiment	**104**	3.68	(2.39)	5.96	(2.06)	4.24	(2.27)	7.23	(1.98)

How explicit/reassuring a video was perceived was indicated on a 1-10 scale ('not at all' to 'very').

Table 4.4 Success of manipulations in the experiment in relation to whether or not participants had (had) breast cancer

	Breast cancer patients/survivors		Healthy women			
	M	**(SD)**	**M**	**(SD)**	**t**	**p**
	n=45		n=50			
Low explicit	3.86	(2.38)	3.6	(2.17)	.55	.58
High explicit	5.82	(2.04)	6.11	(1.74)	-.74	.46
	n=45		n=49			
Low reassurance	4.09	(1.99)	4.41	(1.90)	-.80	.43
High reassurance	6.97	(2.08)	7.46	(1.66)	-1.27	.21

How explicit/reassuring a video was perceived was indicated on a 1-10 scale (‘not at all’ to ‘very’). All t-tests were performed with two-sided significance testing.

Discussion and conclusion

Discussion

In this article, a detailed description of the methodology of a scripted video-vignette study was provided. Based on our results and the choices we made some general recommendations for scripted video-vignettes studies can be generated. However, we also encountered dilemmas for which no golden standard emerged.

General recommendations for scripted video-vignette studies

Validate both written and role-played scripts

Based on our results, we would recommend future studies to validate both written and role-played scripts. To ensure internal validity it is crucial that manipulations succeeded. As we found that the perception of communication depended on the medium through which it was offered (i.e., text versus video), it seems important to (internally) validate the written as well as the role-played scripts. Only some previous studies made explicitly clear they did so [6,31,32,36,37]. Additionally, after validating the written scripts most often changes to the scripts are made. To determine whether these changes are successful, it is important to validate the role-played scripts again. Last, by pilot-testing role-played videos, elements potentially hampering external validity can be detected. For example, our actor-patient had long hair which she wore down in the pre-final videos. Breast cancer survivors correctly remarked that this hair-length is impossible after chemotherapy two years earlier. So, in the final videos her hair was put up.

Involve both experts and lay people in validating the scripts
In the current study, the written and role-played scripts and manipulations were commented on by experts and lay people. Both parties are involved in medical consultations while their perspective on communication can differ [44-46], highlighting the importance of including both experts and lay people in the validation process [3]. So far, few studies have explicitly asked physicians to comment on the manipulations [5,6,32,36,47-49]. Additionally, lay people and physicians both have an unique insight into whether the – role-played – scripts are realistic. For example, while selecting the actor-patient, EvdW remarked that the actress whose reaction towards the bad news was subtle was most realistic.

Keep all but the manipulated communication constant while displaying the exact manipulations
Another important element for ensuring internal validity is the use of a standard script, in which manipulations are varied [3]. Only by creating scripts in which all but the manipulated communication is held constant, causal conclusions about found effects can be drawn. By providing the content of the manipulations it becomes clear which wordings/behaviors influenced outcomes. This holds especially when manipulating specific communication instead of container-concepts consisting of multiple behaviors (e.g., ‘patient-centeredness’) [50,51]. Other studies can than replicate or build further upon specific findings, increasing the evidence-base of specific communication. Until now, only some studies provided this information [2,6,37,49].

Take actions to increase APs’ identification with the video-patient
To ensure external validity it is important that APs succeed to put themselves in the shoes of the video-patient [3]. Therefore, studies may match APs and the video-patient on background characteristics (e.g. gender and age) and take actions to increase AP’s identification with the video-patient. We tried to realize this in various ways, by: i)

including a woman of middle-age as patient, with whom all APs could identify, ii) creating an introduction video to increase emotional involvement, iii) assessing and ensuring participants' identification in the preliminary videos, iv) informing participants about the study aim in the experiment. These methods are more rigorous than previous studies' approaches, who only sometimes assessed identification with the video-patient [32,35,49]. Other methods might also be beneficial, such as matching actors and APs on race or used dialect.

Encountered dilemmas

Not all the choices we made translate themselves into general recommendations. Most choices reflect dilemmas for which insight into the rationales for, and effects of, the possible decisions is lacking. Examples of such dilemmas are: the sources used to create the script (own experience, previous studies and/or theoretical input); the length of a script (whole versus part of a consultation); the nature of the manipulation (verbal, non-verbal, or both); the participants role-playing the scripts (actors versus real doctors/patients); the use of different camera perspectives (focused on the patient, physician or both); the APs included (healthy persons versus patients/survivors); and the number of video-vignettes APs view (one versus multiple). In the current article we underpinned the choices we made in these and related dilemmas. However, other studies may follow other rationales and make other decisions. In an aligned paper, we will discuss the methodological considerations of various encountered dilemmas when creating and implementing scripted video-vignettes more in detail [11].

Moreover, the heterogeneity of studies will make it difficult to achieve 'golden standards' for all methodological considerations. Three examples of heterogeneity in studies influencing methodology are the following. First, some studies may create audio or written vignettes instead of videotaped ones. Although for such studies many of the provided advices still apply, differences also emerge. For example, it may be more difficult to immerse oneself in such vignettes [52] so more attention may be paid to external validity. Second, studies may choose to manipulate other elements than communication, such as characteristics of the environment. For such manipulations the used camera perspective and length of the vignettes may have different influences than when manipulating communication. Last, studies will differ on financial budget available. For example, casting and hiring professional actors may be too expensive for some studies which will settle instead for members of their research team (who may or may not be doctors) to role-play the scripts.

Limitations

Scripted video-vignette studies, and our study in particular, have limitations. First, scripted studies remain proxies for clinical interactions and results must be generalized to clinical patients with caution. Experimental studies should preferably go hand in hand with clinical studies to define the effect of communication in both situations. Second, our study sample might not be representative; less involved women may be underrepresented as women voluntary participated in the validation studies and experiment.

Future studies

In the evolving field of scripted video-vignette studies this article may serve as a starting point for further discussion and scholarship in developing and applying evidence-based vignettes. We encourage researchers to describe their methodological procedure. More specifically, we suggest them to report – and reflect on – the following elements: i) the rationales for conducting a scripted video-vignette study ii) the exact manipulations (and standard script), iii) whether they used an introduction video or other introduction material, iv) when and how the scripts were validated, v) whether actors or real doctors/patients role-played the scripts, vi) the different camera-perspectives used, vii) attempts to increase AP's level of identification, viii) the procedure of the experiment, e.g. how many videos were viewed. Providing this information will increase insight into specific strengths and hurdles of scripted video-vignette studies and provide more insight into a study's quality. Future studies can focus on various encountered dilemmas. For example, more research is needed on the effect of using different camera-perspectives. By following these suggestions, better experimental scripted video-vignette studies can be created which provide more evidence-base for how communication may influence patient outcomes.

Conclusion

Using scripted video-vignette studies to investigate the effect of specific elements of communication provides more insight into these elements' effects, on the premise of using valid scripts and manipulations. Future studies might benefit from general recommendations generated from this study. However, for other choices no golden standard exists.

Practice implications

Creating and administering internally and externally valid scripted video-vignettes is a daunting task. The current article may provide researchers with handles how to do so, such as by involving both experts and lay people in validating the written and role-played scripts and keeping all but the manipulated communication constant. These recommendations and the detailed description of the current study's methodology may serve as a source of inspiration for future scripted video-vignette studies.

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Appendix 4.1 - Final scripts including manipulations

Abbreviation	**Camera perspective**
CAM1	Overview shot of patient/husband and oncologist
CAM3	Shot oncologist
CAM2	Shot patient/husband
T (Total)	Total shot
M (medium)	Middle close up
C (close up)	Face close up
P	Patient
H	Husband
O	Oncologist

Introduction sequence

Verbal	Non-verbal
P: My name is Loes Bakker, I'm 45 years old. I'm married and have two adorable children; a 17 year old girl and a 15 year old boy. Two years ago I was diagnosed with breast cancer. I've had breast-conserving surgery during which the tumor was removed. To be on the safe side, I first received radiation therapy and afterwards chemotherapy to tackle cells which may still be there but which cannot be seen. After a while, my life seemed to get back on track again. However, one month ago I felt a lump in the same breast. Of course, I was in shock and immediately called the hospital. I got an appointment with the surgeon right away. He did a physical exam and felt my lymph nodes. He didn't have a good feeling about it all, so last week I already had a bone scan and CT scan done of my liver and lungs to see if the cancer has come back. I can't believe it.. But I have an appointment with the doctor right now to get the test results. I haven't slept all week, I'm so uptight and I'm afraid the cancer is back.	P+H are sitting in a waiting room on a reading table. On the table some papers are placed. P talks. She looks anxious and nervous. From time to time, she stares and looks restlessly around her. She fiddles with a hands/fingers. Voice falters somewhat.

Diagnosis sequence

Verbal	**Non-verbal**
O: Mr and Ms Bakker, my name is doctor van Ardenne. Welcome. Please, have a seat.	CAM1/T O opens the door, shakes P+H's hands.
Some shuffling, then everybody sits down.	P+H are sitting down, next to each other. They sit opposite O, who has also taken a seat. P leans on the table, H leans more back with this arms folded.
O: So, you went to see the surgeon, Doctor Blom, after you felt a lump in your breast. Doctor Blom did a physical examination and suspected that the cancer might have recurred. Therefore a puncture of a lymph node near the collarbone was done and both a bone scan and CT scan of your liver and lungs were made.	CAM3/M O talks calmly and looks at P+H. He folds and unfolds his hands, somewhat restlessly.
P: Yes, that's correct. That all happened last week. And now I'm already sitting here.	Cam2/M P makes eye-contact and looks away.
O: Yes, it all happens very quickly, doesn't it? I have the test results of the examinations, and we have viewed the scans with all the doctors involved, and unfortunately I do not have good news for you. We have found metastases in both the liver and bones.	Cam3/M O nods. Puts the patient charts in front of him, puts on his glasses and puts them off. Cam2/C
P: Oh no.	P looks straight ahead. 1 second of silence P stares blankly ahead.
O: This is not what we hoped for. It is a very bad diagnosis, and I don't want to beat around the bush.	O calmy continues.
H: No way..	P swallows a tear, shakes her head and looks desperately to H.
P: This is what I was afraid of. How awful! Especially for the kids! This does mean that you can't remove it, right? Or	Question is posed in a soft

can you?	voice, head down, but with eye-contact.
O: With metastases, these kinds of metastases, it is indeed no longer possible to remove the cancer completely and cure you.	CAM3/M O is leaning forwards slightly.
I am very sorry for you. But I do not want to portray things better than they are.	O looks at P and H in a serious and calm manner.
P: No, of course not! But you always hope that it's not too bad.	Cam2/C P shrugs, braces herself somewhat.
And I still feel fine…	
O: Yes, that makes it more difficult to grasp, doesn't it?	P looks forward.
P: Yes. But how bad is it?	She does pose the question firmly and with eye-contact.
O: What do you mean exactly?	CAM3/M O hesitates for a moment. Folds his hands and leans forwards

Prognosis sequence – low explicitness

Verbal	**Non-verbal**
P: Well, how long have I got?	CAM 2/M P and H hold hands.
O: Your life-expectancy?	CAM3/C O sounds a bit uncomfortable/asks for confirmation.
P: Yes, as a rough idea. Do you know that in general terms?	CAM2/M P looks at O in a firm yet slightly anxious way.
O: That's very difficult to predict, because it can differ from person to person. You do have a very serious disease, which will limit your life expectancy. That is the only thing we can say for sure. *There are women who live for quite a long time with the type of breast cancer you have, and there are women who live less long. The comments you often see on television or read in magazines, about 'you*	Cam3/C sighs and starts to talk in a serious way.

only have so long to live', aren't realistic, because we do not know that in any individual case… So, no, I don't know how it will be for you.	
P: Yes, I understand that. That's something you can't predict.	
Oncologist: No	O Nods his head. Leans backwards.

Prognosis sequence – high explicitness

Verbal	**Non-verbal**
P: Okay, so how long have I got?	CAM 2/M P and H hold hands.
O: Your life-expectancy?	CAM3/C O sounds a bit uncomfortable/asks for confirmation.
P: Yes, I would like to know that as specifically as possible.	CAM2/M P looks at O in a firm yet slightly anxious way.
O: That's very difficult. But I can give you some concrete numbers and averages. Would you like me to discuss these with you?	Cam3/C sighs and starts to talk in a serious way.
P: Yes.	
O: When we look at what is known from studies with patients with your type of cancer cell and your metastases, 50% of the patients are still alive after 2 years. So, half the people will die within 2 years, while the other half will live longer than 2 years. Some people might only live for half a year. But others will live much longer, maybe as much as 4 years.	
P: Yes, I understand that. So, you can't predict which group I belong to?	
O: No	O Nods his head. Leans backwards.

Treatment sequence – including reassuring fragments inserted in italics

Verbal	Non-verbal
P: And what now? O: The life expectancy strongly depends on whether the treatments are successful. And that is of course the next question, where do we go from here? You have already had various treatments: radiation, chemo. And now we're again in the situation that we have to do something. And there are still options, which could mean that we can suppress the cancer.	Cam2/M CAM3/C O looks a bit more confident. He shows more eye-contact. Leans slightly forward.
Fragment 1 reassurance:	
O: 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. *P: Yes, good.*	*CAM3/M O continues to look at P* *P pronounces this a bit neutral, not too enthusiastic.*
P: But what can you do? O: Because the cancer has spread to your bones, and also your liver, an operation is not an option. Because your cancer is not hormone sensitive, we also can't give you hormone therapy. That leaves only chemotherapy, if you want that. In principle we will do 3 courses, every 3 weeks. And then we'll look at: a) how you feel and how burdensome the treatment is, and b) how it goes physically, is it working, which we can see with a scan.	CAM1/T Cam3/M O leans backwards. O tries to talk calmly. CAM2/C looks devastated, anxious. CAM1/T
Fragment 2 reassurance:	
O: We will do and will continue to do our very best for you. *P: Thank you*	*CAM3/C O looks at P attentively.* *A bit neutral*
P: So, chemo again? O: Yes. That is something we do not need to decide immediately though. With chemo we might be able to suppress the growth of the tumour, but I cannot assure you that it will help. We only know that after a couple of rounds. But chemo does cause side-effects.	CAM3/C O continues to look attentively.

Of course, you know that from the last time. P: Yes.. We (looks at H) have to discuss this; together but also with the children. But I don't think I have a choice. I have to fight for the children, to make sure they have their mother for as long as possible. That means everything to me. O: I understand. Therefore, I think that it would be a good idea to discuss in detail all the possibilities during our next appointment, if that is okay with you.	CAM2/C P has tears in her eyes. Has her hand in front of her face. P+H make eye-contact. P has a lump in her throat. CAM3/C O looks at P+H. He tries to temper the emotions by continuing the conversation in a matter of fact manner.
Fragment 3 reassurance:	
O: And whatever happens, we will never abandon you. You are not facing this on your own. *P: Thank you.*	*CAM3/C* *P says this, a bit restrained.*
P: But the treatments.. The chemo. Will that be the same chemo as the last time? O: It will be a different chemo than the last time. But you will receive the chemo at the outpatient clinic.	CAM2/M P+H are again quite calm and rational. They do look a bit rigid ahead. CAM3/C
O: Wait, I do have some leaflets that you can take home later on. Oncologist stands up, walks away. Conversation fades away.	CAM1/T

Part 3: The experimental study

5

Explicit prognostic information and reassurance about non-abandonment when entering palliative breast cancer care:

Findings from a scripted video-vignette study

van Vliet LM, van der Wall E, Plum N, Bensing JM. Explicit prognostic information and reassurance about non-abandonment when entering palliative breast cancer care: Findings from a scripted video-vignette study. *Resubmitted*

Abstract

Purpose

When discussing the transition to palliative care for breast cancer patients, oncologists have to find a balance between giving explicit information while not overwhelming patients, and being realistic while remaining hopeful. It is unclear whether patients prefer more or less explicit prognostic information and one realistic way to provide hope may be to reassure patients that they will not be abandoned. We assessed the effect of explicit prognostic information and reassurance about non-abandonment at the transition to palliative care.

Methods

An experimental 2x2 study was employed. Four scripted videos of a bad news conversation were created differing only in the level of 'explicitness of prognosis' and 'reassurance about non-abandonment' (high versus low). Breast cancer patients/survivors (n=51) and healthy women (n=53) watched the video-vignettes. The effects of the different communications on participants' anxiety, uncertainty, self-efficacy and satisfaction were assessed using multilevel analyses, exploring the moderating influences of monitoring/blunting scores.

Results

The highly explicit/highly reassuring video yielded the most positive outcomes; the less explicit/less reassuring video the most negative ($p \leq .05$ for all outcome measures except anxiety). The main effects found were: explicitness and reassurance decreased participants' uncertainty ($p<.001$; $p=.002$) and anxiety (only after reassurance $p=.001$), while increasing self-efficacy ($p=.004$; $p<.001$) and satisfaction ($p<.001$; $p<.001$). High monitors seemed least positive, mainly following explicitness.

Discussion

Explicit prognostic information may lead to better outcomes than general information. Additionally, reassurance about non-abandonment might provide realistic hope, but has to be lived up to. More research is needed to translate these findings into clinical care.

Introduction

The transition from curative to palliative care evokes two distinct needs in cancer patients: to ‘know and understand’ and to ‘feel known and understood’ [1,2]. Oncologists can address these distinct needs by providing information and being empathic – i.e. providing instrumental versus affective care – [1,3], which influences distinct outcomes such as uncertainty and anxiety [4]. Meanwhile, they have to tread the fine lines between giving complete information while not overwhelming patients [5] and being realistic while remaining hopeful [6-8]. However, they lack clear evidence in favor of a specific approach [6].

Most patients want information about their life expectancy [9,10], but the level of explicitness desired varies [11]. Patients often request full disclosure [12,13], which they sometimes regret [14]. Meanwhile, some patients prefer to remain partly ignorant about their life expectancy [12,15,16]. Until now, it has not been clear whether numerical data or qualitative words are preferred when discussing future expectations [12,17]. Unsurprisingly, the prognostic part of consultations is often problematic [17-19]. As not all patients ‘want to know everything’ [6,20], oncologists sometimes avoid providing statistical information, regardless of patients’ preferences [21-23].

In addition to the need for trustworthy instrumental communication, patients have a need for hope [24-27], which can be seen as an affective need. In the literature various definitions are used for hope, such as ‘a confident yet uncertain expectation of achieving a future good’ [28]. There seem to be different ways in which oncologists can provide hope at the transition to palliative care. One largely overlooked but realistic way might be reassurance about non-abandonment [11,29,30]. When entering palliative care, patients need – and thereby experience hope – to be sure that they will be continuously guided [11,29] and that the relationship with their oncologist will continue [30]. More specifically, they want the prognosis discussion to include a commitment about not being abandoned [14]. The importance for patients of being taken care of has been noted by authors [31-33] and guidelines [34,35], but has not often been mentioned as an essential component when breaking bad news.

Patients' coping styles might influence communication preferences. When confronted with a – medical – threat, patients differ in the degree to which they seek information [36-38]. High 'monitors' are found to have high information needs [39-41] and needs for emotional support [39,40,42], while high 'blunters' prefer to avoid threatening information [36,37]. However, further investigation is warranted into whether these preferences hold at the transition to palliative care.

Altogether, the transition to palliative care evokes – among others – feelings of uncertainty and anxiety [43]. In reaction to uncertainty, oncologists can provide more or less explicit prognostic information. In reaction to anxiety, they can reassure patients that they will not be abandoned as their condition worsens. The aim of the current study is to examine the effect of explicit prognostic information and reassurance about non-abandonment at the transition to palliative care on uncertainty and anxiety (and related measures), exploring moderating influences of monitoring/blunting scores.

Methods

Videotape development

An experimental study using a 2x2 design was employed in order to investigate the two above-mentioned communication elements carefully. Four scripted video-vignettes were developed of a consultation in which an oncologist discussed the transition to palliative care with a female breast cancer patient. These video-vignettes were identical in content and communication, but the 'explicitness of prognosis' and 'reassurance about non-abandonment' varied systematically between the vignettes (high or low: see Table 5.1). The scripts and manipulations were based on a qualitative study focused on the above-mentioned dilemmas [11], the biomedical/communicative expertise of the authors and videos of bad news consultations and prior scripted studies. An introductory video was developed in which the video-patient introduced herself and expressed her feelings about the upcoming consultation aiming to increase participants' empathic involvement. To ensure the scripts' internal/external validity, both lay people (breast cancer survivors, healthy women) and experts (oncologists, communication experts) were involved in creating the written and role-played scripts. Professional actors role-played the validated scripts. Detailed information about this process and the final scripts is provided elsewhere [44] while the exact manipulations are displayed in Box 5.1. Videos are available from the authors.

Table 5.1 Communication in the four video-vignettes

Video 1	Video 2	Video 3	Video 4
Explicit + Reassurance +	Explicit + Reassurance -	Explicit - Reassurance +	Explicit - Reassurance -

Box 5.1 Exact manipulations used in the four different videos

Manipulation	Exact content
Explicit high	*Patient: Okay, so how long have I got?* *Oncologist: Your life expectancy?* *Patient: Yes, I would like to know that as specifically as possible.* *Oncologist: That's very difficult. But I can give you some concrete numbers and averages. Would you like me to discuss these with you?* *Patient: Yes.* *Oncologist: When we look at what is known from studies with patients with your type of cancer cell and your metastases, 50% of the patients are still alive after 2 years. So, half the people will die within 2 years, while the other half will live longer than 2 years. Some people might only live for half a year. But others will live much longer, maybe as much as 4 years.* *Patient: Yes, I understand that. So, you can't predict which group I belong to?* *Oncologist: No*
Explicit low	*Patient: Well, how long have I got?* *Oncologist: Your life expectancy?* *Patient: Yes, as a rough idea. Do you know that in general terms?* *Oncologist: That's very difficult to predict, because it can differ from person to person. You do have a very serious disease, which will limit your life expectancy. That is the only thing we can say for*

	sure. There are women who live for quite a long time with the type of breast cancer you have, and there are women who live less long. The comments you often see on television or read in magazines, about 'you only have so long to live', aren't realistic, because we do not know that in any individual case… So, no, I don't know how it will be for you. *Patient: Yes, I understand that. That's something you can't predict.* *Oncologist: No*
Reassuring high	*1) Oncologist: 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.* *2) Oncologist: We will do and will continue to do our very best for you.* *3) Oncologist: And whatever happens, we will never abandon you. You are not facing this on your own.*
Reassurance low	*No fragments were added.*

Participants

Breast cancer patients/survivors and healthy women (age 18-65, with sufficient command of Dutch) were recruited through patient advocacy organizations, health-related websites, message boards and snowball procedures. Ethnic minority women were recruited through a patient advocacy organization and social workers (using their network). Women participated as analogue patients (APs); they viewed the videos while putting themselves in the shoes of the video-patient. The validity of this approach is well documented [45]. Based on a previous study using a similar design [46], a sample size of 93 was required to give 80% power to detect two main effects and one interaction effect using a two-sided .05 alpha and ICC of .20. To control for order effects, we used complete counterbalancing; we therefore aimed to include (24*2*2) 96 women [47].

Procedure

The study was approved by the Medical Ethics Committee of the University Medical Center of Utrecht. Women's background characteristics were assessed prior to the experiment. Groups of one to seven persons were set up, separately for patients/survivors and healthy women. After informed consent was obtained, APs were asked to identify with the video-patient. First, they watched the introduction video and the first part of the bad news consultation. Then they watched the four different videos. Anxiety was assessed before each video and all outcome measures were completed after each video. A distraction task was provided between viewing the videos (looking at an aquarium with background classical music).

Measures

Background measures

We measured the following characteristics: demographic variables, health status (COOP-WONCA [48]), trait anxiety (Stai-trait [49]) optimism (LOT-R [50]), monitoring/blunting coping styles (TMSI shortened version [41]) and whether participants had experiences with loved-ones receiving a life-limiting cancer diagnosis ('similar experiences'). Trait anxiety [15,51], optimism [52] and 'similar experiences' [11,53] were measured as they might influence communication preferences.

Main outcome measures

Uncertainty (0-100 self-created visual analogue scale (VAS), ranging from 'very certain' to 'very uncertain') and anxiety (Stai-state [49]) were main outcome measures. Cronbach's alpha for the Stai-state before and after the video were .90 and .84 respectively. The difference score between the pre-video and post-video Stai-state score was used in all analyses. To lessen the burden of filling in numerous questionnaires in the groups with immigrant women who had difficulties with Dutch language, the Stai-state beforehand was only measured before the first video. This 'pre-score' was used to determine difference scores for each video.

Secondary outcome measures

Secondary outcome measures were self-efficacy (0-100 self-created VAS, ranging from very little to very great belief in ability to deal with the future) and satisfaction (PSQ [54]). The reliability of the PSQ was .90 in this sample. The success of the manipulations – how explicit the prognostic information was perceived as being and how reassuring the oncologist was (about non-abandonment) – was measured using 1-10 scales ('not at all' to 'very'; not measured in the aforementioned ethnic minority groups).

Analyses

Firstly, independent samples t-tests and chi-square tests were performed to compare patients/survivors' and healthy women's background characteristics. Variables that differed between the two groups were included in step four to determine their effect on outcome measures. For subsequent analyses – as participants watched four videos – random intercept linear multilevel regressions were applied, consisting of videos (level 1) nested in participants (level 2). Secondly, we analyzed whether the data for healthy women and patients/survivors could be pooled. Thirdly, the manipulation successes were determined. Fourthly, the influence of the following demographic characteristics on outcome measures was assessed, as they could have influenced communication preferences: age, trait anxiety, optimism, education, 'similar experiences' and ethnicity. The three variables with the strongest effects on outcomes were entered as (centered) covariates in the subsequent models. This number was chosen due to power constraints. Fifthly, the effect of the four videos on all outcome measures was determined. Bonferroni post hoc tests were applied to determine which videos influenced outcomes significantly differently. Sixthly, the main and interaction effects of 'explicitness' and 'reassurance' were calculated (interaction effects were eliminated from the model when not significant). Lastly, the moderating influences of monitoring and blunting scores on the effects of the four videos and the effects of explicitness and reassurance were explored. To do so, interaction effects between monitoring/blunting and the videos/explicitness/reassurance were created. For steps six and seven, we transformed all outcome measures into Fisher z (for normalization). Analyses were conducted using Stata 12.0 with two-sided significance testing at $p \leq .05$.

Results

Sample

Demographic characteristics of the 51 patients/survivors and 53 healthy women participating largely overlapped (Table 5.2). That said, patients/survivors were older ($p<.001$) and their health status was poorer ($p=.003$) compared to healthy women.

Pooling of data

Patients/survivors and healthy women did not respond differently to the four videos (data not shown). The groups were therefore pooled for the main multilevel models while health status was entered as an additional possible covariate.

Table 5.2 Demographic characteristics of participants

	Breast cancer patients/survivors (n=51)		**Healthy women (n=53)**		
	M	(SD)	M	(SD)	p
Age	52.03	(8.50)	41.35	(14.49)	**<.001 (t=4.56)**
Health status (possible range: 7-35, higher is poorer)	17.02	(5.37)	13.75	(5.38)	**.003 (t=3.10)**
Trait anxiety (possible range: 20-80)	37.02	(8.84)	38.49	(9.28)	.41 (t=-.83)
Optimism (possible range: 6-30)	22.53	(3.89)	22.74	(2.93)	.76 (t=-.31)
Monitoring (possible range: 6-30)	20.45	(4.3)	19.58	(4.40)	.31 (t=1.01)
Blunting (possible range: 6-30)	18.47	(4.11)	17.48	(4.60)	.25 (t=1.16)
	N	(%)	N	(%)	
Marital status					.43(*X*=.62)
Married	28	(55)	25	(47)	
Single (includes divorced, widowed)	23	(45)	28	(53)	

- Table 5.2.continued -

	Breast cancer patients/survivors (n=51)		Healthy women (n=53)		
Highest Education					.62 (*X*=.96)
Low (secondary school)	1	(2)	3	(6)	
Medium (secondary school + vocational education)	17	(33)	17	(32)	
High (higher vocational education or university)	33	(65)	33	(62)	
Occupation					.80 (*X*=.06)
Paid job	32	(63)	32	(60)	
No paid job (including unemployed, housewife, student)	19	(37)	21	(40)	
Ethnicity					.22 (*X*=1.54)
Dutch (including Western immigrants)	45	(88)	42	(83)	
Immigrant	6	(12)	11	(17)	
Similar experiences					.06 (*X*=3.68)
Yes	38	(75)	30	(57)	
No	13	(25)	23	(43)	

Manipulation check

The manipulations succeeded. In the highly explicit videos the prognosis was evaluated as being more explicit than in the less explicit videos (high: M=5.96, SE=.19; low: M=3.69, SE=.19, p<.001). The same results applied to the highly versus less reassuring videos (high: M=7.22, SE=.18; low: M=4.25, SE=.18, p<.001).

Covariates

The three demographic characteristics with the strongest effects on outcome measures were trait anxiety (p=.004, self-efficacy), optimism (p=.009, self-efficacy) and education (p<.001, state anxiety). These variables were entered as (centered) covariates in the subsequent models. The following characteristics (not included) also influenced outcomes: ‘similar experiences’ (p=.027, anxiety) and ethnicity (p=.026, anxiety; p=.027, self-efficacy).

Effects of the four videos

Controlled multilevel models showed that the videos had an effect on all the outcome measures (p<.02) but no order effects (data not shown). The lowest scores for uncertainty and anxiety were obtained when the oncologist was both explicit and reassuring, along with the highest scores for self-efficacy and satisfaction. On contrast to, the most negative reactions were found following the less explicit/less reassuring video-vignette. Bonferroni post hoc tests revealed that these differences were significant (p≤.05) for all outcome measures with a trend for anxiety (p=.06). Furthermore, the combination of explicitness and reassurance was better evaluated than either one alone. In the highly explicit/less reassuring condition poorer results were found for uncertainty (p=.01), self-efficacy (p<.001) and satisfaction (p<.001). After the highly reassuring/less explicit video, APs were more uncertain (p<.001) and less satisfied (p=.002) (Table 5.3).

Table 5.3. Effects of the four videos on outcomes

	Explicit + Reassurance +	**Explicit + Reassurance -**	**Explicit - Reassurance +**	**Explicit – Reassurance -**
	M (SE)	M (SE)	M (SE)	M (SE)
Uncertainty [1]	54.71(2.33) +#*	62.72(2.33) #	65.91(2.34) *	68.28(2.34) +
Anxiety [2]	-.87(.43)	.39(.44)	-.56(.44)	.40(.44)
Self-efficacy [1]	51.35(2.09) +#	40.66(2.10) ^#	47.32(2.10) =^	36.42(2.10) +=
Satisfaction [1]	61.13(1.74) +#*	48.65(1.75) ^#	55.09(1.74) =^*	44.67(1.74) +=

All analyses were controlled for (centered) effects of trait anxiety, optimism and education.

[1] *Scores range from 0-100 (ranging from low to high).*

[2] *Difference score between Stai-state before and after viewing the videos.*

Bonferroni post hoc tests (p≤..05):
+ explicit+/reassurance+ with explicit-/reassurance-
 # explicit+/reassurance+ with explicit+/reassurance-
** explicit+/reassurance+ with explicit-/reassurance+*
= explicit-/reassurance+ with explicit-/reassurance-
^ explicit+/reassurance- with explicit-/reassurance+

Main effects and interaction effects of explicitness and reassurance

To illustrate the individual and combined contributions of explicitness and reassurance, controlled multilevel analyses were used to determine the main effects and interaction effects. Only main effects were found. Explicitness decreased APs' uncertainty (p<.001) but not anxiety (p=.562) while increasing self-efficacy (p=.004) and satisfaction (p<.001). Reassurance decreased uncertainty (p=.002) and anxiety (p=.001) while increasing self-efficacy (p<.001) and satisfaction (p=<.001) (Table 5.4).

Table 5.4 Main effects of ‘explicitness’ and ‘reassurance’ on outcomes

	Explicitness			Reassurance		
	B	95% CI	p	*B*	95% CI	p
Uncertainty	-.36	-.50 – -.21	<.001	-.23	-.38 – -.08	.002
Anxiety	-.04	-.17 – .09	.562	-.22	-.35 – -.09	.001
Self-efficacy	.20	.06 – .33	.004	.47	.34 – .61	<.001
Satisfaction	.28	.16 – .40	<.001	.61	.48 – .73	<.001

All analyses were controlled for (centered) effects of trait anxiety, optimism and education. All analyses were performed using Z-scores.

Moderating influences of monitoring and blunting

Exploratory analyses showed that – compared to low monitors – high monitors were more uncertain (p=.031) and anxious (p=.037) after seeing the highly explicit/highly reassuring video and less anxious (p=.045) after the less explicit/highly reassuring video. Explicit prognostic information – independently of reassurance – made them more uncertain (p=.007) and anxious (p=.007) and less self-efficacious (p=.012) and satisfied (p=.048). Blunting scores had no moderating influences (Table 5.5).

Table 5.5 Moderating influence of monitoring and blunting scores on the four videos and main effects of ‘explicitness’ and ‘reassurance’

	Explicit + Reassurance + X		***Explicit + Reassurance – X***		***Explicit – Reassurance + X***		***Explicit – Reassurance – X***		***Explicitness X***		***Reassurance X***	
	Monitor	***Blunter***	***Monitor***	***Blunter***	***Monitor***	***Blunter***	***Monitor***	***Blunter***	***Monitor***	***Blunter***	***Monitor***	***Blunter***
Uncertainty	**.031** ***B*=.04**	.96	.21	.09	.19	.47	.99	.60	**.007** ***B*=.04**	.11	.97	.41
Anxiety	**.037** ***B*=.04**	.91	.23	.40	**.045** ***B*= -.03**	.35	.99	.42	**.007** ***B*=.04**	.54	.61	.43
Self-efficacy	.16	.62	.06	.49	.63	.42	.21	.99	**.012** ***B*=-.04**	.85	.26	.94
Satisfaction	.47	.77	.09	.88	.90	.91	.68	.76	**.048** **B=-.03**	.71	.92	>.99

All analyses were controlled for (centered) effects of trait anxiety, optimism and education. All analyses were performed using Z-scores. P-values are reported. In cases where there are significant effects, standardized betas are reported.

Discussion

Using a scripted video-vignette design, the effects of explicit prognostic information and reassurance about non-abandonment at the transition to palliative breast cancer care were assessed. Our results showed that (a combination of) explicit prognostic information and reassurance about non-abandonment was most positively evaluated by breast cancer patients/survivors and healthy women.

Explicit prognostic information yielded better outcomes than general information, which corresponds to clinical patients' preferences for full disclosure [12,55]. Precise information decreased women's uncertainty, while increasing self-efficacy. Clinical patients often report that uncertainty is worse than the certainty bad news creates [56,57]. While excessively vague information increases distress [10,58], precise information about their condition helps patients plan [12] and make treatment decisions [59,60]. The importance of unambiguous information is stressed by a recent study, showing that a majority of patients receiving palliative chemotherapy wrongly believe in its curative potential [61].

In addition to the findings about explicitness, our results showed that three short affective statements giving reassurance about non-abandonment influenced anxiety and other outcomes. Indeed, the certainty of continuing care seems an overarching – hopeful – theme for clinical patients [29,30]. This evokes the feeling that oncologists 'keep looking after you' and 'will do their utmost' [30]; elements which were described as hope-giving in our previous study [11]. Emphasizing continuing care may thus be a promising way to satisfy patients' desire for hope while remaining realistic.

Interestingly, reassurance decreased anxiety and uncertainty, while explicitness decreased uncertainty but not anxiety. Anxiety – an affective measure – may be insensitive to instrumental communication [62], which also explains our borderline significant differences for anxiety when comparing effects of the different videos with Bonferroni tests. Contrastingly, in addition to decreasing anxiety, reassurance can evoke the feeling of unconditional guidance [29], which might decrease uncertainty about the future and increase perceived self-efficacy. Affective communication does indeed influence several outcomes [63] including self-efficacy [64]. Lastly, satisfaction was influenced by reassurance and explicitness, possibly because the PSQ includes affective and instrumental items, both influencing satisfaction [65]. So, while explicitness and reassurance have distinct influences, the combination seems most promising in bad news consultation.

Contrary to our expectations, high monitors seemed to benefit least from these communications. This result corresponds with previous studies, who concluded that they are often less satisfied with information than low monitors [66,67]. However, other studies concluded that high monitors are generally the ones benefitting the most from detailed information [68-70]. Our results raise questions: whether high monitors' information needs decrease when entering palliative care – as is suggested by a previous study [53] – and which communication styles in this subgroup yield the best outcomes in this situation.

Implications for clinical practice

Our findings have implications for clinical care. The statistical prognostic discussion yielded better results than the general discussion, which might be helpful for oncologists who are reluctant to discuss statistical information due to its uncertain utility for, and effect on individuals [71,72]. We found that stressing the difficulty of predicting an individual's survival, emphasizing that numbers are based on large groups and that there are – negative and positive – exceptions might be a beneficial approach when discussing prognosis in detail. This corresponds to recently proposed strategies, which focus on stressing the impossibility of predicting where a patient will fall on a statistical survival curve [73] or mentioning outliers next to means [74,75]. Indeed, patients who prefer openness about their prognosis appreciate the emphasis on the uncertainty in the statistics [17,76].

However, a minority of patients prefer to be left partly ignorant about their prognosis [12,15,16], emphasizing the importance of determining patients’ information needs before discussing the prognosis. In our study, the patient asked for explicit or general prognostic information and the oncologist checked her wish for explicitness before providing this information, which is in line with current recommendations [77,78] and our previous study [11]. Because we did not manipulate patient communication in this experiment, we cannot draw any conclusions on how oncologists should respond to patients who do not prompt the doctor for information. It is worth noting that our results suggest that high monitors, who often ask many questions [41,66] might not be the ones benefitting (the) most following detailed life-limiting prognostic information (and reassurance).

Following the positive results of reassurance about non-abandonment, oncologists may decide to implement such statements to offer realistic hope. Promising not to abandon patients is one thing; doing so is another, however. Oncologists, who seem increasingly aware of the importance of non-abandonment [30,73,79], may eventually fail this task, often because the patient is referred to hospice care [30]. Han and Arnold [80] suggested that patients’ primary physicians should not withdraw after referring to hospice care, but if necessary discuss their withdrawal beforehand with patients. Several national – cancer – organizations [81-84] advise that general practitioners should have a (continuous) role in palliative care. Others point towards the positive effects of introducing palliative care (teams) early on in this phase [85-87]. Implementation of such initiatives might benefit patients, who feel abandoned when familiar care providers are suddenly unavailable [29,73]. While there is therefore a need to educate – future – oncologists about the potential power of expressing non-abandonment [88] there is first and foremost a need to determine how this promise can best be given *and* kept in busy clinical daily life.

Limitations and future studies

This study has limitations. Firstly, we conducted an experimental study with APs, so clinical patients in this situation might respond differently. Still, in a recent systematic review we found that APs' perceptions are valid [45] and cancer patients/survivors versus healthy women's perceptions in the current study overlapped. Secondly, participants viewed four videos varying slightly in communication. Although we varied the videos' order randomly, and women in a pilot study indicated that they could focus on four videos, for individual participants a habituation effect may have occurred. Thirdly, due to our recruitment methods – e.g. through advocacy organizations – our sample might be biased and less-involved women may be underrepresented. Fourthly, experimental designs inherently reduce the complexity of clinical interactions, stressing the importance of clinical follow-up studies. Last, the limited sample size of our study hampered the analysis of the influence of several background characteristics, e.g. ethnicity.

Future studies might focus on the most beneficial and feasible approach to discussing statistical information from a patient perspective in clinical care. More research on how non-abandonment can best be promised (and that promise kept) in palliative care is needed. Furthermore, studies into other types of – individualized – reassurance, e.g. regarding pain control, would be worthwhile. Specific attention should be paid to the influence of background characteristics on communication needs, starting with the influence of monitoring scores.

Conclusions

Although more research is needed to translate our findings into clinical care, the results presented once again underline the power of communication. In the current climate of personalized care, explicit and reassuring information might be beneficial for most patients, although investigating and acting upon individual's specific preferences should never be neglected.

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6

How do high monitors differ from low monitors at baseline and in response to receiving an incurable cancer diagnosis: Findings from a scripted video-vignette study

van Vliet LM, van der Wall E, Plum N, Bensing J. How do high monitors differ from low monitors at baseline and in response to receiving an incurable cancer diagnosis: Findings from a scripted video-vignette study. *Submitted*

Abstract

Background

The literature shows that people scoring high on ‘monitoring’ have a high need for information and emotional support, become distressed in response to health threats and benefit from receiving detailed information. However, in a previous paper we found that in an analogue patient population high monitors reacted less positive to explicit prognostic information than low monitors when being confronted with an incurable breast cancer diagnosis. Trying to understand these results, the aim of the current article is to provide more insight into the concept of monitoring. To do so we related analogue patients’ monitoring scores to background characteristics including communication preferences, and to responses to threatening information (i.e. receiving an incurable cancer diagnosis).

Methods

Breast cancer patients/survivors (n=51) and healthy women (n=53) were recruited for a study in which their reactions to videotaped medical consultations were measured. At baseline, background characteristics and communication preferences were assessed. Next, they watched four versions of a scripted video-vignette of a bad news consultation, only varying in ‘explicitness of prognosis’ and ‘reassurance about non-abandonment’ (high or low). Following each video, anxiety, uncertainty, satisfaction and self-efficacy were assessed. Research questions were answered with correlations, independent samples t-tests, multivariate tests, bivariate ordered logistic regressions and multilevel models.

Results

Monitoring scores were related to some demographic characteristics and various communication preferences, but not to preferences for explicit prognostic information and reassurance about non-abandonment. Although – compared to low monitors – high monitors’ felt less self-efficacious (visual analogue scale, p=.011) and satisfied (only as measured with the PSQ, p=.050) following viewing

the videos, explicit and reassuring information did yield overall the best outcomes, regardless of monitoring scores.

Conclusions

The literature suggests that high monitors have high needs for information and support, become easily distressed, and benefit from detailed information. This is only partly confirmed in our study. We hypothesize that this might be due to the uncontrollable – aspects of the – situation under study, i.e. the transition to palliative care. The way monitoring is measured and the use of an analogue patient population might also help to explain our findings. More research is needed.

Introduction

Cancer patients' information and communication preferences vary [1]. In this regard, much research has focused on the coping style 'monitoring'. According to Miller [2-5] monitoring refers to the degree to which people seek out or scan for threat-relevant information. From the literature, it seems that high monitors (i.e. people scoring high on 'monitoring') share certain characteristics.

Firstly, high monitors seem to have high needs for information and emotional support [3]. Indeed, in cancer care high monitors show high needs for – detailed – information (i.e. instrumental communication) [6-8]. Simultaneously, monitoring scores are related to the importance placed on empathic (i.e. affective) communication in cancer care [6,7,9,10]. Whether high monitors are also defined by certain background characteristics is less clear. In some studies characteristics such as (young) age – tend to – relate to monitoring scores [8,11,12], while in other studies this relation was absent [2,13-15]. Education was not found to be related to monitoring in a number of studies [2,8,13-17]. While occasionally a relation between monitoring and trait anxiety has been found [11], most studies failed to do so [16,18-20] and the association with depression has been inconsistent [2,13]. Disease status has mostly been unrelated to monitoring scores [8,14,15], but in a HIV-subsample disease status and monitoring were related (in a HPV-subsample this relationship was absent) [13]. In Table 6.1 we provide an illustrative overview of previous studies' associations between monitoring and background characteristics.

Table 6.1 Relations between monitoring scores and demographic/psychological/medical background characteristics as found in previous studies

Background characteristics	Did find a relation with monitoring scores	Found no relation with monitoring scores
Demographic		
Education		Miller et al., 1983 [16] Miller et al., 1988 [2] Miller et al., 1996 [13] Miller et al., 1999 [14] Ong et al., 1999 [8] Steptoe et al., 1991 [17] Timmermans et al., 2007 [15]
Gender	Muris et al., 1993 (women higher) [19] Van Zuuren et al., 1991 (women higher when measured with 5-point answer scale) [18] Van Zuuren 1996 et al., (women higher, only for dental patients) [12] Ong et al., 1999 (tendency for women higher) [8]	Miller et al., 1988 [2] Timmermans et al., 2007 [15] Van Zuuren et al., 1996 (all groups except dental patients) [12] van Zuuren et al., 1991 (when measured with a dichotomous answer scale) [18]
Race		Miller et al., 1988 [2] Miller et al., 1996 [13] Miller et al., 1999 [14]
Marital status		Miller et al., 1988 [2] Miller et al., 1996 [13] Miller et al., 1999 [14]
Age	Van Zuuren et al., 2006 (younger higher) [11] Ong et al., 1999 (tendency younger higher) [8] Van Zuuren et al., 1991 (tendency younger higher, when measured with 5-point answer scale) [18] Van Zuuren et al., 1996 (only in surgical population younger higher) [12]	Miller et al., 1988 [2] Miller et al., 1996 [13] Miller et al., 1999 [14] Timmermans et al., 2007 [15] Van Zuuren et al., 1996 (all populations except surgery) [12] Van Zuuren et al., 1991 (when measured with a dichotomous answer scale) [18]

- Table 6.1 continued -

Occupation/ Employment		Miller et al., 1996 [13] Miller et al., 1999 [14]
Socioeconomic status		Steptoe et al., 1991 [17]
Psychological		
Depression	Miller et al., 1988 (higher monitors were more depressed) [2]	Miller et al., 1996 [13]
Anxiety (trait)	Van Zuuren et al., 2006 (higher monitors were more anxious) [11]	Muris et al., 1993 [19] Van Zuuren et al., 1991 [18] Miller et al., 1983 [16] Davey et al., 1992 [20]
Neuroticisme	Voss et al., 2006 (high monitors were more neurotic) [45]	
Worry	Davey et al., 1992 (higher monitors were more worried) [20]	
Medical		
Disease status	Miller et al., 1996 (in HIV sample higher monitors less likely to be symptomatic) [13]	Miller et al., 1996 (in HPV sample) [13] Miller et al., 1999 [14] Ong et al., 1999 [8] Timmermans et al., 2007 [15]
Quality of life (specific and generic)		Ong et al., 1999 [8]

Secondly, high monitors seem to become (highly) distressed in response to health treats [3,4,21]. This has been found in areas such as genetic testing [22-25] and (colpo/gastro)scopies [11,16]. Moreover, they tend to perceive situations easily as threatening [18,19] and exaggerate the significance of their symptoms [4].

Third, high monitors seem to benefit from receiving detailed information [3-5,21]. But findings in the literature have actually been less consistent than generally assumed. Some studies concluded that high monitors are the ones who benefit the most from receiving explicit information [16,26]. However, positive effects of information provision have not always been found [27-29]. In one study, high monitors were found to react positively to high *and* low levels of information [26] (although in this study information-provision included a live-feedback from a colposcopy, so no pure *information*-provision). In our own research, focused on communication at the transition from curative to palliative breast cancer care and using an analogue patient population, we found that explicit prognostic information was less positively evaluated by high monitors than low monitors (van Vliet et al., resubmitted). Interestingly, the way high monitors react to affective communication has largely been neglected in the literature so far. In our study, there was some indication that high monitors tended to react less positively on reassurance about non-abandonment than low monitors (van Vliet et al., resubmitted). The question remains how to understand these findings.

Therefore, the aim of the current article was to study the concept of monitoring in more detail and determine in what way high and low monitors differ from each other. We therefore focused both on differences in background characteristics and communication preferences, and on differences in responses to threatening information. More specifically, we wanted to test in our sample the following two research questions. First, do high monitors differ from low monitors on baseline measures: a) do they differ on demographic, psychological and medical characteristics, and b) do they differ on preferences for information and emotional support? Second, do high monitors differ from low monitors in response to receiving threatening information: a) do they become more distressed (e.g. anxious, uncertain) than low monitors following hearing an incurable diagnosis, and b) do high monitors in this situation benefit from receiving highly explicit (and reassuring) information or not?

Methods

Design

This article was part of a larger study, in which the effect of communication at the transition to palliative breast cancer care was studied using a scripted video-vignette design. Four scripted video-vignettes of a bad news consultation were created in which a medical oncologist discussed the consequences of having entered the palliative phase of breast cancer care with a female patient. These vignettes were completely identical except for variations in two communication elements: 'explicitness of prognostic information' and 'reassurance about non-abandonment' (high or low; see Box 6.1 for exact manipulations). In an introduction video – aimed at increasing participants' involvement – the video-patient introduced herself. Professional actors role-played the scripts. Detailed information about the process of creating the scripts, and the final scripts is provided elsewhere [30].

Box 6.1 Exact manipulations used in the four different videos

Manipulation	Exact content
Explicit high	*Patient: Okay, so how long have I got?* *Oncologist: Your life expectancy?* *Patient: Yes, I would like to know that as specifically as possible.* *Oncologist: That's very difficult. But I can give you some concrete numbers and averages. Would you like me to discuss these with you?* *Patient: Yes.* *Oncologist: When we look at what is known from studies with patients with your type of cancer cell and your metastases, 50% of the patients are still alive after 2 years. So, half the people will die within 2 years, while the other half will live longer than 2 years. Some people might only live for half a year. But others will live much longer, maybe as much as 4 years.* *Patient: Yes, I understand that. So, you can't predict which group I belong to?* *Oncologist: No*

Explicit low	*Patient: Well, how long have I got?* *Oncologist: Your life expectancy?* *Patient: Yes, as a rough idea. Do you know that in general terms?* *Oncologist: That's very difficult to predict, because it can differ from person to person. You do have a very serious disease, which will limit your life expectancy. That is the only thing we can say for sure.There are women who live for quite a long time with the type of breast cancer you have, and there are women who live less long. The comments you often see on television or read in magazines, about 'you only have so long to live', aren't realistic, because we do not know that in any individual case… So, no, I don't know how it will be for you.* *Patient: Yes, I understand that. That's something you can't predict.* *Oncologist: No*
Reassuring high	*1) Oncologist: 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.* *2) Oncologist: We will do and will continue to do our very best for you.* *3) Oncologist: And whatever happens, we will never abandon you. You are not facing this on your own.*
Reassurance low	*No fragments were added.*

Subjects and procedures

Both breast cancer patients/survivors and healthy women were recruited (age 18-65, with sufficient command of Dutch) through websites of patient advocacy organizations, health-related websites, messages boards and snowball procedures. Prior to the experiment, background measures were being taken. During the experiment participants acted as 'analogue patients': they were asked to place themselves in the shoes of the video-patient and judged the oncologist's communication from this perspective. A recent systematic review concluded that this is a valid approach to study the patient perspective on communication [31]. Participants watched in groups (1-7 people, separately for patients/survivors and healthy women) the introduction video and the first part of the bad news consultation. Next, the four video-vignettes were viewed in random order. In between the vignettes a distraction task was provided. Before every vignette, anxiety was assessed and after every vignette all outcome measures were assessed. Ethical approval was received from the Medical Ethics Committee of the University Medical Center of Utrecht and informed consent provided by the participants.

Measures

Background Measures

a. *Monitoring*. Monitoring scores were assessed with the Threatening Medical Situations Inventory (TMSI) shortened version [8]. Following two medically threatening situations ('choosing for uncertain surgery' and 'vague, suspicious headache') for three monitoring statements (e.g. 'I intend to ask my specialist as many questions as possible') agreement is measured on a scale from 1 to 5 (1='not at all applicable to me' through till 5='strongly applicable to me'). Total monitoring scores could range between 6-30, with a higher score indicating a higher monitoring tendency. Cronbach's alpha was .73.
b. *Demographic, psychological and medical characteristics*. Demographic characteristics were assessed: age, education, ethnicity, occupation, marital status, and whether participants had experiences with loved ones receiving a life-limiting cancer diagnosis ('similar experience'). Optimism (LOTR [32]), trait anxiety (Stai-trate [33]) and blunting (TMSI shortened version [8]; blunting was measured with the 5 items used in the analyses by Ong et al [8] but recoded for all analyses to an also used 6-item scale, which facilitated comparison with the 6-item monitoring scale) were additional measured psychological characteristics. Last, regarding medical characteristics we measured health status (COOP-WONCA [34]) and included type of participant (healthy woman versus survivor/patient).
c. *Communication preferences.* Communication preferences were assessed using the QUOTE-COM, adapted version [35].

The importance of 24 communication elements is indicated on 1-4 scales. Internal consistency of the total scale was .87.

Outcome measures

a. *Uncertainty.* Uncertainty about the future was measured with a self-created 0-100 visual analogue scale (VAS), ranging from 'very certain' to 'very uncertain'.
b. *Anxiety*. Anxiety was measured with the short Stai-state [33] and a self-created 0-100 VAS, ranging from 'not anxious at all' to 'very anxious' (only assessed after each video). The Stai-state consists of ten items concerning how participants are feeling right now (e.g. 'I feel calm'), to be answered on a 1-4 scale. The Stai-state was also measured before every video. Cronbach's alpha for the Stai-state before and after the video was .90 and .84, respectively. The difference score was used in all analyses. Some groups were held with ethnic minority women. In these groups, the Stai-state before was only measured before viewing the first video to lessen the burden of filling in many questionnaires. This pre-score was used to determine the difference score for each video.
c. *Satisfaction.* Satisfaction was measured with the Patient Satisfaction Questionnaire (PSQ [36]) and a self-created 0-100 VAS, ranging from 'not satisfied at all' to 'very satisfied'. The PSQ covers satisfaction with five aspects of the consultation (e.g. the information received) on 0-100 scales. The reliability of the PSQ was .90 in the total sample.
d. *Self-efficacy*. Self-efficacy was measured with a self-created 0-100 VAS, ranging from 'very little belief in ability to deal with the future' to 'very great belief in ability to deal with the future'.

Statistical analysis

First, we assessed the relations between monitoring scores and demographic, psychological and medical background characteristics with correlations, independent samples t-tests and multivariate tests. Second, to determine whether monitoring scores were related to preferences for communication bivariate ordered logistic regression analyses were performed for all 24 items of the QUOTE-COM. We also wanted to determine whether monitoring scores were related to participants' preferences for the two communication elements which were manipulated in our study: (a) explicit prognostic information and (b) reassurance about non-abandonment. Two items in the QUOTE-COM focused on the level of preferred prognostic explicitness (*I think it is important that the oncologist: i) provides specific information about my life expectancy, ii) tells me exactly what my life expectancy is*) and two on the level of preferred reassurance *(I think it is important that the oncologist: i) reassures me that the medical team will take good care of me, ii) gives me the feeling that he will not abandon me*). The two questions' mean score was used as preference for explicitness (alpha .83) and reassurance (alpha .59). Third, to determine whether monitoring scores were related to increased distress following viewing the videos, the main effect of monitoring on all outcome measures was assessed. As participants watched four videos, random intercept linear multilevel regressions were applied, consisting of videos (level 1) nested in participants (level 2). Outcome measures were transformed into Fisher z for normalization. Last, to determine whether high monitors benefited more from high or low explicitness and high or low reassurance the moderating influences of monitoring scores on these effects were graphically displayed. To do so, interaction effects between monitoring scores and the four conditions (explicit high, explicit low, reassurance high, and reassurance low) were calculated (using again a multilevel approach). As no interactions were found between explicitness and reassurance, we collapsed the high and low reassurance conditions for all analyses focused on explicit information and vice versa. Moreover, breast cancer patients/survivors and healthy women did not differ in outcome measures following viewing the videos, so the groups were pooled for the analyses. More specifically, we found no main effect of type of participant on uncertainty (*B*=.13, p=.36), anxiety (Stai-state, *B*=.05, p=.70; VAS, *B*=.19, p=.22), self-efficacy (*B*=-.08, p=.60) and satisfaction (PSQ, *B*=.01, p=.93; VAS, *B*=.07, p=.63) (outcome measures were transformed to Fisher z). All analyses were performed using STATA 12.0, with a two-sided alpha of .05.

Results

Sample characteristics and relations with monitoring scores

Background characteristics of the participants (51 patients/survivors and 53 healthy women) are shown in Table 6.2. Monitoring scores (M=20.01 SD=4.35, range 12-29) were unrelated to the majority of demographic (i.e marital status, ethnicity, 'similar experience') psychological (i.e. trait anxiety, optimism, blunting) and medical (i.e. health status, type of participant) characteristics. A trend was found for a positive relationship with age (p=.078), suggesting that older participants might have somewhat higher monitoring scores. Higher monitoring scores were related to a higher education (p<.001) and having a paid job (p=.008). As these two measures were related (*r*=.21, p=.037), we only controlled for education in the multilevel analyses.

Table 6.2 Demographic characteristics of participants

			Relation with monitoring	
	M	(SD)	*r*	(p)
Age	46.59	(13.03)	*r*=.17	(.078)
Health status (possible range: 7-35, higher is worse)	15.36	(5.59)	*r*=-.02	(.87)
Trait anxiety (possible range: 20-80)	37.77	(9.06)	*r*=-.05	(.63)
Optimism (possible range: 6-30)	22.63	(3.42)	*r*=-.05	(.58)
Monitoring (possible range: 6-30)	20.01	(4.35)	-	
Blunting (possible range: 6-30)	17.97	(4.37)	*r*=.01	(.92)
	N	(%)	t/F	(p)
Marital status			t=1.01	(.31)
Married	53	(51)		
Single (includes divorced, widowed)	51	(49)		

- table 6.2 continued -

			Relation with monitoring	
Highest Education			**F=9.87**	**(<.001)**
Low (< secondary school)	4	(4)		
Medium (secondary school + vocational education)	34	(33)		
High (higher vocational education or university)	66	(63)		
Occupation			**t=-2.69**	**(.008)**
Paid job	64	(62)		
Non-paid job (including unemployed, housewife, student)	40	(38)		
Ethnicity			t=.56	(.58)
Dutch (including Western immigrants)	87	(84)		
Immigrant	17	(16)		
Similar experience			t=-.63	(.53)
Yes	68	(65)		
No	36	(35)		
Type of participant			t=1.01	(.31)
Breast cancer (survivor)	51	(49)		
Healthy woman	53	(51)		

Monitoring scores and communication preferences

Bivariate ordered logistic regression analyses showed that high monitors found it more important than low monitors that the oncologist takes them seriously (p=.021), listens well to what they have to say (p=.033), takes enough time (p=.027), discusses various treatment options (p=.008) and provides information about possible side-effects of medicines (p=.040). A trend was found for the importance of providing information about what to await (p=.088). Interestingly, a negative relation was found with the perceived importance that the oncologist provides hope for the future (p=.003) (see Table 6.3). No relations between monitoring scores and preferences for explicit prognostic information (z=.63, p=.53) or reassurance about non-abandonment (z=.72, p=.47) were found.

Table 6.3 Relation between monitoring scores and importance of communication elements

	I think it is important that the oncologist..	**Monitor score**		
		Beta	***Z***	***p***
A	Investigates me	.06	1.29	.20
B	Determines what is wrong with me	.05	.95	.34
C	Explains well what is going on	.01	.21	.83
D	Is friendly	-.04	-.91	.36
E	Reassures me that the medical team will take good care of me	.04	.98	.33
F	Takes me seriously	**.19**	**2.30**	**.021**
G	Listens well to what I have to say	**.13**	**2.13**	**.033**
H	Is open with me	.06	1.11	.27
I	Takes enough time for me	**.11**	**2.21**	**.027**
J	Provides advice what I can do about my complaints	.06	1.37	.17
K	Empathizes with me	.01	.23	.82
L	Provides enough attention to me	.06	1.33	.18
M	Does something about my complaints	.01	.14	.89
N	Provides good information about the treatment	.04	.74	.46
O	Provides enough information about what awaits me	.10	1.71	.088
P	Provides specific information about my life expectancy	.07	1.57	.12
Q	Takes the final decision about the treatment or help I will get	-.06	-1.53	.13
R	Discusses different treatment options with me	**.14**	**2.64**	**.008**
S	Gives me the feeling he will not abandon me	.04	.86	.39
T	Let me (participate to) decide about the help or treatment I will get	.07	1.45	.15
U	Provides information about possible side effects of medicines	**.10**	**2.06**	**.040**
V	Provides much information at once	-.02	-.45	.65
W	Gives me hope for the future	**-.13**	**-3.02**	**.003**
X	Tells me exactly what my life expectancy is	<-.01	-.10	.92

Main effect monitoring scores on outcomes

Multilevel analyses were controlled for the centered effects of education, trait anxiety and optimism as these variables strongly (p<.01) influenced any outcome measures. Following viewing the videos, compared to low monitors, high monitors felt less self-efficacious (*B*=-.05, p=.011) and less satisfied as measured with the PSQ (*B*=-.04, p=.050) while the relation with the VAS-scale for satisfaction revealed a trend (*B*=-.03, p=.091). The effect on uncertainty also showed a trend (*B*=.03, p=.061) and the effect on anxiety (Stai-state: *B*=.02, p=.27; VAS: *B*=.02, p=.25) was not significant.

The relationship between monitoring scores and evaluation of explicitness and reassurance

As illustrated in Figure 6.1, explicit prognostic information led – irrespectively of monitoring scores – to better results than low explicitness for all outcome measures, except for anxiety as measured with the Stai-state (for high monitors, low explicitness led to better outcomes on the Stai-state than high explicitness). Next, reassurance was always better evaluated than low reassurance, irrespectively of monitoring scores, as can be seen in Figure 6.2.

Figure 6.1 Graphic display of the moderating influence of monitoring on high and low explicitness

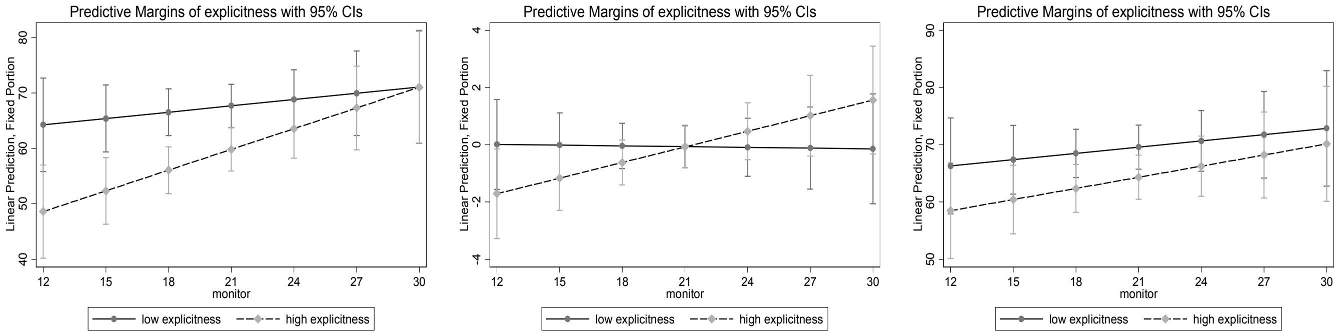


Figure 6.1a – effect of low and high explicitness on uncertainty (0-100 scale) for various monitor scores

Figure 6.1b – effect of low and high explicitness on anxiety (difference score) for various monitor scores

Figure 6.1c – effect of low and high explicitness on anxiety (0-100 scale) for various monitor scores

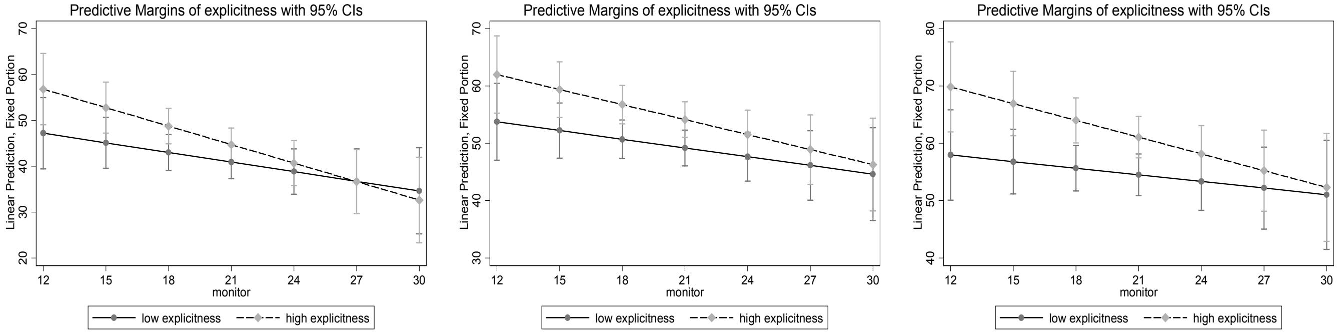
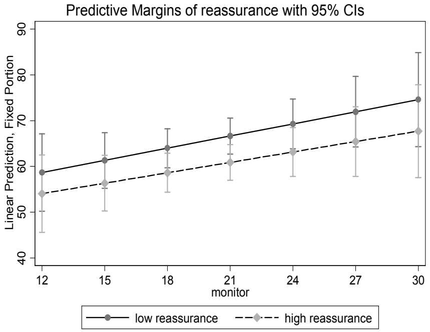
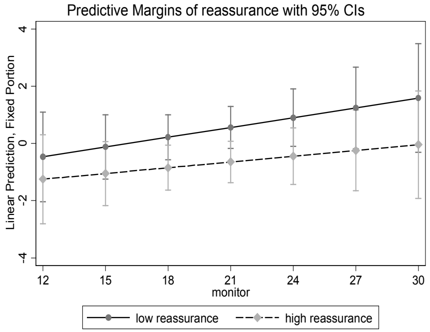


Figure 6.2 Graphic display of the moderating influence of monitoring on high and low reassurance





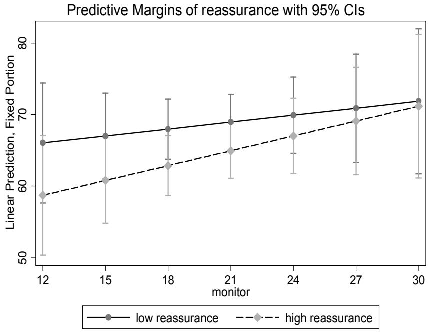
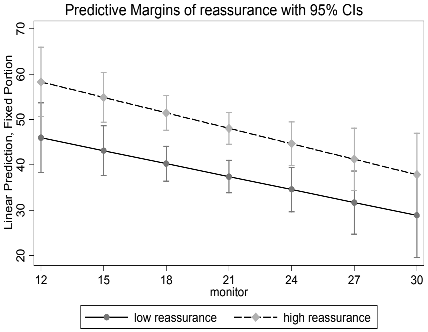
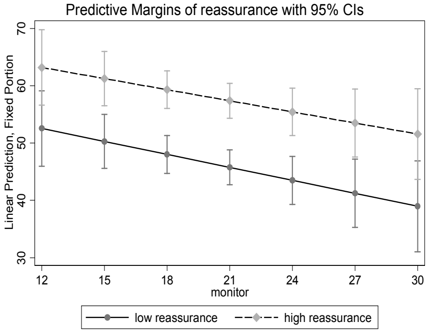


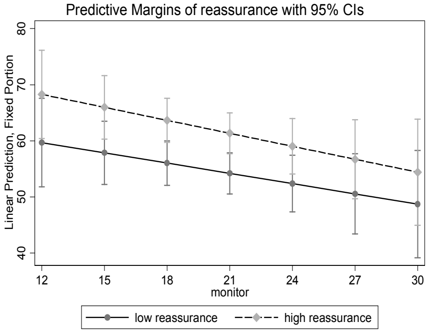
Figure 6.2a – effect of low and high reassurance on uncertainty (0-100 scale) for different monitor scores

Figure 6.2b – effect of low and high reassurance on anxiety (difference score) for different monitor scores

Figure 6.2c – effect of low and high reassurance on anxiety (0-100 scale) for different monitor scores







Discussion

The current article aimed to provide more insight into the concept of monitoring. We therefore determined how high and low monitors differ from each other in background characteristics and communication preferences, and in responses to receiving threatening information regarding an incurable cancer diagnosis. Overall, monitoring scores of breast cancer patients/survivors and healthy women (data were pooled as these groups did not differ in outcome measures or monitoring scores) were related to some demographic characteristics. Although high monitors had an increased preference for various types of instrumental and affective communication, they had no increased preference for explicit prognostic information and reassurance about non-abandonment compared to low monitors. While they did feel more distressed following receiving an incurable diagnosis than low monitors, both explicit and reassuring information yielded overall the best results, irrespectively of participants’ monitoring scores.

To start with, our results seem to indicate that high monitors form a different patient group than low monitors at baseline, but the found differences in background characteristics in our sample were somewhat surprising. More specifically, we found that higher monitors were better educated, had more often a paid job and tended to be older than low monitors. This does not seem to overlap with previous studies, who did find no relations between education or occupation and monitoring scores (see Table 6.1). The age effect we found was in the opposite direction of previous studies, although this effect remained a non-significant trend. Next, we found no differences in psychological (or medical) characteristics between high and low monitors, while inconsistent findings in this area are reported in the literature. How to interpret these findings is difficult. Different studies have used different patient samples. As we used an analogue patient population with voluntary participation our sample might have been biased. Whatsoever, this study has shed no new light on the background characteristics of high versus low monitors (see also Table 6.1).

When focussing on communication preferences, differences between high and low monitors became more apparent and more in line with previous findings. High monitors placed a greater importance than low monitors on certain elements of instrumental and affective communication. More specifically, high monitors felt more than low monitors that it was important to discuss various treatment options and medicines' side effects, but did not have a higher preference for shared decision making. The latter finding is inconsistent with the results of a previous study in cancer care, in which monitoring was related to a preference for participation in decision making [8]. However, that particular study was about the initial discussion of treatment options at the start of oncological treatment, when preferences for shared decision making might be different from those in the latter stages of disease [37]. On the other hand, this result is consistent with a finding in general care – in which high monitors desired even a less active role than low monitors [2] – and with the findings from a study that high monitors, when under threat, are inclined to search for support [38]. This brings us to the affective side of communication. Previous studies have consistently reported that high monitors have higher needs for emotional support [6,7,9,10]. Also in our study high monitors found it more important to be taken seriously, get enough time and being listened to than low monitors. This is in line with the proposition that high monitors form a demanding patient group [3]. One can only speculate why these people want so much information about treatment options, medication side effects and emotional support, while at the same time they have a negative preference for hope-giving by the oncologist. Maybe, hope-giving is a threatening message in itself for high monitors, because it confronts them with a loss of control over what might happen soon (death). However, the reason why monitoring was negatively related to a need for hope remains uncertain, especially as we do not know how participants interpreted this question, and hope is a multidimensional construct [39]. Last, monitoring scores were also unrelated to a preference for both explicit prognostic information and reassurance about non-abandonment, indicating that the found differences in effects of these manipulated communication styles in our study cannot be attributed to differences in preferences between high and low monitors.

That high monitors benefitted less from explicit prognostic information than low monitors seems to contradict common thought, but might be explained by the uncontrollability of the threatening – aspect of the – situation under study. Monitoring scores are related to an inclination for various coping strategies, including using active/problem-solving coping strategies [12,18,38]. This might clarify why this coping style is thought of to be more adaptive in controllable situations [5] (although it has also been suggested that high monitors are inclined to yield control to a more competent expert [4], but this has not been found in the cancer setting [8] or our study). Contrary, low monitors seem to have an advantage in uncontrollable situations [40]; they are able to distract themselves from and do not focus extensively on threatening information [41,42]. In such situations – or aspects of situations – more explicit information might have a cost for higher monitors, as it focusses attention on the unavoidable and unsolvable danger [43] thereby perhaps fuelling their tendency to experience intrusive thoughts about the medical threat (e.g. to think and dream about it and to be reminded of it) [13,44]. Taken these findings into consideration, it may be less surprising that low monitors benefited more from explicit prognostic information than high monitors at the transition to palliative care.

An alternative – but not mutually exclusive – explanation of our results and why our results do not completely overlap with previous studies might lie in the way monitoring can be measured. The two main questionnaires used are the Miller Behavioral Style Scale (MBSS) [42] and the Threatening Medical Situations Inventory (TMSI) [12] or TMSI shortened version [8]. The relationship between monitoring scores as determined with the TMSI and the MBSS are less than perfect [12], categorizing the same patients sometimes differently as high versus low monitors [23]. So, the use of different questionnaires coming to different scores might contribute to the different results found regarding monitoring.

A last possible explanation why our results deviate to some extent from previous studies is the aforementioned fact that we used an analogue patient population. It goes without saying that clinical patients' distress following receiving an incurable diagnoses cannot be compared with analogue patients' distress. However, a recent systematic review concluded that analogue patients' perceptions of communication largely overlap with clinical patients' perceptions [31]. Moreover, our study showed that (former) breast cancer patients were comparable with healthy volunteers in monitoring scores and outcome measures, adding to the validity of the chosen methodological approach.

Limitations and future studies

This study has limitations that mainly center around the generalizability of our results. A first limitation is the abovementioned use of an analogue patient population. Secondly, our mean monitoring score of 20.01 (SD=4.35, range=12-29) exceeds those of previous – Dutch – studies (Timmermans et al [15]: M=16.5, SD=4.7, range=7-30; Ong et al [8]: M=17.8, SD=5.24, range=7-30). It seems likely that high monitors were more interested in participating in this study than low monitors. Moreover, contrary to the studies mentioned above, our study included only women, who – tend to – have higher monitoring scores than men (e.g. [8,19], see Table 6.1). Thirdly, the study only refers to patients with breast cancer and we could not rule out differences in needs and attitude between this group of patients and other cancer patients. Fourth, our sample size and thus our power were limited. Therefore, our results need to be interpreted with caution and replicated in larger studies. Last, we explained the finding that high monitors reacted least positively to explicit prognostic information mainly by the uncontrollability of this aspect of entering palliative care. However, we did not determine how uncontrollable participants found this – aspect of the – situation.

Future studies might focus in more detail on the concept of monitoring. According to the conceptual definition of Miller high monitors are those who typically scan – i.e. monitor – for threat-relevant information [2-5]. However, our results indicated that high monitors might not prefer, and consequently not seek for, increasingly detailed information across all aspects of all situations. How communication preferences and evaluations of high versus low monitors are influenced by – the prospect of – situations varying in levels of controllability deserves still more attention. Last, although most studies, including ours, found that monitoring is a construct largely independent of psychological characteristics, this has not been consistently found (e.g. associations with neuroticism [45] and worry [20] are reported, see Table 6.1). So, more research into such relations is needed.

Conclusion

The literature suggests that high monitors have high needs for information and support, become easily distressed and benefit from receiving detailed information. This was only partly confirmed in our analogue patient sample. Monitoring scores were related to certain demographic characteristics and communication preferences in line with the literature, although not to preferences for the two communication elements that were manipulated in our study: explicit prognostic information and reassurance about non-abandonment. Nevertheless, high monitors became more distressed than low monitors following an incurable diagnosis, while they did benefit less from receiving explicit prognostic information (and reassurance about non-abandonment), compared to low monitors. We hypothesized that the uncontrollability nature of an incurable diagnosis – and more specifically prognosis – might explain our results. The way monitoring is measured and the use of an analogue patient population might also contributed to our results. More research into the concept of monitoring is needed.

Acknowledgements

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7

Summary and discussion

Summary and discussion

Introduction

When patients are diagnosed with an incurable form of (breast) cancer they are devastated. So, it is important to communicate such information with the greatest possible care for their needs. An often used framework for patients' needs is to divide them in two types, the *need to know and understand* and *the need to feel known and understood* [1,2]. To help patients handle evoked feelings of uncertainty and anxiety oncologists can react on these needs by providing instrumental and affective communication [1,3]. While discussing the transition to palliative care, oncologists face two main dilemmas, which were described in Chapter 1.

First, it is unclear whether patients prefer more or less explicit – prognostic – information. While most patients report that they want as much information as possible [4-6], it is also common to hear patients state that they wish to receive not too much information [7-9]. A substantial minority prefers to remain partly ignorant about their estimated life expectancy [10-13]. High monitors generally seem to prefer and benefit from receiving more, and high blunters from less information [14-17]. It has been suggested that oncologists should tailor the level of – prognostic – information [18-22], but there is a lack of studies on and recommendations for patients' preferred level of explicitness.

Second, patients seem to have both a need for hope [21,23-25] and realism [21,24-26]. While it is often recommended that oncologists should balance between being hopeful and realistic [21,27,28], advice on how this should be done is largely lacking. This might be because hope and realism are often thought of in terms of cure and extended survival [23] creating the impression that oncologists have to choose between being either hopeful or realistic. However, hope seems to be a broader construct [23,24]. There might be several ways in which oncologists can provide hope at the transition to palliative care, such as by being empathic [23].

In this thesis we aimed to provide more insight into the patient perspective on how oncologists can, at the transition from curative to palliative breast cancer care, balance between i) providing explicit and more general – prognostic – information, and between ii) being hopeful and realistic at the same time. For this second question, we mainly focused on the potential of the use of affective communication to provide hope. To answer both research questions, first a qualitative study and subsequently an experimental video-vignette study including analogue patients was performed. As the validity of this latter design and type of participant was still unknown, a second aim of this thesis was to provide more insight into and evidence for the validity of using scripted video-vignette studies including analogue patients. To this end, a systematic review was conducted and the different steps in creating the scripts were described.

Summary of the main findings

We divided the current thesis in three parts, being 1) the qualitative study, 2) the methodological phase, and 3) the experimental study. We will now discuss our main findings in the three different parts.

The qualitative study

Chapter 2 provides the results of our qualitative study about how oncologists can tread the fine lines between providing explicit and general information and between being realistic while remaining hopeful when discussing various topics at the transition to palliative breast cancer care. Participants (breast cancer survivors/healthy women) thought that this diagnosis shatters a patient's future perspective which oncologists should help to regain during this consultation. To achieve this, realistic personalized information is needed about the medical situation – e.g. diagnosis and prognosis next to information about available support – e.g. emotional guidance and the role of a specialized nurse –. Most participants wanted to discuss diagnostic information explicitly and discuss treatment-related information only explicitly in follow-up consultations. Preferences for the explicitness of prognostic information varied. Besides, realistic hope could be created. Hope seemed to have many faces, and could be provided by stressing medical (treatment) possibilities and by reassuring patients that they would not be abandoned throughout their disease. Hope also comes from within, such as hope for a miracle. Many women thought they would appreciate space to make their own decisions, which was also defined as hopeful. As participants remarked that patients' preferences may vary, they suggested that oncologists should tailor their communication; either by using intuition, or by asking patients about their preferences. Last, participants thought that it would be important for oncologists to create the impression of sufficient time and displaying an empathic yet professional attitude.

The methodological phase

The results of a systematic review on the validity of video-vignette studies including analogue patients were described in **Chapter 3**. Studies using videos of clinical consultations were included as well as studies using scripted video-vignettes. Many studies provided either general, ethical or methodological rationales for conducting a video-vignette study including analogue patients. Scripted studies provided more specific – methodological – rationales and paid the most efforts to test and increase both internal and external validity. For example, they involved experts or analogue patients in the process of creating the – role-played – scripts and manipulations (internal validity) and/or they assessed whether analogue patients could identify with the video-patient (external validity). While analogue patients' perceptions of communication largely overlapped with clinical patients' perceptions as found in the literature, a meta-analysis revealed that using analogue patients for the evaluation of health communication can overcome ceiling effects, which are often found in clinical patients.

Based on the results of the qualitative study, we decided to investigate the effects of more or less explicit prognostic information and more or less reassurance about non-abandonment (an affective operationalization of ‘hope’) in more detail. So, 4 versions were created of the same consultation in which the transition from curative to palliative breast cancer care was discussed. In these vignettes all communication was held constant, except that the level of explicitness of prognostic information (high/low) and the level of reassurance about non-abandonment (high/low) were systematically varied. An introduction video was created in which the video-patient introduced herself. The process of creating and validating the written and role-played scripts was described in **Chapter 4**. Both experts (oncologists/communication researchers) and lay people (breast cancer survivors/healthy women) commented on the written and role-played scripts. Scripts were adjusted in line with their comments. This ensured both internal validity (i.e. the success of the manipulations) and external validity (i.e. the realism of the scripts). The validated scripts were role-played by professional actors and shown in a subsequent experimental study to analogue patients (healthy women and breast cancer patients/survivors), who again ensured the success of the manipulations.

The experimental study

Chapter 5 describes the main results of the experimental study using the role-played scripted video-vignettes. As aforementioned, both healthy women and breast cancer patients/survivors viewed the four video-vignettes (using a complete counterbalancing approach). Before each video their anxiety was measured. After each video, uncertainty, anxiety, self-efficacy and satisfaction were measured. The effects of the different communication styles on these outcome measures were analysed, exploring the moderating influences of ‘monitoring’ and ‘blunting’. We found that the highly explicit/highly reassurance video yielded the best outcomes, while the lowly explicit/lowly reassurance the worst. These differences were significant for all outcome measures expect for anxiety. Moreover, both explicit prognostic information and reassurance about non-abandonment independently of each other decreased analogue patients' uncertainty, while increasing their self-efficacy and satisfaction. Only reassurance had a significant effect on decreasing anxiety. Contrary to our expectations, high monitors reacted less positively to explicit information compared to low monitors, while there was some indication that they also tended to react less positively to reassurance about non-abandonment.

Last, in **Chapter 6** we studied in greater detail the concept of monitoring. More specifically, we determined the relation of participants' monitoring scores with background characteristics including communication preferences and with responses to the four videos. High monitors differed on certain demographic characteristics (e.g. education) from low monitors and placed greater importance on various aspects of instrumental and affective communication (e.g. discussing various treatment options, being listened to). Moreover, they showed increased levels of distress following viewing the videos compared to low monitors. Although they had no increased preference for receiving explicit prognostic information and reassurance about non-abandonment, these communication styles did yield overall the best outcomes for all monitoring scores.

General discussion

We will now place these findings into a broader perspective. This general discussion is followed by a discussion of methodological considerations. Next, implications for clinical care are described. Finally, we will put forward suggestions for future studies and provide a conclusion.

Explicit versus general information needs

In our qualitative study participants stressed a need for biomedical information. They preferred explicit information regarding the diagnosis while information regarding treatment options should be discussed explicitly in later consultation for most participants. High monitors might form an exception in this regard; in the experimental study they did express an increased need for discussing various treatment options and side-effects compared to low monitors. The importance to discuss diagnostic and treatment-related information is stressed in the literature [24,29] since patients report to have high information needs in these areas, especially regarding treatment options [6,11,30]. Our finding that most participants did not want to receive all treatment-related information at once is noteworthy, as patients' recall of medical information is often problematic [31,32], especially regarding treatment-related information [33,34].

Explicit versus general prognostic information needs

According to our results the tension between patients' need for complete information, while avoiding information-overload seems to lie in the area of prognostic disclosure (Chapter 2 and 5). Overall, we found that the majority of participants appreciated a detailed discussion concerning their life expectancy. In line with uncertainty management theory [35,36], some patients indeed report that uncertainty about their situation is worse than the certainty which bad news can imply [37,38]. For these patients, knowing what they are facing can help them to make treatment decisions [29,39] and future plans [11]. These rationales were also put forward by women in our experimental study preferring the explicit prognosis (see Box 7.1). That said, in both the qualitative and experimental study a subset of women preferred more general information. For these patients – according to uncertainty management theory – maintenance of uncertainty is appreciated, as it gives room for believing in a bright future [35]. Indeed, some participants in our experimental study remarked that the general prognosis made them feel less pinned down on a specific time-frame (see Box 7.1). Altogether, explicit prognostic information seems to be preferred by the great majority but not all, highlighting the difficulty to provide uniform and clear-cut advices on how to discuss prognostic information, suggesting a differentiated and tailored approach instead.

Box 7.1: Reasons participants put forward to receive explicit or general prognostic information

And what do you might want to finish in your life? Or arrange or prepare for the end you are approaching. That is very important to me; that you do have a bit of an estimate of how (long, red) it might be…

If you are undergoing a treatment, which can give you a lot of side-effects, you perhaps live one month longer, but you have so many side-effects that you don't have your quality of life (…) Quality of life is really important.

Therefore are those statistics important (…). You are not that statistic, but it is good to know them to base a decision upon.

Because words can get also a predictive value (…). And that (a general prognosis, red), keeps it more open and I think that that is very healthy.

And if I don't know (my life expectancy, red), then I will try to accept it and arrange everything. But meanwhile live a normal live.

And the very explicit (prognosis, red) sounds also very hard and definitive and cold. Yes, so convincingly 'this is it'. While I think that your own contribution plays an elemental role as well.

Patient characteristics influencing prognostic preferences: Control and previous experiences

Aiming to provide more insight into a personalized approach, several characteristics have been put forward in our project which might influence preferences for more or less explicit prognostic information. In the qualitative study, women who expressed a higher need to be in control reported higher preferences for explicit information overall. This finding corresponds with findings from previous studies [40,41]. Next, women's previous experiences with deaths of loved ones influenced their preferences; especially when loved ones outlived a poor prognosis participants were more inclined to favour general prognostic information. How strong this effect can be was illustrated by a study of Robinson [42] in which a patient – suffering from incurable cancer – her only hope focused on cure mainly because one of her family members had survived a poor prognosis for years. But the most complicated predictor seems to be participants' monitoring coping style.

Patient characteristics influencing prognostic preferences: Monitoring and blunting coping styles

We found that high monitors – despite showing an increased need for various instrumental and affective communication behaviours – had no increased preference for explicit prognostic information at baseline and benefited less than low monitors from this style of communication (Chapter 5 and 6). One previous study found that high monitors expressed no increased need for a full palliative – prognostic – disclosure [43], so the high information needs of monitors might not hold in all – aspects of – situations. At first sight this does not seem to stroke with our qualitative study's result, in which women with a higher need for control preferred more explicit information. However, whether these women were high monitors was unknown and whether this preference specifically held for prognostic information – as high monitors in our experimental study did prefer more treatment-related information – was not determined. In Chapter 6 we hypothesized that the uncontrollability of an incurable diagnosis and more specifically prognosis might explain the effects prognostic information had on high versus low monitors (next to the possibility that our – somewhat deviating – results might be explained by the monitoring questionnaire we used and the fact that we used an analogue patient sample). It has been suggested that low monitors have an advantage following uncontrollable situations [44]; they can distract themselves more easily from threatening information [45,46] while high monitors are inclined to ruminate about threats [47,48]. To put this in the framework of uncertainty management theory, for both high and low monitors keeping uncertainty alive by general information was the least appreciated. However, high monitors have more difficulty in dealing with the certainty that is elicited by an explicit prognosis than low monitors. These findings ask for more research and might also have implications for clinical care, as will both be discussed later.

Next to the effect of monitoring, we also explored the moderating influence of blunting on how prognostic information was being evaluated; this produced no significant effects (Chapter 5). Although previous studies found that high blunters are more satisfied with more general information [49,50] this might not be the case concerning prognostic information. Moreover, it should be noted that more studies have focussed on, and found effects of monitoring scores compared to blunting scores [51-54]. So, it might also be that monitoring is a more important coping style to take into account than blunting in medical threatening situations.

Other possible patient characteristics influencing prognostic preferences

Of course, there are several other characteristics potentially influencing information preferences. In the experimental study we controlled for the influences of trait anxiety, education and optimism. These characteristics are known to influence communication needs or reactions, as also described in Chapter 1. Future studies could investigate the effects of these and other patient characteristics on the needs for and evaluations of more or less explicit prognostic information. However, although background characteristics seem to influence communication preferences, oncologists should always tailor communication to each individual's preference, as was also mentioned in our qualitative study. Suggestions for how to do so will be provided later, but let us first focus on the second dilemma of balancing hope with realism.

Hope versus realism

The current thesis showed that a need for hope and realism might not be as conflicting as often thought and the crux seems to lie in providing realistic hope. The provision of realistic information was obvious for participants in our qualitative study. They expected that bad news consultations start with an honest discussion about the current situation and their future perspective, tailored to their preferred level of explicitness. The need for realistic information has been stressed in the literature [25,26,30,55]. As has been described, in patients that have received unclear and dishonest information at the time when their cancer was diagnosed, the quality of life up till four years after diagnosis is impaired [56].

While realism seems to be the prerequisite, hope can and has to be built on this fundament. In the qualitative study, several methods of how oncologist can provide – realistic – hope to patients that have entered the palliative phase of their disease, were put forward. Some methods can be categorized in the 'medical domain' of hope, mostly based on instrumental communication. For example, the discussion of – realistic – treatment options can provide hope, which corresponds to findings from previous studies [26,57]. According to our qualitative analyses there is 'always something that can be done', ranging from palliative treatment options to pain medication. The importance of stressing possibilities instead of impossibilities has been mentioned in the literature [57,58]; when oncologists say that 'nothing can be done' this has a lasting negative effect on bereaved family members [59]. Next to this medical domain, the 'doctor-patient relationship' is another domain of hope which oncologists can influence, primarily based on affective communication. For many patients knowing that they have a say in their care – themed 'a space to choose' in our qualitative study – is important [55] and hope-giving [26,60]. Next, as described in Chapter 1, empathic behaviour is often perceived by patients as being hope-giving [23]. In this regard, providing reassuring statements regarding non-abandonment might be particular promising during bad news consultations.

Reassurance about non-abandonment

Reassuring patients that they will not be abandoned by the oncologist and the hospital requires only a little time investment but can have a profound effect (Chapter 2 and 5). Women in our qualitative study remarked that they would be afraid to be left alone. In our experimental study, adding 30 seconds of reassuring comments that this would not happen was enough to decrease anxiety. This result provides empirical evidence for previous qualitative findings that non-abandonment is an important – hope-giving – theme for patients with – incurable – cancer [61,62]. Also in this regard there is 'always something that can be done', according to our qualitative study. Moreover, this effect was present in the experimental study for all participants – also for high monitors who placed no increased importance on such reassurance compared to low monitors and even less importance on 'being provided with hope', although we do not know how they interpreted this latter question – stressing the overall positive impact of reassurance about non-abandonment.

Unfortunately, simply teaching future oncologists to provide reassuring statements might fail to reach its aim. It might be that the accompanying non-verbal behaviour is also essential, as it has been found that when a verbal competent message is accompanied by a congruent versus incongruent non-verbal message the latter increases distress significantly [63]. Just like with prognostic information needs, it might be possible that patients' previous experiences with health care practitioners abandoning their loved ones or themselves influences the extent to which patients believe such statements, although this explanation is still speculative. But most importantly, it is one thing to express non-abandonment but another to live up to this promise. In Chapter 5 we discussed that (due to the organization of health care), patients' care providers sometimes lose track of their patients as they are, for example, referred to hospice care [62]. The suggestion has been put forward that palliative care – teams – should be introduced early in the palliative phase [64-66] just as the importance of the – continued – care of the general practitioner [22,67-69]. Alternatively, oncologists should never completely abandon their patients after referring to hospice care or discuss this with patients beforehand [70], as they indeed feel abandoned when known care providers are suddenly not available anymore [61,71].

The hope for a miracle

While oncologists seem to be the designated persons to provide hope in both the medical domain and the domain of the doctor-patient relationship, hope seems not to be limited to these domains (or this messenger). Most importantly, hope can come from the personal domain, i.e. patients' relationships with themselves, their loved ones and an afterlife [60,72,73]. According to our qualitative study, hope is also something that comes from within, such as the hope for a miracle. This seems to be a persistent hope in advanced cancer patients; they are able to hold an unrealistic hope for cure and realistic future perspective simultaneously [42,60,74]. In our experimental study a patient herself in the palliative phase of cancer expressed this attitude. In the following citation, she describes how her daughter bought her tickets for Cirque du Soleil in November. *'I said "November?! But I may not be here anymore then..". "Yes, come on!" said my daughter. So, now my aim is November'.* This attitude corresponds with a recent study in which all advanced cancer patients still hoped for a cure, while at the same time making advance care plans (thinking about treatment choices they would want if they became unable to speak for themselves) [42].

According to the stress-coping theory, an initial denial of the implications of a life-limiting prognosis may be adaptive to have any hope at all [75]. However, sporadically this denial is persistent, leaving no room for realism and the preparation for death. Based on (longitudinal) research Vos [76,77] suggests that health care providers might best respect this reaction, while trying to discuss what information patients are ready to hear, which might create room for further discussion. This suggestion corresponds largely with the conclusion of a recent review to 'watch and wait' in such instances [78]. However, occasionally oncologists are partly responsible for patients' unrealistic hope for a cure as they are reluctant to rectify this belief while patients are reluctant to discuss bad news. This situation has been extensively described in a longitudinal study of The et al [79] in which both lung cancer patients and their doctors focused on the success of chemotherapy to shrink the tumour to an invisible size, although they both cognitively knew the disease would recur. In these situations unrealistic hope is not (counter)balanced with realistic future expectations, as seems to be the most desirable situation; when patients lose realism, their chance to arrange their affairs can be lost [57] while when patients lose hope, their will to live can be lost [80,81].

Methodological considerations

The validity of scripted video-vignette studies including analogue patients

The second aim of this thesis was to provide more insight into the validity and usefulness of scripted video-vignette studies including analogue patients. As discussed in Chapter 1, this methodology offers the opportunity to vary and determine the causal effects of specific – theory-based – communication elements by testing them in laboratory-like settings using large groups of participants who view the same stimuli. From our systematic review we can conclude that compared to clinical video-vignette studies scripted studies pay in general more efforts to increase and test both internal and external validity. These studies might also need to do so, as they depict a role-played consultation. That said, paying attention to validity in scripted studies – e.g. by involving both experts and lay people in the creation of the scripts – does presumably increase their quality, leading to the most valid results.

Another validity issue concerns whether analogue patients can be used as proxies for clinical patients when studying the patient perspective on communication. According to our systematic review, this seems indeed to be the case, taken some limitations into account. The long-term relationship between doctors and patients influencing evaluations – and possibly leading to ceiling effects –, cannot be captured with analogue patients. Moreover, as certain background characteristics influence communication preferences, these might be important to take into account when generalizing analogue patients' perceptions to clinical care. Lastly, health outcomes are obviously impossible to study by using analogue patients.

The validity of the current study

Internal validity of the scripts

Following the validity of scripted video-vignettes studies including analogue patients in general, we now want to reflect on the validity of the current study (see also Chapter 4). Regarding internal validity, some strengths can be noticed. To start with, we used data from various sources to write the scripts; the qualitative study, unpublished interviews with oncologists, the expertise of an oncologist/communication expert and videos of previous scripted video-vignette studies/clinical bad news consultations. Moreover, the written and role-played scripts were validated by experts (oncologists/communication researchers) and lay people (breast cancer survivors/healthy women (role-played only)), ensuring that the manipulations were successful. Also in the experimental study the manipulations were found to be successful. Lastly, to ensure that analogue patients' own perceptions of the communication were assessed, and not how they perceived the video-patient's perception, during the manipulations the camera was focused on the oncologist.

But there were also limitations. It remains a limitation that no patients in the palliative phase of their disease were included to validate the scripts. This was because in the qualitative study following ethical arguments we only included survivors and some of them participated in the validation process. Next, to ensure the success of the manipulations from all possible viewpoints, we could have objectively coded them.

External validity of the scripts

Also considering the external validity of our study some strengths can be noted. A strength of our approach was that the experts and lay people found the written and role-played scripts overall realistic. Moreover, actors were casted and the opinions of experts and lay people were used to choose the final actors. In addition, in the experiment we used an introduction video in which the video-patient introduced herself, aimed to increase analogue patients' empathic involvement. For the same reason we also made use of close-ups of the video-patient at emotional moments during the script.

Still, limitations remain. To start with, we did not measure the degree to which analogue patients could identify with the video-patient in the experimental study, which with hindsight we should have done. Next, our videos – excluding the standard introduction and diagnosis sequence – were 3½-4 minutes long, covering a part of the consultation. One could argue that it would have been more realistic if we had depicted a whole consultation. However, our goal was to focus on very specific communication elements. Moreover, creating longer scripts would have taken much more time and the chance that we had not found any effects, given our small manipulations, would have been increased. That said, Fogarty et al [82] found effects of a 40-seconds manipulation during an 18-minute scripted consultation.

One noteworthy element potentially limiting the external validity of our scripts was that our video-patient very clearly stated what kind of prognostic information (explicit versus general) she preferred. Clinical patients often do not explicitly state their preferences [83,84]. That said, in our validation studies participants found the scripts overall realistic. According to an involved oncologist there is a new generation of patients who use various – internet – platforms to get information about their disease, and who are less reluctant to ask explicit questions. Moreover, the patient only stated how explicit she wanted prognostic information after the doctor verified her request for information about her life-expectancy. Both in our qualitative study and in the literature [21,85] it has been suggested that oncologists should ask patients about their preferences for prognostic information.

Use of various types of analogue patients

Overall, our results showed little differences in how communication was perceived between healthy women and breast cancer patients/survivors, providing additional evidence for the validity of including healthy women when studying communication in cancer care. Some differences were found in communication preferences expressed in the qualitative study, as survivors sometimes seemed to have lower expectations of oncologists' communication skills and a higher need to manage their own life. It might be that these women have had more negative experiences during their own care, resulting in a higher need to take control. In this regard, a recent study found that people with many health problems seemed to be less open to advice from their health insurer regarding their choice of care provider compared to healthier people [86]. However, in the experimental study the patients/survivors and healthy women did not respond differently to the four videos, which is in line with previous studies in cancer care [82,87].

The representation of the current sample

The representation of our sample also suffers from some challenges. First of all, participants were partly recruited through patient advocacy organizations and health-related websites. It can be argued that by using this approach more assertive and involved women were included, biasing our sample. Consequently, this might also help to explain why we found a higher mean monitor score in our experimental study than reported in previous studies (Chapter 6). Secondly, although we deliberately have tried to recruit women of ethnic minorities in our study, these women were underrepresented in the current study, especially in the qualitative study. Third, despite efforts to recruit less educated women (e.g. by placing message boards in ‘poor’ neighbourhoods) these women were also underrepresented in our study. Lastly, we excluded male participants. Gender can influence communication preferences [25] and our sample would not have been large enough to take this variable into account, next to the fact that including also a male video-patient would have required creating extra video-vignettes, decreasing standardization of our study. These and other limitations hamper the generalizibility of our results to patient groups outside our sample.

Study design

As described in Chapter 1, the use of an experimental design provided several advantages in our study, such as the opportunity to determine causal effects of communication [88,89]. We also overcame ceiling effects that are often found in clinical patients

[90,91]; satisfaction scores for the videos varied between 44.67 and 61.13 (0-100 scale).

However, our design also suffered from limitations. Firstly, we used only a white female patient and white male oncologist in our video-vignettes. Communication is sometimes differently perceived when it is provided by a male versus female physician [92,93]. Women of ethnic minorities might have had more difficulty to place themselves in the shoes of the white video-patient. However, we decided to not create multiple videos varying in race and gender of both the oncologist and patient as it would have been very difficult to standardize the behaviour (e.g. intonation, non-verbal) of all actors and our focus was on the effect of the manipulated communication. Secondly, our sample was not large enough to determine the influence of several background characteristics. Due to limited time available, we included less participants than we originally had aimed. Although this did not affect our power to detect main effects, it did decrease the chance of finding moderating (or mediating) effects. Thirdly, we focused on breast cancer, potentially limiting the generalizability to other cancer types. Lastly, we claim to study the patient perspective on communication but included also healthy women. Although letting healthy women watch cancer consultations will always remain a proxy of reality, we did provide evidence for the validity of this type of analogue patient.

Measurements

Last, we would like to reflect on some measurements used in the experimental part of our project. Most importantly, we argue to manipulate 'hope' in the experimental study but did not include 'hope' as outcome measure. We choose to do so for two reasons. Firstly, hope is often measured using the Herth Hope Index [94]. This questionnaire includes statements as 'I can recall happy/joyful times', which would presumably have failed to measure the effect of our manipulated communication. Secondly, we could have measured 'hope' with a self-created visual analogue scale. However, hope is still an ambiguous concept. So, had we explicitly asked participants how *hopeful* they felt after the videos the validity of this question could have been uncertain, as some participants could have interpreted it as 'hope for survival', while others could have interpreted it as 'hope for non-abandonment'. However, this explanation remains speculative. Future studies using this methodology and manipulating ‘hope’ might include several visual analogue scales measuring different operationalizations of hope, which with hindsight we could have done as well.

Next, participants watched all four videos. We choose this approach – which was tested in a pilot group – as it allowed participants to compare all the different styles and showing them less videos would have resulted in a larger sample size. To control for order effects we used a complete counterbalancing approach [95] and reported in Chapter 5 that no order effects were found. That said, whether our results would have been different if we had showed larger numbers of participants less videos remains an unanswered question, which should be addressed in future research.

Last, there are various ways to determine and conduct analyses with monitoring (and blunting) scores, which might lead to different outcomes (as partly described in Chapter 6). The two main questionnaires, the MBSS [46] and TMSI [96], categorize some patients differently as high versus low monitors [49]. Regarding the analyses, some studies have divided their sample into low versus high monitors using a median split [53], others subtracted blunting from monitoring scores to come to a group of monitors (using a median split) [97,98] and other studies, including ours, used monitoring as continuous scale [47,54], which we believe is the most sensitive method to study the influence of these scores. Moreover, we measured – using the TMSI shortened version – blunting with 5 items as these items were also used in the analyses by Ong et al [54]. However, as blunting is also measured and used in analyses with all 6 items [50] we recoded our 5-item scale to a 6-item scale and used these scores in our analyses. This facilitated comparison with the monitoring scale (also 6 items).

Implications for practice

The suggestions for clinical practice we will now offer are focused on the role of the oncologist when discussing the transition to palliative care, but are also relevant for other types of health care professionals and other moments throughout the – palliative – cancer care path. The results of the current project form the starting point of these recommendations. However, it is premature to pose convincingly direct recommendations from our experimental design, so we have taken the freedom to also base recommendations on other research and literature, as well as our own reflections.

Balancing explicit with general information

From our project follows that most patients may need explicit information regarding their disease status and – now or later – regarding treatment options. Clinical patients have indeed high information needs in these areas, especially regarding treatment options [6,11,30]. Meanwhile, patients too often misunderstand the extent of their disease and aim of treatment [99,100] and recall of provided information is often impaired [31,32]. So, it might be wise to check patients' understanding of information provided in these areas [58,101] and repeat this information in subsequent consultations if necessary. Moreover, according to our qualitative study during an initial bad news consultation the treatment-related information should not be discussed in too much detail. However, high monitors in the experimental study had compared to low monitors increased needs to discuss various treatment options and medicine's side-effects. So, it can be argued that also treatment-related information and presumably diagnostic information should be tailored to the individual's wish. The approaches we will discuss next to tailor prognostic information can therefore also be applied to these and other (biomedical) areas of information.

Balancing explicit with general prognostic information: tailoring information

Although tailoring has beneficial effects [102], information-provision in the cancer setting seems largely standardized [34]. Therefore we would like to discuss three approaches which oncologist can use to tailor prognostic information. These approaches largely, though understandably, lack empirical testing.

First, in our qualitative study, participants reported that oncologists may use their intuition to tailor information. However, not without reason do oncologists report that they find the prognostic part of bad news consultations challenging [103]. Moreover, when oncologists use their intuition, their predictions of patients' preferences are often incorrect [104,105]. This might apply when they assume that low monitors, who do not often ask questions in palliative cancer consultations [50], benefit from general prognostic information. According to our experimental study low monitors benefited – even the most – from explicit information. This means that oncologists should not lightly infer that patients are not interested in getting more information, simply because they do not ask.

Therefore, a second approach is to ask patients about their preferences before discussing prognostic information. This can take the form of asking patients directly what kind of prognostic information they prefer and then provide this information [106]. Alternatively, oncologists can start by providing general prognostic information, and then ask patients whether this is enough (for now) or whether they prefer more explicit information. This second method was (in addition to the first method) stressed in our qualitative study.

Complicating the suggestion of determining patients' preferences to tailor information are the situations in which patients continue to ask questions, which might *not* best be handled with the provision of only more information. According to the literature, sometimes patients' body language reveals that they are overwhelmed, e.g. by looking down and avoiding eye-contact, while they say they want to receive much information. It has been advised that oncologists discuss what they observe and explore these emotions instead of providing more information [106]. High monitors might show this reaction as they are prone to ask questions in – palliative – cancer care [50,54] which might also reflect a sign of their increased emotional distress. Altogether sensing, checking and monitoring (both verbally, and nonverbally) how patients want to receive prognostic information and react on the information they receive seems essential.

Providing general or explicit prognostic information

Following these three approaches, the question arises what kind of words and/or numbers oncologists can use to discuss general or explicit prognostic information. The answer to this can only be hypothesizing. For patients who prefer general prognostic information, it might be enough to stress that the disease is incurable, e.g. by using statements like in our experimental study: *'You do have a very serious disease, which will limit your life expectancy. That is the only thing we can say for sure'.* However, information needs can change over time [107] and the initial stress of this diagnosis may lead to temporary denial [75]. It might be therefore wise to explain this to patients and empathize that they can always ask for more prognostic information at a later point in time and – ask permission to – provide the opportunity for this by raising the topic in future consultations [108].

However, the large majority of patients will probably prefer to receive immediately more explicit prognostic information. Based on the previous outlined approaches, we would suggest asking beforehand whether patients want statistical information. In our study, we used the question '*I can give you some concrete numbers and averages. Would you like me to discuss these with you?'*. Oncologists are often reluctant to provide statistical information, as this information does not apply to an individual [109,110]. Therefore, it might be wise to not only provide mean or median time frames, but also stress the inherent uncertainty of statistics for individual patients [71]. Patients themselves also sometimes stress that it is important to not be too definite with time frames, as patients might fixate on this [7]. Another important aspect of discussing statistical information might be to stress (positive and negative) outliers [106,111]. Both approaches were also applied in our experimental study, leading to the most beneficial results.

Balancing realism with hope

Providing realistic information

Few people would argue that patients do not need realistic information. As aforementioned, this does not imply that all patients have to be provided with very specific – statistical – information, but when such and other information is given it has to be realistic [21,24-26]. At the same time, our qualitative study indicated that the hope oncologists provide at the transition to palliative care needs to be realistic as well.

Providing hope: stressing (treatment)possibilities instead of impossibilities

Indeed, there might be different ways in which oncologists can still nurture patients' hope, even in the face of incurable illness. Based on the literature and our findings, we suggest that there are two – aforementioned – domains in which oncologists can provide hope; the medical domain and the domain of the doctor-patient relationship, using both instrumental and affective communication. In the medical domain it seems, following our qualitative study, hopeful to stress medical (treatment) possibilities; ranging from treatments to prolong life to (pain)medication to improve quality of life. It has been suggested in the literature that an approach to discover patients' hopes might be – again – to ask patients about them [112]. Taken these answers as starting point, oncologists can stress the possibilities that are realistic, thereby fostering patients' realistic hopes.

Providing hope: reassurance about non-abandonment
In the domain of the doctor-patient relationship using empathy can provide hope [23]. The use of affective statements ensuring non-abandonment might, according to our project, be especially promising. Following suggestions in the literature such a promise does not seem to imply that oncologists can never transfer patients to hospice care, palliative care teams or the general practitioner. It does seem to imply that this should be done gradually (i.e. palliative care teams should be introduced early [64-66]) and in consultation with the patient [70]. A continued role of general practitioners, as suggested in the literature [22,67-69] might be especially relevant in the Dutch setting, where every patient has a general practitioner whose role in providing (palliative) cancer care is likely to be strengthened in the future ([67] NHG personal communication). Unfortunately, nowadays general practitioners still often encounter problems in information-exchange and continuity of care when caring in out-of-hours shifts for patients in the palliative phase [113].

Hope for the best, prepare for the worst
According to clinical studies, in the personal domain of hope, the continuing hope of patients for a cure seems to exist in parallel with acknowledging the incurable status of the disease [42,60,74]. An useful approach has been put forward in the literature that sheds some light on this paradoxical future perspective, called *Hope for the best, prepare for the worst* [112]. According to this approach, as long as patients hope for the best (e.g. a miracle) but meanwhile acknowledge and prepare for the worst (e.g. they are making a living will), 'unrealistic' hope and realism can be present simultaneously. An example:
Doctor: "The cancer being in your bones means that though we still have treatments that can lengthen your life, this cancer won't ever completely go away."
Patient: "I have to keep my hope that I'll be cured."
Doctor: "I share that hope with you then. I'm wondering whether we could also talk about what will happen if things don't go as we hope." (page 422) [24].

Only in rare cases patients persist to deny the realistic information that they are dying, which in most cases might best be respected by oncologists [76-78].

Exploring previous experiences

Another element which oncologists could take into account when discussing the transition to palliative care are patients' previous experiences with cancer and palliative care, as they might influence their communication preferences [43] and presumably also their hopes [42]. As aforementioned, in our qualitative study when a loved one outlived a poor prognosis, women were less inclined to prefer explicit prognostic information.

Communication trainings

Last, we would like to pose suggestions regarding communication courses for medical oncologists. Oncologists find it difficult to discuss recurrence, the lack of further treatment options [114] and end-of-life issues [115]. In addition, they belief that a lack of training hampers effective communication [115,116]. Against this background it may see surprising that there is much heterogeneity in communication courses between different countries [117] and also within countries, such as the Netherlands.

When focussing on the Dutch situation, future oncologists ought to be good communicators [118]. However, there is no national obligatory curriculum on communication, not for trainees in internal medicine [118] neither for trainees in the subsequent medical oncology specialization [119]. The communication courses the university hospitals in the Netherlands provide for general medical specialist trainees seem to be heterogeneous. For example, only half of the medical centers seem to offer obligatory communication courses for medical specialists in training (in the undergraduate part of their training, communication courses are obligatory in all Dutch academic medical schools). Inquiries with representatives of all universities learned that all courses could focus on breaking bad news if participants wished to do so, or if they choose this specific module. However, only at two university medical centers the module 'breaking bad news' seems obligatory for trainees in general internal medicine. To the best of our knowledge most of the UMC's pay attention to communication skills during the subsequent specialization in medical oncology. However, only at one medical center a communication course is mandatory, which however does not include a specific module on the transition to palliative care or bad news consultations.[1]

It will come as no surprise that we would suggest that physicians in training of becoming oncologists (in whatever specialization be it, medical, surgical, gynaecological etc oncology), follow obligatory courses on communication, and on breaking bad news in particular. Although guidelines on breaking bad news might be taught earlier during medical school – as in this period there is much attention on communication courses – providing training in specific communication skills should be recommended during the specialization in oncology as at that time trainees are confronted in practice with similar situations. We therefore suggest that such communication trainings should be implemented nationwide, and follow national guidelines such as the recently renewed IKNL guideline [19]. This should be supplemented by the patient perspective on these guidelines, as we already discussed that patients' priorities might divert from professionals' priorities [120]. Last, in line with the suggestion of a European consensus meeting [117] it would be worthwhile that practicing oncologists follow 'booster-courses' during their working years in this 'art of medicine'. We would suggest that these communication courses take place every five years, so that oncologist keep up to date on the latest evidence-based knowledge on communication. This seems plausible, as communication influences patients' assessment of care profoundly [121] and communication courses can improve oncologists'

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[1] Websites of the UMCU, UMCG, UMCN, AMC, VUMC, EMC, LUMC and MUMC were searched and responsible representatives personally contacted to provide additional information about the content and obligation of the communication courses. Not all representatives responded.

communication skills when discussing the transition to palliative care [122].

Future studies

Finally, we would like to pose practical, theoretical and methodological suggestions for future studies. Practically, future studies might focus on the effect of more or less explicit prognostic information and the effect of offering reassurance about non-abandonment in clinical care. A related area to study is how reassurance about non-abandonment can be lived up to in busy clinical daily life. Last, more knowledge should be gathered on the patient perspective on communication. For example, the renewed IKNL guideline on breaking bad news was commented upon by experts, but – so far – not by patients (personal communication IKNL). The communication preferences of ethnic minority patients would be especially relevant to study in this regard, as this group is growing in the Netherlands and in non-Western cultures it is not so obvious to discuss an incurable diagnosis or prognosis [123].

In the theoretical domain, two areas deserve more attention. Firstly, in the current project, we focused on how oncologist can provide hope at the transition to palliative care and provided empirical evidence for the effect of reassurance about non-abandonment in this regard. However, as outlined in Chapter 1, hope is a multidimensional construct. For example, hope can be seen as a feeling or as an object (verb versus noun) [124], can focus on different domains [23,24] and can be particular (hope for a certain outcome such as making it till Christmas) as well as generic (a general positive future perspective) [125]. Acknowledging and focussing on these different faces of hope instead of trying to come to an overall definition might be more valuable in leading towards a better understanding of what hope comprises. Secondly, as already argued in Chapter 6, more research into the concept of monitoring would be worthwhile. High monitors might not have in all – aspects of –

situations an increased need for information compared to low monitors. Moreover, different monitoring questionnaires might come to different monitoring scores [49]. Last, monitoring scores are often unrelated, but occasionally related to other constructs (e.g. trait anxiety [126]).

Last, methodological issues warrant further investigation. This project has taken a first step in unravelling the validity of scripted video-vignettes studies including analogue patients, but there is still much knowledge to be gathered, regarding the effects of type of analogue patient, studied communication elements and outcome measures. More direct comparisons between clinical patients' perceptions (measured following a video-taped consultations) and analogue patients' perceptions are necessary.

Conclusion

This thesis provided more insight into the patient perspective on how oncologists when discussing the transition to palliative breast cancer care, can balance between i) giving explicit and more general – prognostic – information and between ii) being hopeful and realistic at the same time. Overall, explicit prognostic information was more appreciated than general prognostic information. Realistic hope can be created by stressing (treatment) possibilities and reassuring patients that they will not be abandoned. Empirical evidence for the effect of reassurance about non-abandonment was provided. Last, the use of scripted video-vignette studies including analogue patients seems to be a valid approach to study the patient perspective on communication, while taken into account described precautions. Most importantly, although more research is needed to translate our results to clinical care, the power of communication is once again stressed by the current project: explicit prognostic information and reassurance about non-abandonment can soften the impact of a devastating message as entering palliative cancer care.

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Samenvatting (Dutch Summary)

Introductie

Borstkanker is de meest voorkomende kanker voor vrouwen. Voor sommige patiënten komt een moment waarop duidelijk wordt dat zij niet meer van de ziekte kunnen genezen. Op dat moment start de zogenaamde ‘palliatieve fase’ waarin de behandeling primair gericht is op behoud van kwaliteit van leven. Wanneer bij (borst)kankerpatiënten een ongeneeslijke vorm van kanker wordt vastgesteld, stort hun wereld in. Bij de eerste diagnose ongeneeslijke vorm van kanker staat de confrontatie met de eindigheid van het menselijk bestaan voorop. Dit is het moment waarop bij uitstek een beroep gedaan wordt op de communicatieve vaardigheden van de medische – en andere – zorgprofessionals. Volgens een veel gebruikt model hebben patiënten in medische consulten twee behoeften: een *need to know and understand* (een behoefte aan informatie over wat er aan de hand is wat er gedaan kan worden) en een *need to feel known and understood* (een behoefte aan emotionele steun en gezien te worden als persoon). Om de onzekerheid en angst hanteerbaar te maken, kunnen oncologen reageren op deze twee behoeften door gebruik te maken van zogenoemde ‘instrumentele’ en ‘affectieve’ communicatie; zoals het geven van informatie en het bieden van empathie. Terwijl ze dit doen worden oncologen wel geconfronteerd met verschillende dilemma’s.

Expliciete versus algemene informatie en realisme versus hoop

Ten eerste is het vanuit de literatuur nog niet duidelijk hoe expliciet patiënten – prognostische – informatie willen. Enerzijds geven patiënten vaak aan ‘zoveel mogelijk’ informatie te willen ontvangen. Anderzijds is het ook gangbaar dat patiënten zeggen ‘niet teveel’ informatie te willen. Een substantiële minderheid van de patiënten wil inderdaad geen volledige openheid over hun levensverwachting (prognose). Mensen die hoog scoren op het persoonlijkheidskenmerk ‘monitoring’ (de mate waarin mensen onder dreiging zoeken naar informatie) lijken een grote behoefte aan informatie te hebben (en ook aan empathie). Ten tweede hebben patiënten zowel behoefte aan hoop als aan realisme. Hoop wordt vaak geassocieerd met hoop op genezing en/of een langere tijd te leven. Doordat veel patiënten ook in de palliatieve fase nog blijven hopen op genezing, wordt de indruk gewekt dat artsen moeten kiezen tussen het geven van hoopvolle of realistische informatie. Echter, het lijkt erop dat hoop in de palliatieve fase niet beperkt is tot hoop op genezing, maar dat het een breder concept is. Er lijken meerdere manieren te bestaan om patiënten hoop te bieden tijdens de overgang naar de palliatieve fase, zoals door het gebruik van empathie.

Experimenteel scripted video-vignette onderzoek

De meeste studies naar het patiëntperspectief op communicatie worden in de klinische setting uitgevoerd, maar aan deze methode kleeft een aantal nadelen. Zo is het onmogelijk om in klinische interacties communicatie te standaardiseren, is het vaak onethisch om communicatie systematisch te manipuleren, en wordt communicatie vaak gezien als ‘containerbegrip’ zonder oog te hebben voor de specifieke elementen waaruit communicatie bestaat. Er is dan ook behoefte aan experimenteel onderzoek, waarbij het (causale) effect van communicatie kan worden onderzocht, met aandacht voor de specifieke elementen waaruit die communicatie bestaat.

Een manier om experimenteel onderzoek te doen is door gebruik te maken van gescripte video-vignetten. Bij deze methode ontwikkelen onderzoekers verschillende versies van een script waarin een gesprek tussen een arts en patiënt letterlijk is uitgeschreven. Alle communicatie wordt gelijk gehouden tussen deze versies, terwijl er één of twee elementen systematisch worden gevarieerd. Er kan bijvoorbeeld een basisscript worden ontwikkeld en een extra script waarin drie empathische opmerkingen worden toegevoegd (om het effect van empathie te onderzoeken). Deze scripts worden uitgespeeld (door acteurs of echte artsen/patiënten), opgenomen op video en dan gebruikt in een experiment. In dit experiment wordt aan (ex)-patiënten en/of gezonde mensen (zogenaamde ‘analoge patiënten’) gevraagd om te kijken naar één of meerdere video’s, zich in te leven in de patiënt in de video en dan de communicatie te beoordelen vanuit dit patiëntperspectief.

Doelen

Het primaire doel van dit proefschrift is om meer inzicht te verschaffen in het patiëntperspectief op optimale communicatie tijdens het slechtnieuwsgesprek waarin de overgang naar de palliatieve fase in borstkanker wordt besproken. Hiervoor richten we ons op het beantwoorden van de vraag hoe oncologen het beste kunnen balanceren tussen i) het geven van expliciete versus algemene – prognostische – informatie, en ii) het bieden van hoop en realisme op hetzelfde moment (oftewel: hoop bieden zonder de werkelijkheid geweld aan te doen). Voor dit tweede dilemma richten we ons vooral op het potentieel van affectieve communicatie om hoop te bieden. Een tweede doel van dit proefschrift is om meer inzicht te verschaffen in en bewijs te bieden voor de validiteit van gescripte video-vignette studies inclusief analoge patiënten om het patiëntperspectief op communicatie systematisch te onderzoeken.

Samenvatting van de belangrijkste resultaten per onderzoeksfase

Dit proefschrift is opgebouwd uit 3 delen/fasen: i) de kwalitatieve studie, ii) de methodologische fase, en iii) de experimentele studie. De belangrijkste resultaten per onderzoeksfase zullen achtereenvolgens besproken worden.

De kwalitatieve studie

In de kwalitatieve studie (Hoofdstuk 2) voerden we groepsgesprekken met ex-borstkankerpatiënten en gezonde vrouwen over hoe oncologen bij het bespreken van de overgang naar de palliatieve fase kunnen balanceren tussen het geven van expliciete versus algemene en realistische versus hoopvolle informatie. De participanten gaven aan dat als zij de boodschap zouden krijgen dat ze ongeneeslijk ziek zijn, zij hun gevoel van toekomstperspectief zouden verliezen. Een belangrijke rol voor de oncoloog zou moeten zijn patiënten gedurende dit gesprek te helpen dit toekomstperspectief te hervinden. Dit zou moeten geschieden door eerst eerlijke persoonlijke medische informatie en informatie over beschikbare steun te verschaffen. Diagnostische informatie wilden de meeste vrouwen expliciet ontvangen, terwijl informatie over behandelingen pas op een later moment expliciet hoefde te worden. Participanten verschilden sterk ten aanzien van hoe expliciet ze prognostische informatie wilden ontvangen. Een interessante bevinding uit deze kwalitatieve studie was dat hoop vele gezichten heeft. Hoop kan worden gegeven, door het benadrukken van medische (behandel)mogelijkheden, maar ook door te benadrukken dat de patiënte niet verlaten zal worden gedurende het ziekteproces. Hoop is daarnaast ook iets dat van ‘binnenuit’ komt, zoals de hoop op een wonder. Veel vrouwen wilden nog het gevoel hebben eigen keuzes te kunnen maken gedurende hun ziekteproces, wat ook als hoopvol werd ervaren. Participanten gaven aan dat patiëntvoorkeuren kunnen variëren. Oncologen moeten daarom hun communicatie aanpassen (‘tailoren’) aan de individuele patiënt, door het gebruik van intuïtie of door patiënten te vragen naar hun voorkeuren. Als laatste werd het belangrijk gevonden dat een arts de indruk wekt genoeg tijd te hebben en een empathische, maar tegelijkertijd professionele houding heeft.

De methodologische fase

In Hoofdstuk 3 is door middel van een systematische literatuurstudie getracht meer inzicht te geven in de validiteit van video-vignette studies inclusief analoge patiënten. Zowel studies die video’s gebruikten van klinische consulten (klinische studies) als die gescripte, geacteerde video’s (scripted studies) gebruikten werden geïncludeerd. Scripted studies gaven meer specifieke (methodologische) redenen voor het uitvoeren van een video-vignette onderzoek dan klinische studies. Daarnaast besteedden deze studies ook meer aandacht aan interne validiteit (experts of analoge patiënten werden bijvoorbeeld betrokken in de creatie van de scripts), en externe validiteit (analoge patiënten gaven bijvoorbeeld aan hoe goed ze zich konden inleven in de video-patiënt). De percepties van analoge patiënten op communicatie kwamen grotendeels overeen met de percepties van klinische patiënten zoals gevonden in de literatuur, terwijl ze minder vaak extreem positief waren over communicatie.

Op basis van de resultaten van de kwalitatieve studie besloten we het effect van algemene versus expliciete prognostische informatie en minder versus meer geruststelling voor blijvende begeleiding (operationalisatie van de term ‘hoop’) meer in detail te onderzoeken. Hiervoor werden vier gescripte video-vignetten ontwikkeld van een slechtnieuwsgesprek waarin een arts de overgang van de curatieve naar de palliatieve fase bespreekt met een borstkankerpatiënte (Hoofdstuk 4). Deze video’s waren nagenoeg gelijk aan elkaar; zij verschilden slechts in de mate waarin de arts expliciet was over de prognose (hoog versus laag) en de mate waarin de arts de patiënt geruststelde dat ze niet alleen zou worden gelaten gedurende haar ziekte (hoog versus laag). Ook werd er een introductie-video gecreëerd waarin de video-patiënte zichzelf voorstelde om het daarmee voor de participanten gemakkelijk te maken zich met de patiënte in de video te identificeren. Oncologen, communicatie-onderzoekers, ex-patiënten en gezonde vrouwen waren betrokken in de ontwikkeling van de scripts. Dit verzekerde dat deze realistisch waren en de manipulaties succesvol (externe versus interne validiteit). De scripts werden uitgespeeld door professionele acteurs en in een experiment getoond aan analoge patiënten, ((ex-)patiënten en gezonde vrouwen) die wederom het succes van de manipulaties bevestigden.

De experimentele studie

In het experiment werden de vier video’s getoond aan (ex-) borstkankerpatiënten en gezonde vrouwen die zich inleefden in de video-patiënte en de communicatie van de arts beoordeelden vanuit dat patiëntperspectief. De video waarin de arts zowel expliciet als geruststellend was leidde tot de beste uitkomsten (de laagste gevoelens van onzekerheid en angst, en hoogste gevoelens van tevredenheid en self-efficacy). De video waarin de arts algemeen bleef en geen geruststelling gaf leidde tot de slechtste uitkomsten. Zowel expliciete als geruststellende informatie leidden, afzonderlijk van elkaar, tot de beste uitkomsten. Tegen onze verwachting in vonden we dat vrouwen die hoog scoorden op ‘monitoring’ minder positief reageerden op expliciete informatie dan vrouwen die laag scoorden op ‘monitoring’, en leek het erop dat ze ook geneigd waren minder positief te reageren op geruststellende informatie (Hoofdstuk

5). In Hoofdstuk 6 keken we in meer detail naar het concept monitoring. We vonden dat hoog monitors verschilden van laag monitors in verschillende achtergrondkenmerken en dat hoog monitors een grotere behoefte hadden aan verschillende vormen van affectieve en instrumentele communicatie. Daarnaast reageerden ze met meer stress op de vier video's dan laag monitors. Hoewel ze geen grotere behoefte hadden aan expliciete prognostische informatie en geruststellende informatie over blijvende begeleiding, leidden deze communicatiestijlen over het algemeen wel tot de beste uitkomsten voor alle monitoring scores.

Discussie en aanbevelingen voor de praktijk

Balans tussen expliciete en algemene – prognostische – informatie

Uit dit proefschrift bleek dat de meeste participanten diagnostische informatie meteen en behandelinformatie pas op een later moment expliciet wilden bespreken. Hoog monitors vormen hier wellicht een uitzondering op, zij hechtten, meer dan laag monitors, belang aan het bespreken van behandelinformatie (inclusief bijwerkingen).

De balans tussen het geven van expliciete en algemene informatie moet waarschijnlijk het meest worden gezocht tijdens het bespreken van de prognose. De meeste participanten waardeerden expliciete prognostische informatie meer dan wanneer de arts alleen in algemene termen sprak over de levensverwachting. Deze informatie is bijvoorbeeld nodig voor het nemen van (behandel)beslissingen. Een minderheid van de participanten bleef echter liever onzeker over hun precieze levensverwachting.

Op basis van de resultaten van ons project lijkt een aantal achtergrondkenmerken een mogelijke relatie te hebben met een behoefte aan meer of minder expliciete prognostische informatie. Hieronder vallen de behoefte aan controle (meer behoefte aan controle lijkt te zijn gerelateerd aan een grotere behoefte aan expliciete informatie) en eerdere ervaringen met kanker (wanneer participanten hadden meegemaakt dat geliefden langer leefden dan de prognose, hadden ze vaker een voorkeur voor meer algemene prognostische informatie). Tegengesteld aan onze verwachtingen waren hoog monitors degenen die het minst (maar wel nog steeds) profiteerden van expliciete prognostische informatie. Dit komt mogelijkerwijs door de oncontroleerbaarheid van het beloop van een ongeneeslijke ziekte. Al kunnen achtergrondkenmerken informatiebehoeften beïnvloeden, informatie moet altijd worden aangepast aan de behoeftes van iedere individuele patiënt (dit wordt ‘tailoren’ genoemd).

Er zijn verschillende manieren beschreven in de literatuur – en in mindere mate in onze studie – over hoe oncologen prognostische informatie kunnen tailoren. Ten eerste kunnen artsen hun intuïtie gebruiken. Dat is wel moeilijk (ondefinieerbaar, niet aan te leren) en kan tot foutieve inschattingen leiden. Dit laatste zou vooral kunnen gebeuren bij laag monitors, die niet vaak vragen stellen, maar, zoals onze experimentele studie liet zien, wel profiteerden van expliciete prognostische informatie. Een tweede optie is om patiënten te vragen naar hun informatiebehoefte. Dit kan door hen eenmaal te vragen of ze liever expliciete of algemene informatie krijgen, maar kan ook door te beginnen met het geven van algemene informatie en aansluitend te vragen of dit genoeg is of niet. Deze twee mogelijkheden werden genoemd in onze kwalitatieve studie. Als laatste wordt in de literatuur ook gesteld dat patiënten soms zeggen dat ze veel informatie willen, terwijl hun lichaamstaal laat zien dat ze overweldigd zijn. Dit is mogelijkerwijs een reactie van hoog monitors, die vaak veel vragen stellen, wat ook een teken van hun emotionele stress kan zijn. In dit soort situaties wordt aangeraden om eerst stil te staan bij deze emoties in plaats van meer informatie te geven.

Balans tussen realisme en hoop

Uit dit proefschrift bleek dat de balans tussen realisme en hoop kan worden gevonden in het bieden van realistische vormen van hoop. Realistische informatie was voor participanten in onze kwalitatieve studie eenduidig. Hoop leek ondertussen vele gezichten te hebben. Artsen moeten zich ervan bewust zijn dat ze in een medisch uitzichtloze situatie toch hoop kunnen geven, bijvoorbeeld door te benadrukken dat de patiënt er nooit alleen voor zal komen te staan.

Uit de literatuur blijkt al dat empathie (affectieve communicatie) hoop kan bieden en patiënten geruststellen dat ze blijvend zullen worden begeleid is volgens ons project hierin een veelbelovende methode. Een dergelijke geruststelling hoeft, zoals onze experimentele studie liet zien, niet veel tijd te kosten, maar kan wel een groot effect sorteren. Enkele kanttekeningen bij het geven van geruststelling voor blijvende begeleiding als vorm van hoop werden wel genoemd in dit proefschrift. Deze belofte moet bijvoorbeeld wel waargemaakt worden. In de literatuur wordt gesuggereerd dat het zinvol is dat palliatieve zorgteams al vroeg in de palliatieve fase betrokken worden evenals het belang van de continue rol van de huisarts. Als laatste bleek uit onze kwalitatieve studie – en de literatuur – dat hoop ook kan worden geboden door instrumentele communicatie, namelijk door het bespreken van realistische (behandel)opties om de kwaliteit van leven te verbeteren en om het leven te verlengen.

Validiteit van scripted video-vignette studies inclusief analoge patiënten

Het tweede doel van dit proefschrift was meer inzicht te verschaffen in de validiteit van gescripte video-vignette studies inclusief analoge patiënten, waarvoor we verder bewijs vonden. Door middel van deze methodologie is het mogelijk om het causale effect van specifieke communicatie-elementen te bepalen, door deze te testen in laboratorium-achtige settings waarbij groepen participanten dezelfde video(s) zien en beoordelen. Scripted video-vignette studies besteedden volgens onze literatuurstudie over het algemeen meer aandacht aan validiteit dan klinische studies. Een sterk punt van ons project was dat zowel experts als leken betrokken werden om de validiteit van de scripts te waarborgen. Een beperking van onze benadering was dat er geen patiënten in de palliatieve fase betrokken waren bij de validering van de scripts en dat we in de experimentele studie niet gemeten hebben hoe goed analoge patiënten zich konden inleven in de video-patiënte. Uit het systematisch literatuuronderzoek bleek verder dat de perceptie op communicatie van analoge patiënten grotendeels overeenkomt met die van klinische patiënten. In de experimentele studie reageerden gezonde vrouwen en (ex-)patiënten hetzelfde op de vier video's. Dit duidt erop, in lijn met voorgaande studies, dat gezonde vrouwen kunnen worden ingezet om het effect van communicatie in de oncologische setting te onderzoeken. Aan het gebruik van scripted video-vignette studies inclusief analoge patiënten kleven natuurlijk ook beperkingen. Zo is het bijvoorbeeld niet mogelijk om het effect van een langdurige arts-patiënt relatie te onderzoeken.

Conclusie

Dit proefschrift verschafte inzicht in het patiëntperspectief op hoe oncologen, tijdens het bespreken van de overgang van de curatieve naar de palliatieve fase van borstkanker, kunnen balanceren tussen het geven van expliciete en algemene – prognostische – informatie, en hoop kunnen bieden zonder de werkelijkheid geweld aan te doen. Het gebruik van een scripted video-vignette studie inclusief analoge patiënten om dit te onderzoeken bleek valide te zijn. Hoewel meer onderzoek nodig is om onze resultaten naar de klinische praktijk te kunnen vertalen onderstreept dit proefschrift opnieuw het effect van communicatie: zowel expliciete prognostische informatie als de geruststelling voor blijvende begeleiding kunnen de vaak verwoestende impact van de diagnose van een ongeneeslijke vorm van (borst)kanker verzachten. Daarbij moet benadrukt dat in deze tijd waarin ‘personalized medicine’ het sleutelwoord is in de behandeling van onder andere patiënten met kanker, ook de communicatie ‘tailored’ moet zijn op de individuele patiënt.

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Curriculum Vitae

Liesbeth van Vliet was born on 20 January 1985 in Lusaka, Zambia. She studied Clinical Psychology at the Erasmus University Rotterdam, the Netherlands from which she graduated in 2008. For her master thesis she performed a study at the Erasmus MC-Sophia Children's Hospital Rotterdam on the impact of paediatric palliative cancer care on parents' psychological distress following the death of their child. From 2007-2008 she worked as a scientific teacher in Psychology at the Erasmus University Rotterdam. In 2008 she started with her PhD project at NIVEL, which was part of the SPINOZA program of Prof. dr. Jozien Bensing. During her PhD project, she was a member of the international research groups 'GULIVeR' and 'Verona Sequence Analysis'. From October-December 2012 she finished her PhD project as a visiting scholar at King's College London, Department of Health Psychology. Since January 2013 she is working as a senior researcher at the Cicely Saunders Institute, King's College London, in the EURO-IMPACT project (European Intersectorial and Multi-disciplinary Palliative Care Research Training). In this position she is currently writing a guideline on the clinical applicability of symptom assessment in palliative care.

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