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COMMUNICATING ABOUT CONCERNS IN ONCOLOGY

KIM BRANDES



COMMUNICATING ABOUT CONCERNS IN ONCOLOGY

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The research described in this dissertation was conducted at the Amsterdam School of Communication Research (ASCoR), University of Amsterdam, the Netherlands. The research was funded by the Netherlands Organisation for Scientific Research (NWO Graduate Programme).

Communicating about concerns in oncology

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CHAPTER 1: INTRODUCTION

“You are always afraid. You don't have trust in your own body any more. Cancer, the total package, the uncertainty, it is horrible”

(female cancer patient who participated in a focus group; chapter 5 and 6).

The majority of cancer patients and survivors (64%) experience serious concerns such as fear (Dutch Cancer Society, 2016). When such concerns accumulate, they can lead to high levels of psychological distress which can be detrimental for patients and survivors. For instance, psychological distress can worsen pain or lead to depression (Chochinov, 2001; Heaven & Maguire, 1998). To prevent such an accumulation of concerns, it is important that healthcare providers and patients communicate about concerns in an optimal way (Ryan et al., 2005).

Optimal communication about concerns can be enhanced if patients participate actively by expressing their concerns in a consultation (Street, Makoul, Arora, & Epstein, 2009; Street, 2001). Providers can contribute to optimal communication about concerns by listening actively, exploring concerns and responding with empathy (Back & Arnold, 2014; Ryan et al., 2005). This optimal communication is associated with positive outcomes for patients such as reduced levels of psychological distress and better well-being (de Haes & Bensing, 2009; Street et al., 2009). However, optimal communication is hard to achieve. For example, many patients feel that their concerns have not been discussed optimally (Farrell, Heaven, Beaver, & Maguire, 2005; Hill, Amir, Muers, Connolly, & Round, 2003). One of the reasons for suboptimal communication about concerns is that patients often do not express their concerns explicitly but rather express them implicitly as indirect cues or hints (Grimsbø, Ruland, & Finset, 2012; Zimmermann, Del Piccolo, & Finset, 2007). These indirect cues and hints are difficult to recognize and providers are therefore sometimes unable to address concerns, or lack the skills that are essential for effective cue responding (Butow, Brown, Cogar, Tattersall, & Dunn, 2002). Another reason is that, instead of actively stimulating patients to express their concerns clearly, providers often wait until a patient expresses one. Patients, however, often do not initiate concern expression themselves (Hack, Degner, & Parker, 2005). It is still unclear why patients often do not initiate concern expression in a consultation despite the possible benefits.

To date, most research about optimizing the communication of concerns has been focused on the behavior of the provider and not on the behavior of the patient (Zimmermann et al., 2007). Similarly, there is a lack of knowledge about how patients can be optimally supported to express their concerns. This dissertation therefore aims to gain insight into how communication about concerns during a consultation can be improved by exploring the factors that explain and support patients' concern expression. What explains and what supports concern expression is examined from two different

theoretical perspectives; a behavior change perspective and a stress-coping perspective. Hereafter, the focus of this dissertation, the current state of the literature on concern expression and both theoretical perspectives are discussed.

Focus on the patient

The focus of this dissertation is on the patient. In healthcare research, patient-centered care is nowadays seen as a “golden standard”. A central part of patient-centered care is that care is provided according to the preferences, values and needs of the patient (Epstein et al., 2005). In line with patient-centered care, research about patient-provider communication has shifted in the past decades from a paternalistic bio-medical model, in which providers guide the communication in consultations, to a bio-psychosocial model, in which the patient is central and the needs and preferences of the patient should guide the communication (Bensing & Verhaak, 2004). Due to these changes in healthcare and patient-provider communication, both patients and providers have the responsibility to contribute to the consultation. It is therefore important that a patient clearly indicates his or her needs and preferences and concern expression is one of the possibilities to do that (Street, 2001). Expressing concerns in a consultation can be difficult for patients and they might therefore benefit from interventions that aim to improve their concern expression. Most research on concern expression, however, has focused on interventions to improve the communication of the provider (e.g., elicitation of concerns and responding to expressed concerns; Zimmermann et al., 2007). While this research is of great importance, additional research on the patient is needed to explain and support patients’ concern expression. Therefore, patients are the focus of this dissertation.

Concerns and concern expression

Concerns can comprise a variety of topics like concerns about medical topics such as side-effects of treatment, psychosocial topics such as the emotional burden a partner and/or children might experience, and practical topics such as work (Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premlatha, 1996; Mellblom et al., 2014). Until now, concern expression in consultations is mainly examined by investigating which concerns patients have and asking whether patients felt that their concerns were discussed (e.g., Farrell et al., 2005; Hill et al., 2003). Furthermore, studies have used coding manuals such as the VR-CODES (Del Piccolo et al., 2011; Zimmermann et al., 2011) and the Roter Interaction Analysis System (RIAS; Roter & Larson, 2002) to assess the number of actual expressed concerns in a consultation and the responses of providers. Concerns and concern expression are operationalized differently across studies. To illustrate, in some studies that use concern lists (i.e., lists with topics of concerns that patients can fill out prior to their consultation) to gain insight into what kind of topics patients are concerned about, concerns are operationalized as “issues

of importance” (e.g., Heaven & Maguire, 1998). In studies using a coding manual to assess the number of concerns that are expressed in consultations, concerns are operationalized as “emotions” and concern expression as “an explicit expression of an emotion” (VR-CoDES; Del Piccolo et al., 2011; Zimmermann et al., 2011). In part 1 of this dissertation the latter operationalization of concern expression is used. We chose this operationalization because it is widely used in the concern expression literature.

Interventions to support concern expression

Various interventions have been developed to stimulate concern expression in oncology consultations. These interventions are mostly focused on providers’ communication and consisted of communication skills trainings with the aim to improve providers’ elicitation of concerns (e.g., Butow et al., 2008; Heaven & Maguire, 1996) and providers’ responses to patients’ expressed concerns (e.g., Butow et al., 2008). The provider interventions, however, have shown only small or no effects on providers’ elicitation of concerns (Butow et al., 2008; Heaven & Maguire, 1996). Patient interventions have mainly focused on the use of concern lists prior to consultations (e.g., Ghazali, Roe, Lowe, & Rogers, 2013; Ghazali, Roe, Lowe, & Rogers, 2015; Heaven & Maguire, 1998). Some concern lists are also used as aids for both the patient and the provider (Heyn, Ruland, & Finset, 2012; Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008). These patient interventions have shown that they are helpful for providers to identify distress in patients (Tuinman et al., 2008). One study also showed that a concern list can lead to significantly more expressed cues and concerns in an oncology consultation (Heyn et al., 2012). However, the number of clear expressed concerns in this study only comprised 18.7% of the total expressed cues and concerns. Thus, concern expression might not have been supported in the most optimal matter in this study. In order to know how to support patients’ concern expression, it is crucial to first understand what factors explain why some patients do and other patients do not express their concerns. When these factors are known, concern expression can be targeted in an intervention accordingly.

Two theoretical perspectives

To examine what explains and supports patients’ concern expression, two theoretical perspectives are used in this dissertation; a behavior change perspective (part 1 of the dissertation) and a stress-coping perspective (part 2 of the dissertation). These two different theoretical perspectives were adopted to explore concern expression as thoroughly as possible. The behavior change perspective was chosen because it offers guidance in how to identify determinants that explain a behavior (in this case concern expression) and intervention targets that can support a behavior (specific elements of determinants that can be targeted in an intervention to affect a change). Using a behavior change

theory has the advantage that determinants are proposed that are expected to have a causal relation with intention and behavior (Michie & Abraham, 2004; Michie & Prestwich, 2010). Thus, when little is known about what explains a behavior (as it was the case of concern expression), a behavior change theory can offer a good starting point to unravel underlying determinants. Where the behavior change perspective has behavior (i.e., concern expression in the consultation) as an endpoint, the stress-coping perspective sheds light on what can possibly happen when concerns are expressed in a consultation (i.e., providers' responses to concern expression and consequences for coping). Furthermore, in addition to the behavioral determinants that are proposed by the behavior change perspective, the stress-coping perspective offers insights into other factors that can explain concern expression, namely the needs that patients have prior to the consultation (Bensing & Verhaak, 2004). Thus, the stress-coping perspective was chosen for its potential to offer another perspective into what explains and supports concern expression.

A behavior change perspective (part 1 of the dissertation)

Interventions that are developed via a behavior change approach (i.e., first identifying determinants that might serve as intervention targets and then developing an intervention accordingly) have been shown to be more effective in changing intentions and behaviors than interventions that do not follow this approach (Avery, Donovan, Horwood, & Lane, 2013). The integrative model of behavioral prediction (IMBP; Fishbein, 2000) was chosen in this dissertation as a starting point to identify determinants that explain patients' intention to express concerns in consultations. The IMBP was selected because it incorporates determinants such as attitudes and self-efficacy. Some of these determinants have been proposed in qualitative studies as possible determinants of concern expression (e.g., van Bruinessen et al., 2013; Henselmans et al., 2012). The IMBP posits that behavior is determined by the intention to perform the behavior. An intention is formed on the basis of someone's attitude (i.e., positive and negative feelings and attributes towards the behavior), perceived social norm (i.e., the extent to which individuals believe that others want them to perform the behavior) and self-efficacy (i.e., the extent to which an individual thinks that he or she is capable of performing the behavior). Further, the IMBP proposes that an individual should not encounter any barriers and must possess the adequate skills to perform the behavior in order to translate an intention into actual behavior (Fishbein, 2000; Fishbein & Yzer, 2003; Fishbein & Cappella, 2006).

After the determinants have been tested to establish which ones have a causal relation with patients' intention to express concerns, an intervention can be developed in which these determinants are targeted (Fishbein & Cappella, 2006). Ideally, the determinants will be targeted separately and together to clearly investigate the change generating process (i.e., exploring whether targeting a

determinant resulted in a change in intention or not; Michie & Abraham, 2004). Although the IMBP approach has been used in many studies to change intentions and behaviors (e.g., Boudewyns & Paquin, 2011; Robbins & Niederdeppe, 2015; Zhao et al., 2006), it has never been applied to concern expression. The behavior change perspective is adopted in this dissertation to examine whether it is an appropriate model for explaining and supporting concern expression.

The stress-coping perspective (part 2 of the dissertation)

Next to understanding the underlying determinants of concern expression, it is important to understand how the nature of concerns can impact patients' concern expression. While there are no specific behavior change theories in which the nature of concerns are embedded, stress-coping theories (e.g., the stress-coping model) can offer guidance because in these theories concern expression is incorporated. The stress-coping model (Bensing & Verhaak, 2004) is a framework that incorporates patients' needs to express concerns and might therefore complement the IMBP in unravelling what explains and supports concern expression. The stress-coping model explains that stress in patients can lead to two different needs; an instrumental need and an emotional need. An instrumental need refers to the need to know and understand (e.g., information about symptoms and side-effects). An emotional need refers to the need to feel known and understood (e.g., the need for emotional support and to express concerns). This framework proposes that a provider should respond with instrumental behavior when an instrumental need is expressed (e.g., providing information). This could lead to problem-focused coping. When an emotional need is expressed, a provider should respond with an emotional behavior (e.g., showing empathy), which can result in emotional coping. The needs that patients have are possibly related to the nature of patients' concerns. For example, patients experience concerns about topics that are instrumental (e.g., medical topics) and topics that are emotional (e.g., psychosocial topics). We adopted the stress-coping perspective to qualitatively investigate how the nature of patients' concerns can be understood and how these insights can be used to explain and support concern expression.

Aim of the dissertation

The aim of this dissertation is to gain insight into how communication about cancer patients' concerns during a consultation can be improved. In order to address this aim, two research questions are proposed:

1. What explains cancer patients' concern expression during consultations?
2. What supports cancer patients' concern expression during consultations?

Dissertation outline

This dissertation consists of five papers that are based on four different datasets. **Chapters 2 and 3** are based on one survey dataset. **Chapters 5 and 6** are based on one focus group dataset.

Chapter 4 consists of two studies based on two datasets. In **part 1 (chapters 2, 3 and 4)** concern expression is examined from a behavior change perspective and in **part 2 (chapters 5 and 6)** from a stress-coping perspective (see Figure 1 for the outline of the dissertation). The studies and outline of this dissertation are based on progressive insights, which means that the aim and research questions of a subsequent study were inspired by the results of the previous studies.

Chapter 2 examines which types of barriers, i.e., barriers related to the behavior of the provider, barriers related to the logistics of a consultation and/or barriers related to the legitimacy of expressing concerns, are most influential in preventing patients' concern expression during a consultation.

Chapter 3 investigates which determinants, derived from the IMBP, are related to patients' intention to express concerns in a consultation. Further, it is examined which content of the determinants needs to be targeted in an intervention to accomplish a change in intention. **Chapter 4** then tests the effects of messages in which the determinants are targeted separately and together on patients' attitudes, perceived social norm and intention to express concerns. Additional analyses are performed to explore the differences between patients who had a potential to change and those who had no potential to change. In **chapter 5**, patients' concerns are explored qualitatively and classified according to the stress-coping model into instrumental and emotional concerns. A new framework is proposed in which the nature of patients' concerns is embedded. In **chapter 6** patients' needs for interpersonal and mediated communication support in expressing concerns are assessed. A framework for the different needs for support for instrumental and emotional concerns about medical, psychosocial and practical topics is presented. Last, **chapter 7** provides the summary, general discussion and conclusion of this dissertation. Furthermore, implications for future research and practice are discussed.

	Behavior change perspective	Stress-coping perspective
Explaining concern expression	Chapters 2 and 3	Chapter 5
Supporting concern expression	Chapter 4	Chapter 6

Figure 1. Outline of the dissertation

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PART 1:
BEHAVIOR CHANGE PERSPECTIVE





CHAPTER 2:

PATIENTS' REPORTS OF BARRIERS TO EXPRESSING CONCERNS DURING CANCER CONSULTATIONS

An adapted version of this chapter was published as Brandes, K., Linn, A.J., Smit, E.G., & van Weert, J.C.M. (2015). Patients' reports of barriers to expressing concerns during cancer consultations. *Patient Education and Counseling*, 98, 317-322. doi: 10.1016/jpec.2014.11.021

Abstract

The objective was to identify cancer patients' most influential barriers to expressing concerns during cancer consultations in a new manner by examining patients' reports of perceived barriers and perceived occurrence of barriers in consultations. Two online focus groups ($N = 16$) and an online survey ($N = 236$) were conducted among cancer patients and cancer survivors. The online focus groups and survey were used to examine two elements of patients' barriers, i.e., patients' reports of possible barriers and perceived occurrence of these barriers in consultations. Composite scores of these two elements were calculated to determine influential barriers. Results showed that the most influential barriers were related to providers' behavior (e.g., providers do not explicitly invite patients to express concerns) and the logistics of the consultation (e.g., perceived lack of time). To conclude, the results of this study indicate that influential barriers to expressing concerns are barriers that patients cannot overcome themselves (i.e., they are related to providers' behavior or logistics of the consultation). A collaborative approach between researchers, providers and policy makers is needed to overcome these barriers. The results of this study can be used to develop strategies to overcome barriers to patients expressing concerns.

Introduction

Almost 38% of the cancer patients experience clinical psychological distress of such high levels that it requires treatment (Carlson et al., 2004). Unfortunately, psychological distress is not often detected by healthcare providers, which can affect patients' suffering and impair their overall well-being (Chochinov, 2001; Ryan et al., 2005). If patients clearly express their concerns in a consultation, providers' recognition of psychological distress can improve (de Haes & Bensing, 2009; Ryan et al., 2005; Street, Makoul, Arora, & Epstein, 2009; Street, 2001). However, patients often do not clearly express their concerns but rather express concerns as indirect cues (Grimsbø, Ruland, & Finset, 2012; Heyn, Ruland, & Finset, 2012; Zimmermann, Del Piccolo, & Finset, 2007).

Patients' tendency to express their concerns as cues can be problematic since providers often find it difficult to detect cues (Butow, Brown, Cogar, Tattersall, & Dunn, 2002). Patients clearly expressing their concerns can therefore be beneficial for both the provider (e.g., the provider gets more insight into what is going on with the patient) and the patient (e.g., the patient could receive relevant information to deal with concerns). However, many cancer patients experience communication barriers that may prevent them from clearly expressing their concerns during a consultation (Henselmans et al., 2012; Okuyama et al., 2008; Sepucha, Belkora, Mutchnick, & Esserman, 2002; Street, 2001).

Studies on communication barriers have mainly explored barriers to patient participation in general (Henselmans et al., 2012; Sepucha et al., 2002; Street, 2001). Although expressing concerns is a component of patient participation (Street, 2001; Street & Millay, 2001), studies hardly differentiate between expressing concerns and other components of patient participation such as question asking. Barriers to expressing concerns can differ from barriers to question asking. Patients will express concerns to satisfy an affective need (i.e., the need to feel known and understood) and to facilitate emotional coping with their disease while they will ask a question to satisfy an instrumental need (i.e., the need to know and understand) to facilitate problem-oriented coping (Bensing & Verhaak, 2004). Hence, studies that focused on barriers of patient participation in general might not have captured the differences between barriers to expressing concerns and question asking and knowledge on the barriers to expressing concerns is lacking.

To our knowledge, there is only one study that did specifically examine cancer patients' perceived barriers to expressing concerns (Okuyama et al., 2008). This study provided valuable insight into patients' barriers, but it did not assess patient reports explaining whether patients perceive the

occurrence of these barriers in cancer consultations or not. More insights into patients' reports of their experiences with the occurrence of barriers in consultations can be relevant to determine the magnitude of the barriers. Especially since patients' experiences with communication in consultations is one of the core elements of patient-centered communication (Epstein et al., 2005). Thus, in order to develop good strategies to overcome patients' barriers, the actual experiences of patients need to be taken into account. Therefore, this study aims to examine patients' barriers to expressing concerns in a new manner, namely by creating a composite score of patients' reports of possible barriers and perceived occurrence of the barriers in cancer consultations to determine the most influential barriers to expressing concerns.

Types of barriers

In this study three types of barriers to expressing concerns are distinguished: (1) barriers related to the providers' behavior (2) barriers related to the logistics of the consultation and (3) legitimacy barriers. Communication barriers regarding providers' behavior have been described extensively in the patient participation literature (Henselmans et al., 2012; Sepucha et al., 2002; Street, 2001). For example, when providers do not explicitly invite patients to discuss concerns, patients can perceive this as a barrier that prevents them from expressing a concern (Okuyama et al., 2008). Logistical barriers are described in the health behavior change literature (Fishbein, 2000; Fishbein & Yzer, 2003; Fishbein & Cappella, 2006) and often include time and location which are also barriers that seem to play a role in expressing concerns. For example, patients can believe that their provider has limited time to discuss concerns (Okuyama et al., 2008; Sepucha et al., 2002). Furthermore, in the patient participation literature it is also stressed that patients can perceive barriers about the legitimacy of expressing concerns (Henselmans et al., 2012; Okuyama et al., 2008; Street, 2001). For example, patients can have the belief that expressing concerns will deteriorate the relationship with their provider (Okuyama et al., 2008). The present study examines to what extent patients report to perceive these barriers and their occurrence in consultations.

Methods

Procedure of the study

This study consisted of several steps: (1) literature was reviewed to gain insight into the possible barriers to expressing concerns, (2) a pre-study consisting of online focus groups was conducted to explore any new barriers that were not described in the literature and (3) a survey based on the literature and the pre-study was administered to examine the most influential barriers. The current study was approved by the ethical committee of the authors' university (2013-CW-74).

Pre-Study

Participants and procedure

Participants of the online focus groups (OFGs) were recruited via patient association websites. Inclusion criteria were: (1) being 18 years or older and (2) being treated for cancer (currently or in the past). Sixteen participants agreed to participate and signed an informed consent form. A-synchronic OFGs were chosen for the following reasons: (1) it is a feasible way to include participants who are ill, (2) it allows participants to react for a longer period of time and to take their time to construct a more in-depth reaction and (3) it can remove possible barriers to discuss sensitive topics such as emotional concerns regarding cancer (Stewart & Williams, 2005).

Participants were randomly assigned to one of the two a-synchronic OFGs. During the five days that the study was active, the OFGs were conducted on a secure website that could be entered with a code name and a password. A semi-structured interview guide was developed on the basis of the barriers that were derived from the literature. Every day a new open-ended question or statement was posted. After a topic was posted, participants were asked to give their reactions and to engage in a discussion with each other. A moderator (KB) facilitated the discussion by repeating statements or reactions of participants and asking if other participants could react. Participants always received an email after a new theme was posted on the website to remind them that they could give reactions. All themes remained posted on the website for the entire week so that participants could always go back to a topic and post another reaction or read the reactions of other participants.

Analysis and results

The majority of participants of the OFGs ($n = 9$) were female and the mean age was 56.69 years ($SD = 9.29$). Most of the participants had been diagnosed with urologic cancer ($n = 7$) or breast cancer ($n = 6$). The data of the OFGs were categorized and analyzed using MAXQDA10. As a first step in analyzing the OFG data, we meticulously reviewed and read the reactions of the participants and we then categorized the reactions into the three main categories that were derived from the literature: (1) barriers related to the provider's behavior (2) barriers related to the logistics of the consultation, and (3) legitimacy barriers. Furthermore, we explored whether the examples that participants mentioned within those categories, were in line with examples that were derived from the literature. Table 2.1 shows an overview of the categories of barriers and the examples that were derived from the literature and the OFGs.

In total sixteen barriers were mentioned during the OFGs. Eleven of those sixteen barriers were also mentioned in other literature on patient participation and expressing concerns. Participants endorsed five barriers that were not described in the literature but were elicited by the moderator. Four of the five barriers could be categorized as logistical barriers, namely (1) the consultation before the patient's consultation overran its time, (2) the provider constantly looks at his or her computer screen, (3) there are interns present in the consultation room and (4) there are family members or a spouse present in the consultation room. Furthermore, one new legitimacy barrier was mentioned, namely feeling ashamed to express concerns (see Table 2.1).

Table 2.1*Barriers to Expressing Concerns*

Construct	Online focus groups (N=16)	Literature
Barriers related to providers' behavior		
My provider does not react with empathy when I express a concern	x	x ^a
My provider does not provide me with the right information to reduce my concerns	x	x ^b
My provider does not explicitly invite me to discuss my concerns	x	x ^c
My provider already gives me a lot of information during a consultation	x	x ^d
My provider gives me the feeling that I am stupid when I express my concerns	x	x ^d
My provider responds defensively when I express my concerns	x	x ^d
Barriers related to the logistics of the consultation		
My provider does not have time to listen to my concerns	x	x ^{d,e}
The consultation before my consultation overran its time	x	
My provider constantly looks at his or her computer screen	x	
There are interns present during the consultation with my provider	x	
My provider is replaced by another provider	x	x ^d
I bring my spouse or family members to a consultation	x	
I could not choose my own provider	x	x ^d
Legitimacy barriers		
I am afraid that I waste my provider's time when I express my concerns	x	x ^c
I feel ashamed when I express my concerns	x	
I am afraid that expressing my concerns will deteriorate the relationship with my provider	x	x ^c

Note. The letters next to the X's refer to the literature about the barriers. ^a= Zimmerman et al. (2007), ^b= Henselmans et al. (2012), ^c= Okuyama et al. (2008), ^d= Sepucha et al. (2002) and ^e = Street (2001).

Survey

Participants and procedure

Participants of the online survey were recruited via patient association websites, kanker.nl (a large panel of cancer patients in the Netherlands) and a cancer patient panel of the authors' university. The inclusion criteria were the same as those of the OFGs. In total 236 participants completed the survey.

Measures

First, the survey elicited background characteristics. Sixteen barriers were included in the survey (Table 1). In order to calculate composite scores for the barriers, participants had to report to what extent a certain situation could possibly be a barrier on a 7-point scale (1 = *strongly disagree* to 7 = *strongly agree*) and how often these situations occurred on a 4-point scale (1 = *never* to 4 = *always*). Last, three subscales were created: providers' behavior barriers (six items, $\alpha = 0.76$), logistical barriers (seven items, $\alpha = 0.61$) and legitimacy barriers (three items, $\alpha = 0.85$).

Analysis

Based on the QUOTE methodology (van Weert et al., 2009) composite scores, i.e., Quality Impact Indices (QIIs), were calculated by multiplying the possible barrier scores of the items with the fraction (%/100) of participants that indicated perceived occurrence in practice on that item (i.e., possible barrier score * proportion of perceived occurrence of the barrier). In order to calculate the fraction of occurrence, this scale was recoded (0 = *the barrier sometimes occurred* and 1 = *the barrier often occurred*). Thus, when participants had a mean score of 4.80 (on the 7-point possible barrier scale) on the item "my provider does not respond with empathy" and this barrier occurred often according to 49.6% of the participants, the QII score would be $4.80 * 0.496 = 2.38$. A QII score of .60 or more indicated a potential barrier and a QII score of 1.75 or more an influential barrier (Brouwer, Sixma, Triemstra, & Delnoij, 2006; van Weert et al., 2009).

Results

Participants

Most participants (55.5%) were female. The mean age was 57.23 years (SD = 12.25) and the majority were diagnosed with breast cancer (24.0%) or digestive-gastrointestinal cancer (20.9%). Table 2.2 shows the background characteristics of the participants.

Table 2.2*Background Characteristics of 236 Participants of the Survey*

Characteristic	N	%
<u>Gender</u>		
Male	105	44.5
Female	131	55.5
<u>Age</u>		
M (SD)	57.23(12.25)	
Range	20-83	
<u>Educational level</u>		
Low	56	23.7
Middle	58	24.6
High	122	51.7
<u>Living arrangements</u>		
Alone	41	17.4
Partner	123	52.1
Partner and child(ren)	56	23.7
Child(ren)	10	4.2
Other	6	2.6
<u>Type of cancer</u>		
Breast	63	24.0
Digestive-intestinal	55	20.9
Heamatologic	41	15.6
Gynaecological	4	1.5
Urologic	51	19.4
Lung	4	1.5
Skin	14	5.3
Head and neck	2	0.8
Other	29	11.0

Table continues on next page

Characteristic	N	%
<u>Patients still undergoing treatment</u>		
Yes	112	47.5
No	124	52.5
<u>Treatment</u>		
No treatment	11	2.1
Surgery	163	31.8
Chemotherapy	116	22.7
Radiotherapy	106	20.7
Immunotherapy	13	2.5
Hormone replacement therapy	48	9.4
Chemoradiation	3	0.6
Goal directed therapy	12	2.3
Unknown	1	0.2
Other	39	7.6

QII scores barriers

Barriers related to providers' behavior had on average the highest mean QII score ($M = 1.44$, $SD = 0.56$) followed by logistical barriers ($M = 1.33$, $SD = 0.47$). According to the mean QII score, legitimacy barriers ($M = 0.26$, $SD = 0.12$) formed hardly any barriers to expressing concerns. Within the subscales several specific influential barriers could be identified. For the barriers that were related to providers' behavior the most influential barriers were: providers not responding with empathy after a concern was expressed ($M = 2.38$, $SD = 0.99$), providers not inviting the patient explicitly to discuss concerns ($M = 2.18$, $SD = 1.20$), and providers not providing the patient with the right information to reduce concerns ($M = 2.14$, $SD = 0.97$). For barriers related to the logistics of the consultation, the most influential barriers were: patients could not choose their own provider ($M = 2.49$, $SD = 1.35$) and the idea that providers do not have time to listen to concerns ($M = 2.26$, $SD = 0.90$). Table 2.3 shows participants' mean QII scores on the subscales of the barriers and the separate items.

Table 2.3

Means and Standard Deviations of Possible Barriers and QII scores and the Percentage of Patient Reports on Barriers that Occurred in Consultations

Item description	Possible barriers M (SD)	Occurrence in consultations %	QII score M (SD)
Barriers related to providers' behavior			1.44 (0.56)
My provider does not react with empathy when I express a concern	4.80 (2.00)	49.6	2.38 (0.99)
My provider does not provide me with the right information to reduce my concerns	4.54 (2.06)	47.0	2.14 (0.97)
My provider does not explicitly invite me to discuss my concerns	3.62 (1.99)	60.2	2.18 (1.20)
My provider already gives me a lot of information during a consultation	2.94 (1.72)	50.0	1.47 (0.86)
My provider gives me the feeling that I am stupid when I express my concerns	4.42 (2.31)	4.2	0.19 (0.10)
My provider responds defensively when I express my concerns	4.76 (2.08)	5.9	0.28 (0.12)
Barriers related to the logistics of the consultation			1.33 (0.47)
My provider does not have time to listen to my concerns	5.18 (2.06)	43.6	2.26 (0.90)
The consultation before my consultation overran its time	2.88 (1.91)	41.5	1.20 (0.79)
My provider constantly looks at his or her computer screen	4.35 (2.13)	19.1	0.83 (0.41)
There are interns present during the consultation with my provider	2.63 (1.84)	6.8	0.18 (0.13)
My provider is replaced by another provider	4.17 (1.99)	13.6	0.29 (0.12)
I bring my spouse or family members to a consultation	2.53 (1.86)	29.2	1.79 (1.31)
I could not choose my own provider	3.50 (1.89)	71.2	2.49 (1.35)
Legitimacy barriers			0.26 (0.12)
I am afraid that I waste my provider's time when I express my concerns	4.08 (2.24)	7.6	0.31 (0.17)
I feel ashamed when I express my concerns	4.35 (2.18)	6.8	0.30 (0.15)
I am afraid that expressing my concerns will deteriorate the relationship with my provider	4.00 (2.18)	4.2	0.17 (0.09)

Note. $N = 236$. a Perceived barriers were measured on a 7-point scale (1 = *strongly disagree* to 7 = *strongly agree*). QII score = Quality Impact Indices score. A QII score of .60 or more indicated a potential barrier and a QII score of 1.75 or more an influential barrier

Discussion and Conclusion

This study aimed to examine patients' barriers to expressing concerns in a new manner by combining patients' reports of possible barriers with patients' reports of perceived occurrence of the barriers in consultations. The most influential barriers in cancer consultations were related to providers' behavior and the logistics of the consultation. These results confirm similar findings from previous studies on perceived barriers to patient participation (e.g., Henselmans et al., 2012; Okuyama et al., 2008; Sepucha et al., 2002; Street, 2001) and contributes to these studies by showing that patients also report that these barriers occur during cancer consultations.

Influential barriers related to providers' behavior were about providers not responding with empathy, providers not explicitly inviting patients to discuss their concerns and providers not providing patients with the right information to reduce concerns. These aspects of providers' behavior have been described in many studies (e.g., Arora, 2003; Bensing, Verheul, Jansen, & Langewitz, 2010; Butow et al., 2008; Butow et al., 2002; Henselmans et al., 2012; Jansen et al., 2010; Mazzi et al., 2013; Ryan et al., 2005; Zimmermann et al., 2007). The results of this study emphasize that these aspects need to be targeted in interventions aiming to reduce barriers to expressing concerns. For example, such an intervention could consist of communication skills training for providers. The effectiveness of communication skills training on providers' empathetic responses and elicitation of concerns has been shown in an oncology setting (Rao, Anderson, Inui, & Frankel, 2007). However, the results of the current study show that, according to patients' experiences, these skills are not always used in oncology consultations. Perhaps this is this case because the skills are not always thoroughly trained with role-plays in which providers actually have to use the skills. It has been argued that role-play with simulated patients might have a greater effect on the attainment of skills than didactic methods (Lane & Rollnick, 2007). Future research could further explore the longitudinal outcomes of training that includes role-play and whether patients perceive less barriers in consultations with providers who have received role-play training.

Influential barriers related to the logistics of the consultation were about patients' lack of opportunity to choose their own provider and providers' lack of time to listen to concerns. When patients choose their own provider, there might be more concordance between the provider and the patient. This can influence patients' trust in their provider and possibly their concern expression (Street, O'Malley, Cooper, & Haidet, 2008). However, little research has been conducted in this area. Future studies could further explore whether there are differences in patients who could or could not choose their own provider on different communication outcomes such as expressing concerns. Furthermore, when

patients can determine their own consultation length beforehand, this can possibly influence their expression of concerns. In a recent study among GPs (Sampson et al., 2013), patients were given the opportunity to determine their own consultation length. This resulted in a more balanced consultation with patients being better able to manage consultation time and feeling more confident to be assertive. Being assertive during a consultation is a form of patient participation just like expressing concerns (Street, 2001). Therefore, it is possible that giving patients the opportunity to determine their own consultation length also influences expression of concerns. Future research could further examine this in an oncology setting.

By taking into account patients' reports on the perceived occurrence of barriers during cancer consultations, this study also yields different results than previous studies. For example, Street (2001) argued that legitimacy barriers, such as patients' belief that they might waste their providers' time when they express concerns, play a role in expressing concerns. Although patients strongly agreed that they perceive legitimacy barriers, they also indicated that they do not perceive the occurrence of these barriers in consultations. It could be that patients can overcome these barriers themselves during consultations. For example, patients hold the belief that they will waste their provider's time when they express a concern but during a consultation they will express a concern regardless of their belief.

It has to be noted that patients in our sample were highly educated and middle aged. Research indicates that this particular group of patients is most communicative during consultations (Street, Gordon, Ward, Krupat, & Kravitz, 2005). There is a possibility that patients who are less educated do experience more legitimacy barriers to expressing concerns compared to patients who are highly educated. Furthermore, barriers related to providers' behavior and the logistics of the consultation were identified as influential barriers by a highly-educated sample and could even be more influential in a lower-educated sample. Particularly patients who are less educated might therefore benefit from interventions that empower patients to express concerns such as concern prompt lists (Ghazali, Roe, Lowe, & Rogers, 2013). A replication of this study among a different sample (e.g., less educated patients) is warranted to determine whether the same barriers are experienced.

This study relies solely on patients' reports of barriers. It would be interesting to further explore patients' barriers by including observational data. For example, by comparing patients' experiences of barriers that are related to providers' behavior (e.g., not responding with empathy) with a recorded consultation that has been coded with the Verona coding manual or RIAS, which both include the coding of providers' reactions to patients expressing concerns (Del Piccolo et al., 2011; Roter & Larson, 2002). A study (Schinkel, Schouten, & van Weert, 2013) has compared patients' perceptions

of information provision with observational data and reported low correlations between the two measures, showing that it is difficult to use patients' reports as a proxy for observational data for this particular communication outcome. A comparison study of patients' perceptions and observational data regarding barriers to expressing concerns can provide insight into whether patients' perceptions of barriers are a reliable proxy for observational data.

To conclude, the most influential barriers for patients to express concerns during cancer consultations are barriers related to providers' behavior (e.g., providers do not explicitly invite patients to discuss concerns) and the logistics of the consultation (e.g., perceived lack of time in a consultation for expressing concerns). In other words, barriers which patients cannot overcome themselves. To reduce these barriers, a collaborative approach from researchers, providers and policy makers is needed.

Practice implications

The results of this study can be used to develop strategies to overcome barriers to patients expressing concerns during cancer consultations. These strategies should particularly be focused on providers' behavior (e.g., communication skills training) and the logistics of the consultation (e.g., policy makers could consider making it possible for patients to choose their own provider).

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CHAPTER 3: UNRAVELING THE DETERMINANTS OF CANCER PATIENTS' INTENTION TO EXPRESS CONCERNS

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Abstract

Little is known about the behavioral determinants that underlie cancer patients' intention to express concerns during a consultation. This information can be relevant to developing effective interventions for cancer patients. In this study, the integrative model of behavioral prediction (IMBP) is used as a framework to unravel the determinants of patients' intention to express concerns. The objectives of this study are to examine which of the IMBP determinants (attitude, perceived social norm and/ or self-efficacy) are significantly related to intention and what content of these determinants can be targeted to effect a change in patients' intention. An online survey based on the IMBP determinants was distributed. A total of 236 cancer patients and cancer survivors participated. The results of the survey showed that patients' attitudes and perceived social norm were the most important determinants of their intention to express concerns. The largest change in patients' intention might be achieved by targeting the affective attitude, referring to the extent to which patients believe that expressing concerns is (un)pleasant, and the social norm, referring to the extent to which patients feel (un)supported by significant others in expressing concerns.

Introduction

A life-threatening disease such as cancer can evoke many concerns in patients (Farrell, Heaven, Beaver, & Maguire, 2005). A concern is defined as: “an unpleasant current or recent emotion” (Zimmermann et al., 2011, p.144). Concerns that are experienced by patients include medical concerns (e.g., patients are worried about the possible side-effects of their treatment), psychosocial concerns (e.g., patients are anxious that they might not survive cancer) and practical concerns (e.g., patients are concerned about whether they can keep their jobs; Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premlatha, 1996; Hill, Amir, Muers, Connolly, & Round, 2003).

Studies have indicated that many cancer patients do not express these concerns sufficiently. For example, patients often express their concerns indirectly with cues (i.e., unclear verbal or non-verbal hints of experienced concerns) rather than directly and explicitly (Grimsbø, Ruland, & Finset, 2012; Heyn, Ruland, & Finset, 2012). Healthcare providers often do not notice those cues and indicate that they better detect concerns when these concerns are expressed explicitly (Butow et al., 2008). When concerns are explicitly verbalized by patients, it is easier for healthcare providers to respond adequately. Receiving adequate information to address concerns has been associated with positive outcomes for patients, such as better psychological well-being (De Haes & Bensing, 2009; Street, Makoul, Arora, & Epstein, 2009). In contrast, when patients do not explicitly express concerns, and these concerns remain undetected, they can worsen and possibly lead to depression (Chochinov, 2001; Ryan et al., 2005). Thus, it is important to support patients in expressing their concerns. Interventions focusing on patients' concern expression could provide support; however, these interventions are scarce.

Previous interventions to facilitate concern expression have mainly targeted the communication behavior of healthcare providers during the consultation (e.g., eliciting concerns; Butow et al., 2008). These interventions have not always been effective in improving concern expression. For example, Butow and colleagues (2008) did not find any significant effects of their communication skills training on healthcare providers' elicitation of concerns. A possible reason for the lack of effects could be that only the behavior of the provider is targeted. Interventions that target the behavior of both the provider and the patient are often more effective in improving patient participation during oncology consultations (Brandes, Linn, Butow, & Van Weert, 2015). Thus, existing interventions that focus on providers' behavior might be more effective if they are combined with interventions that focus on patients' concern expression. As previously noted, interventions targeting patients' concern expression are scarce. To develop an effective intervention for patients, it is important to identify the determinants that explain their intention to express concerns (Fishbein, 2000).

From behavioral theories such as the integrative model of behavioral prediction (IMBP; Fishbein, 2000), we know that individuals' attitudes, perceived social norm and self-efficacy can predict their intention to perform any given behavior. Moreover, studies that use behavioral theories such as the IMBP to inform their intervention development are more effective in changing intentions and health behavior than interventions that do not follow this approach (Avery, Donovan, Horwood, & Lane, 2013). A few studies on concern expression have examined the determinants of intention from the IMBP individually (e.g., Manne, Alfieri, Taylor, & Dougherty, 1999; Okuyama et al., 2008; Zakowski et al., 2003). However, to our knowledge, there are no studies that have assessed attitude, perceived social norm and self-efficacy together to examine which of these are most strongly related to patients' intention to express concerns and are therefore potential candidates for intervention targets. Thus, this study aims to address this gap in the literature by using the IMBP as a framework.

Theoretical Background

Integrative Model of Behavioral Prediction

The IMBP is based on several health behavior models: the health belief model (Janz & Becker, 1984; Rosenstock, 1974), the social cognitive theory (Bandura, 1986), the theory of reasoned action (Fishbein & Ajzen, 1975) and the theory of planned behavior (Ajzen, 1991). Behavioral theories such as the IMBP guide researchers in intervention development. By identifying the determinants that predict individuals' intention to perform a health behavior, researchers can determine possible intervention targets. Researchers can then properly evaluate which elements of their intervention worked and led to a change in intention (Fishbein & Capella, 2006; Michie & Prestwich, 2010).

The IMBP has frequently functioned as a framework for understanding why individuals do or do not intend to perform a behavior and for identifying potential intervention targets in different health communication domains; for example, this model has been used to explore the determinants of intention in the contexts of getting tested for sexual transmitted diseases (Boudewyns & Paquin, 2011), getting vaccinated against the human papillomavirus (Dillard, 2011) and maintaining healthy sleep behaviors (Robbins & Niederdeppe, 2015). The IMBP has also been applied in cancer research to explore determinants that are related to cancer prevention behaviors, cancer detection behaviors and cancer-related information seeking (Smith-McLallen & Fishbein, 2009; Smith-McLallen et al., 2011). These studies were all successful in explaining variance in intention and in identifying potential intervention targets. In addition, Fishbein (2000) argued that the IMBP can be applied to any given behavior. Thus, this study uses the IMBP as a starting point to understand why cancer patients do or do not intend to express their concerns and to identify intervention targets.

The IMBP proposes that background characteristics, such as demographic (e.g., age), disease (e.g., time since diagnosis), and psychological (differing by behavior) characteristics, should be taken into account as control variables (Fishbein, 2000). This study includes psychological characteristics as control variables that have been suggested in the literature as possibly influencing patients' concerns and concern expression, namely, patients' monitoring coping style (Miller, 1995), cancer-related stress reactions (Stanton et al., 2002) and illness perceptions (Hagger & Orbell, 2003). Furthermore, the IMBP postulates that individuals' intention to perform a behavior will determine their behavior. Individuals' intention is formed by their attitudes toward the behavior, the perceived social norm and their self-efficacy regarding performance of the behavior. Attitude refers to individuals' positive and/or negative feelings toward performing a behavior. Perceived social norm refers to the extent to which individuals believe that people who are important to them (e.g., spouse and family) want them to perform the behavior. Self-efficacy refers to the extent to which individuals believe that they are able to perform the behavior (Fishbein, 2000; Fishbein & Capella, 2006; Fishbein & Yzer, 2003). In addition to models like the theory of planned behavior that propose the same determinants of intention, the IMBP has the advantage of including measures (i.e., barriers and skills) that possibly moderate the intention-behavior gap. This gap can occur when individuals who have a perfect intention to perform a behavior fail to act on it (Fishbein, 2000; Fishbein & Capella, 2006; Fishbein & Yzer, 2003). The intention-behavior gap can be targeted best when individuals already have a perfect intention. However, research shows that patients' intention to express concerns might not be optimal (Street, 2001). Therefore, the focus of this study is on explaining intention.

Past studies have indicated that, in line with the IMBP, attitudes (e.g., Okuyama et al., 2008), perceived social norm (e.g., Zakowski et al., 2003) and self-efficacy (e.g., Street, 2001) play a role in patients' concern expression; thus, it can be expected that these determinants are also related to patients' intention to express concerns. Therefore the objective of this study is to examine whether cancer patients' attitudes, perceived social norm and self-efficacy to express concerns are positively related to their intention to express concerns during a consultation.

Although studies have examined the relations among the different determinants of intention (i.e., patients' attitudes, perceived social norm and self-efficacy with concern expression; e.g., Manne et al., 1999; Okuyama et al., 2008; Street, 2001), none of these studies has compared these determinants to examine which are most strongly related to patients' intention to express concerns. To examine the latter, we propose the following research question:

Research question 1: Which of the determinants (attitudes, perceived social norm and/or self-efficacy) has/have the strongest relation to patients' intention to express concerns during a consultation?

Accomplishing Changes in Intention

After the identification of the determinants (i.e., attitudes, perceived social norm and self-efficacy) that are significantly related to intention, it is still unknown what content of those determinants (i.e., the specific content of patients' attitudes, perceived social norm and self-efficacy) must be addressed to effect a change in intention. Information about the specific content that can contribute to a change in intention can be used as a starting point to determine intervention targets. One of the techniques that can be used to identify that specific content is a percentage to gain analysis (Brennan, Gibson, Liu, & Hornik, 2013). With this analysis, it is possible to calculate what content of the determinants can yield the largest change in intention when they are successfully targeted in an intervention for concern expression (Brennan et al., 2013; Hornik & Woolf, 1999). For example, when an intervention is designed to target patients' intention, and attitude would be a strong determinant of intention, the content of patients' attitudes (e.g., whether it is pleasant or unpleasant to express concerns during a consultation) can provide insight into what must be targeted to effect a change in intention. It is unknown what content of the IMBP determinants must be targeted to accomplish a change in cancer patients' intention to express concerns (the content will also depend on the determinants that are significantly related to intention). Therefore, the second research question is as follows:

Research question 2: What specific content of the determinants of intention (the content of patients' attitudes, perceived social norm and/or self-efficacy) should be best targeted in an intervention to accomplish the largest change in cancer patients' intention to express concerns during a consultation?

Methods

Participants and Procedure

The participants were recruited via patient association websites, kanker.nl (a national panel of cancer patients in the Netherlands), and a panel of cancer patients from the authors' university. Participants were eligible if they were at least 18 years old and if they were currently receiving or had in the past received treatment for cancer. This study was approved by the ethical committee of the authors' university (2013-CW-74).

Study Design

The items in the survey were based on IMBP questionnaires (Francis et al., 2004; Montano & Kasprzyk, 2008). In accordance with the IMBP, the survey first elicited background characteristics of the participants, including whether participants were undergoing treatment for cancer at the time of the survey. Participants who indicated that they were currently undergoing treatment were asked the questions about the IMBP determinants (attitude, perceived social norm, self-efficacy and intention) in the present tense (i.e., the questions concerned consultations in their current cancer treatment). If participants indicated that they were not currently undergoing treatment, they were asked the questions about the IMBP determinants in the past tense (i.e., the questions asked them to reflect back on consultations in their past cancer treatment). During the survey, the definition of concern expression was given several times (i.e., clearly and explicitly verbalizing emotions experienced during the disease). The survey was pre-tested by one cancer patient and one cancer survivor, neither of whom was included in the study.

Measures

First, background characteristics (i.e., demographic, disease and psychological characteristics) were elicited. The disease and psychological characteristics that were measured in this study have been commonly used in previous studies on cancer communication. Second, questions were asked about the participants' intention to express concerns during a consultation. Finally, in accordance with the IMBP, questions about the determinants of intention were asked, namely participants' attitudes, perceived social norm and self-efficacy to express concerns during a consultation. Attitude, perceived social norm and self-efficacy were operationalized with validated IMBP measures (Francis et al., 2004; Montano & Kasprzyk, 2008).

Background Characteristics Measures

Demographic and disease characteristics. The participants were asked to specify their gender, age and level of education. Level of education was recoded as high (higher vocational education and university), middle (senior secondary vocational education and university preparatory vocational education) or low (primary education, lower vocational education, preparatory secondary vocational education and intermediate secondary vocational education). The participants also indicated the date that they were diagnosed (which was recoded as time since diagnosis in months), whether they were still receiving treatment, their treatment goal (curative or palliative), their type of cancer and what types of treatments they had had.

Psychological characteristics. Monitoring coping style was measured with a three item 5-point scale derived from the Threatening Medical Situation Inventory (TMSI; Miller, 1987; Van Weert, Jansen, De Bruijn, Noordman, Van Dulmen, & Bensing, 2009). Statements on, for example, reading as much as possible about cancer could be rated from 1 (*not at all applicable to me*) to 5 (*strongly applicable to me*). The total scores on monitoring coping styles were derived by the sum of scores on the three items ($\alpha = .84$, range 3-15, $M = 11.70$, $SD = 3.25$). A higher score indicated a higher monitoring coping style.

Cancer-related stress reactions were measured with the Dutch version of the Impact of Events Scale (Van der Ploeg, Mooren, Kleber, Van der Velden, Peter, & Brom, 2004), which divides cancer-related stress reactions into intrusive thinking (seven items, $\alpha = .89$, range 0-35, $M = 18.88$, $SD = 8.96$) and avoidant thinking (eight items, $\alpha = .79$, range 0-40, $M = 14.08$, $SD = 8.59$). The participants indicated on a 4-point scale (0 = *not at all*, 1 = *rarely*, 3 = *sometimes* and 5 = *often*) whether they had experienced certain stressful situations, such as having bad dreams about cancer. The total scores of the subscales were calculated as the total scores of their items.

Illness perceptions were measured with the Dutch version of the Brief Illness Perceptions Questionnaire (De Raaij, Schröder, Maissan, Pool, & Wittink, 2012). The participants had to indicate on a 10-point scale per illness perception whether a given statement, such as that cancer influenced their daily lives, applied to them. A higher score indicated a more threatening perception of cancer (eight items, $\alpha = .63$, range 0-10, $M = 6.79$, $SD = 1.36$).

IMBP Measures

Intention. Intention to express concerns was measured with three items (Francis et al., 2004; Montano & Kasprzyk, 2008) in which participants had to indicate whether they intended to express their concerns during their next consultation with their healthcare provider on a 7-point scale (1 = *strongly disagree* to 7 = *strongly agree*, $\alpha = .95$, $M = 4.66$, $SD = 1.87$).

Attitude. Attitude was measured with six items on 7-point semantic differential scales (Francis et al., 2004; Montano & Kasprzyk, 2008). The participants had to indicate whether expressing concerns toward their healthcare provider was *unpleasant-pleasant*, *bad-good*, *not useful-useful*, *not helpful-helpful*, *a disadvantage-an advantage*, and *not stressful-stressful* ($\alpha = .86$, $M = 5.91$, $SD = .98$).

Perceived social norm. Perceived social norm was measured with eight items (Francis et al., 2004; Montano & Kasprzyk, 2008). The participants had to indicate on a 7-point scale (1 = *strongly disagree* to 7 = *strongly agree*) whether their significant others (i.e., people who were important to them) *expected* or *wanted* them to express their concerns toward a healthcare provider and whether they complied with those expectations or wishes. Thereafter, the participants had to indicate whether their significant others (i.e., their spouse, children, siblings and friends) wanted them to express concerns toward their healthcare provider. Furthermore, the participants were asked whether they believed that other cancer patients expressed their concerns to their healthcare providers ($\alpha = .82$, $M = 5.90$, $SD = 1.01$).

Self-efficacy. Self-efficacy was measured with five items (Francis et al., 2004; Montano & Kasprzyk, 2008). The items measured, for example, whether the participants found it easy to express concerns, whether the participants felt able to express concerns toward their healthcare provider and whether they decided themselves to express concerns toward their healthcare provider on 7-point scales (1 = *strongly disagree* to 7 = *strongly agree*, $\alpha = .81$, $M = 5.32$, $SD = 1.26$).

Analysis

First, bivariate correlations were calculated to assess whether attitude, perceived social norm and self-efficacy were positively related to patients' intention to express concerns. Second, a hierarchical regression analysis was conducted with standardized variables to examine whether attitude, perceived social norm or self-efficacy had the strongest relation with intention. Variables were added in the hierarchical regression analysis in two steps: (1) demographic, disease and psychological characteristics and (2) attitude, perceived social norm and self-efficacy. Finally, percentages to gain in intention were calculated as proposed by Brennan and colleagues (2013). Intention and the content of the determinants that were related to intention were recoded as 1 = *desired* (everyone who had the maximum score and did not need an intervention) and 2 = *all others* (everyone who did not have the maximum score and could benefit from an intervention). Thus, by recoding intention in two categories, the participants who may or may not benefit from an intervention were separated. Thereafter, a cross-tabulation was used with intention and the content of the determinants of intention. The percentage to gain represented the proportion of patients who would have a positive change in their intention when an intervention was 100% successful in targeting the specific content of a determinant (i.e., the percentage of patients who had a maximum score on, for example, both the intention scale and the unpleasant/pleasant content of the attitude scale minus the percentage of patients who only had a maximum score on the intention scale). For example, if 15% of all the participants would have the maximum score on the intention scale, and 30% of the participants

would have the maximum score on both the intention scale and the unpleasant/pleasant content of the attitude scale, then the percentage to gain would be $30\% - 15\% = 15\%$. Thus, in this example, under the ideal circumstances of an intervention that was 100% effective, 15% of the patients would change their intention to express concerns after they were exposed to an intervention targeting the unpleasant/pleasant content of their attitudes. This analysis was conducted for the content of each determinant.

Results

Response

In total, 268 participants started the online survey, and 236 participants (88.1%) completed it. A non-response analysis showed that the participants who did not complete the survey differed in gender from those who did complete it ($\chi^2(1) = 9.70, p < .001$). Of the 32 participants who did not complete the survey, the majority were female ($n = 27; 84.4\%$). The survey was also completed by more females ($n = 131; 55.5\%$). However, the percentage of females in the non-response group was higher. The participants who did not complete the survey were also younger ($M = 48.55, SD = 12.99$) than the participants who did complete it ($M = 56.32, SD = 11.82; p = .004$). The participants who did and did not complete the survey did not differ in their level of education.

Participants

The majority of the participants were female (55.5%), lived together with a partner (52.1%) and had children (80.1%). The mean age of the sample was 57.23 ($SD = 12.25$), and approximately half of the participants were highly educated (51.9%). All the demographic characteristics of the participants are displayed in Table 3.1.

Almost a quarter of the participants had been diagnosed with breast cancer (24.0%), and a fifth had digestive-gastrointestinal cancer (20.9%). More than half of the participants were not undergoing treatment at the time they completed the survey (52.5%). Furthermore, surgery (31.8%), chemotherapy (22.7%) and radiotherapy (20.7%) were the most received treatments. All the disease characteristics are shown in Table 3.2.

Table 3.1*Demographic Characteristics of the Participants (N=236)*

Characteristic	N	%
<u>Gender</u>		
Male	105	44.5
Female	131	55.5
<u>Age</u>		
<i>M (SD)</i>	57.23 (12.25)	
Range	20-83	
<u>Educational level</u>		
Low	54	23.4
Middle	57	24.7
High	120	51.9
<u>Living arrangements</u>		
Alone	41	17.4
Partner	123	52.1
Partner and child(ren)	56	23.7
Child(ren)	10	4.2
Other	6	2.6
<u>Children</u>		
Yes	189	80.1
No	47	19.9
<u>Employed</u>		
Yes	91	38.6
No	145	61.4
<u>Ethnicity</u>		
Dutch	228	96.6
Other	8	3.4

Note. n varies due to missing data

Table 3.2*Disease Characteristics of the Participants (N=236)*

Characteristic	N	%
<u>Type of cancer</u>		
Breast	63	24.0
Digestive-gastrointestinal	55	20.9
Heamatologic	41	15.6
Lung	4	1.5
Gynaecological	4	1.5
Urologic	51	19.4
Head and neck	2	0.8
Skin	14	5.3
Other	29	11.0
<u>Time since diagnosis (months)</u>		
<i>M (SD)</i>	55.5 (59.9)	
<u>Patients still undergoing treatment</u>		
Yes	112	47.5
No	124	52.5
<u>Treatment intent</u>		
Curative	144	61.0
Palliative	84	35.6
Unknown	8	3.4
<u>Treatment</u>		
No treatment	11	2.1
Surgery	163	31.8
Chemotherapy	116	22.7
Radiotherapy	106	20.7
Immunotherapy	13	2.5
Hormone replacement therapy	48	9.4
Chemoradiation	3	0.6
Goal directed therapy	12	2.3
Unknown	1	0.2
Other	39	7.6

Note: n varies due to missing data or multiple answers

Explaining intention

The overall objective of this study is to examine whether cancer patients' attitudes, perceived social norm, and self-efficacy to express concerns are positively related to their intention to express concerns. Bivariate correlations (Table 3.3) showed that patients' attitudes ($r = .21, p = .001$), perceived social norm ($r = .32, p < .001$) and self-efficacy ($r = .14, p = .031$) were all positively related to their intention to express concerns during their next consultation.

Table 3.3

Correlations between Attitude, Perceived Social Norm, Self-efficacy and Patients' Intention to Express Concerns

Measure	1	2	3	4
1. Intention		.21**	.32***	.14*
2. Attitude			.27***	.42***
3. Perceived social norm				.13*
4. Self-efficacy				

Note. $N = 236$.

* $p < .05$. ** $p < .01$ *** $p < .001$

The first research question was as follows: "Which of the determinants (attitude, perceived social norm and/or self-efficacy) has/have the strongest relation with patients' intention to express concerns during their next consultation?" A hierarchical regression analysis was conducted to answer this research question. As a first step, in accordance with the IMBP, demographic, disease and psychological characteristics of the patients were entered. These background characteristics explained 7% of the variance in patients' intention to express concerns ($F(10, 213) = 1.60, p = .108$). As a second step, attitude, perceived social norm and self-efficacy were added. This second step yielded a significant R^2 change of 12% ($p < .001$). The final model explained 19% of the variance in patients' intention to express concerns ($F(13, 210) = 3.66, p < .001$). Perceived social norm had the strongest relation with intention ($b^* = .26, p < .001$), followed by attitude ($b^* = .17, p = .022$). Self-efficacy did not have a significant relation with intention in the final model ($b^* = .03, p = .671$). Table 3.4 shows the entire hierarchical regression analysis.

Table 3.4*Hierarchical Regression Analysis Predicting Intention to Express Concerns*

Predictor	ΔR^2	b*
<u>Step 1</u>	.07	
Gender		.10
Age		-.01
Level of education		-.02
Time since diagnosis		-.02
Undergoing treatment		.11
Treatment goal		.02
Monitoring coping style		.20***
Intrusive thinking		-.06
Avoidant thinking		.02
Illness perceptions		.09
<u>Step 2</u>	.12***	
Attitude		.17*
Perceived social norm		.26***
Self-efficacy		.03
<u>Total R²</u>	.19***	
N	236	

* $p < .05$. *** $p < .001$.

Percentage to Gain Analysis

The second research question was as follows: “What specific content of the determinants of intention (the content of patients’ attitudes, perceived social norm and/or self-efficacy) should be best targeted in an intervention to accomplish the largest change in cancer patients’ intention to express concerns during their next consultation?”

The hierarchical regression analysis showed that perceived social norm had the strongest relation with intention. Attitude also had a significant relation with intention. Therefore, percentage to gain analyses were conducted for the content of both attitude and perceived social norm because they are both potential candidates for intervention targets (see Appendix 3.1 for the cross-tabulations per content measure). For attitude, the highest percentages to gain in intention could be yielded for

the affective component of patients' attitudes, namely the extent to which patients felt unpleasant when they expressed concerns during a consultation (20.0%). The second highest percentage to gain could be achieved with the extent to which patients believed that expressing concerns could be disadvantageous (17.4%). For perceived social norm, the highest percentage to gain in intention could be yielded for an injunctive norm component, namely the extent to which patients believed that significant others did not want them to express concerns during a consultation (14.4%) and for the extent to which patients complied with the wishes or expectations of significant others (12.9%).

Discussion

This study aimed to use the IMBP to identify the determinants that are related to cancer patients' intention to express concerns. The results show that patients' attitudes and perceived social norm underlie their intention to express concerns during their next consultation. We also examined what content of patients' attitudes and perceived social norm could yield the largest improvement in intention and are potential candidates for intervention targets. Potential candidates for intervention targets are: (1) the extent to which patients think that expressing concerns during a consultation will make them feel (un)pleasant, (2) the extent to which patients believe that expressing concerns can be (dis)advantageous, (3) the extent to which patients believe that significant others do (not) want them to express concerns in a consultation and (4) the extent to which patients comply with the wishes or expectations of significant others.

The results show that particularly patients' affective attitudes (i.e., the extent to which concern expression during a consultation can be (un)pleasant) in particular are related to their intention to express concerns. An attitude consists of both a cognitive (i.e., positive/negative attributes of the behavior) and an affective (i.e., positive/negative feelings about the behavior) component (e.g., Fabrigar & Petty, 1999; Trafimow & Sheeran, 1998). Some studies have shown that the affective component of an attitude is a stronger predictor of intention than the cognitive component (e.g., French et al., 2005; Lowe, Eves, & Carroll, 2002). This may also be the case for patients' intention to express concerns. Concern expression is classified in the literature as an affective behavior (Bensing & Verhaak, 2004; Street & Millay, 2001), and therefore, the affective component of patients' attitude could be most decisive in their overall attitude formation and their intention to express concerns.

The extent to which patients believed that their significant others wanted them to express concerns during a consultation was also related to patients' intention to express concerns. It is possible that

patients hold this belief because they think that their significant others might not be able to cope with their concerns (Zhang & Siminoff, 2003), for example, because in some cases spouses or family members have had avoidant reactions when cancer patients have tried to express their concerns about their disease at home (Manne et al., 1999; Zakowski et al., 2003; Zhang & Siminoff, 2003). Other studies (e.g., Clayton, Butow, & Tattersall, 2005) suggest that spouses and family members do prefer openness about patients' concerns during medical consultations so that the patient can receive adequate information to address his or her concerns. Thus, it seems that the support of spouses and family members can differ among patients and situations. Interventions are needed for those patients who feel that they do not receive adequate support from their significant others. More research in this area is needed to explore why certain patients feel that they do not receive adequate support from their significant others.

Because of the cross-sectional data collection, the results of this study must be interpreted with care. Nonetheless, little was previously known about what should be targeted in concern expression interventions, and the results of this study can function as a starting point for determining intervention targets in this area. Studies that actually target patients' attitudes and perceived social norm are needed to establish whether patients' intention to express concerns, and consequently their behavior, can improve. For example, we found that the largest change in intention could be yielded by addressing patients' affective attitudes (i.e., the unpleasant feeling that patients could experience when they expressed concerns). Future studies could try to target patients' affective attitudes by developing interventions that focus on affective persuasion. Matching an intervention to the component of an attitude that must be targeted will increase its effectiveness (e.g., Fabrigar & Petty, 1999). In the case of an affective attitude, this could be done by providing the patients with positive emotional consequences of concern expression (Abraham & Michie, 2008; Michie et al., 2013). Future studies could try to target patients' perceived social norm similarly. Such an intervention can inform patients about the approval of people who are important to them regarding concern expression during consultations (Abraham & Michie, 2008).

Another direction for future research is to expand on the current study by identifying other determinants of cancer patients' intention to express concerns. The IMBP is a model that combines determinants from many behavioral theories, and it is proposed that the model can be applied to any given behavior (Fishbein, 2000). However, the IMBP only explained 19% of the variance in cancer patients' intention to express concerns. Although this is a promising starting point because little was previously known about what predicts cancer patients' intention to express concerns, it would be useful to know which other determinants could contribute to the explained variance. For example,

expressing concerns is an affective behavior; therefore, affective determinants such as anticipated emotions (e.g., regret; French et al., 2005) or personality characteristics of communication (e.g., being introvert or extrovert; Street, 2001) might also explain variance in why patients do or do not intend to express their emotions.

This study had some limitations that must be addressed. First, we only used direct measures for the determinants, and we did not measure the underlying beliefs of patients' attitudes and perceived social norm. Measuring the underlying beliefs of these determinants would give more detailed information to guide the development of an intervention. However, we did look at the content of these determinants to give the most comprehensive implications that were possible on the basis of the available data. Second, the cross-sectional nature of the study made it impossible to properly investigate the relation between intention and behavior. This relation can be examined best by measuring intention and behavior at different time points. Thus, to further examine the intention-behavior relation for concern expression, future studies could distribute an IMBP survey and then, at a later point in time, audio- or videotape a consultation to code the number of concerns that patients express. Finally, we recruited patients via patient association websites and panels, which could have yielded a sample that was not completely representative of the cancer patient population. Recruiting patients in a less biased environment, such as a hospital waiting room, could perhaps result in a more representative sample, and replication of this study in such a setting is therefore recommended.

To conclude, this study examined cancer patients' intention to express concerns in a new manner, namely by using the IMBP to unravel its underlying determinants. We found that patients' affective attitudes and perceived social norm are related to their intention to express concerns. Future studies could examine how these determinants of intention can be targeted most effectively by, for example, exploring interventions that focus on affective persuasion and on the approval by family members of concern expression.

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Appendix 3.1

Cross-Tabulations with Percentage to Gain Analyses for All the Underlying Measures for Attitude, Perceived Social Norm and Communicative Skills

Cross-Tabulation of Attitude Measure Unpleasant - Pleasant and Intention

(n = 236)	Attitude Unpleasant - Pleasant		
Intention to express concerns	All others	Desired	Total
All others	93.4%	65.2%	85.2%
Desired	6.6%	34.8%	14.8%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $34.8\% - 14.8\% = 20.0\%$

Cross-Tabulation of Attitude Measure a Disadvantage – an Advantage and Intention

(n = 236)	Attitude a Disadvantage - an Advantage		
Intention to express concerns	All others	Desired	Total
All others	95.9%	67.8%	85.2%
Desired	4.1%	32.2%	14.8%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $32.2\% - 14.8\% = 17.4\%$

Cross-Tabulation of Attitude Measure Not Stressful - Stressful and Intention

(n = 236)	Attitude Not Stressful - Stressful		
Intention to express concerns	All others	Desired	Total
All others	91.9%	73.6%	85.2%
Desired	8.1%	26.4%	14.8%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $26.4\% - 14.8\% = 11.6\%$

Cross-Tabulation of Attitude Measure Bad - Good and Intention

(n = 236)	Attitude Bad – Good		
Intention to express concerns	All others	Desired	Total
All others	95.0%	75.2%	85.2%
Desired	5.0%	24.8%	14.8%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $24.8\% - 14.8\% = 10.0\%$

Cross-Tabulation of Attitude Measure Not Useful - Useful and Intention

(n = 236)	Attitude Not Useful - Useful		
Intention to express concerns	All others	Desired	Total
All others	95.4%	76.6%	85.2%
Desired	4.6%	23.4%	14.8%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $23.4\% - 14.8\% = 8.6\%$

Cross-Tabulation of Attitude Measure Not Helpful – Helpful and Intention

(n = 236)	Attitude Not Helpful - Helpful		
Intention to express concerns	All others	Desired	Total
All others	93.5%	78.3%	85.2%
Desired	6.5%	21.7%	14.8%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $21.7\% - 14.8\% = 6.9\%$

Cross-Tabulation of Perceived Social Norm Measure Significant Others Want the Patient to Express Concerns and Intention

(n = 236)	PSN People Who are Important Want the Patient to Express Concerns		
	All others	Desired	Total
Intention to express concerns			
All others	91.5%	70.8%	85.2%
Desired	8.5%	29.2%	14.8%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $29.2\% - 14.8\% = 14.4\%$

Cross-Tabulation of Perceived Social Norm Measure Compliance with the Expectations and Wishes regarding Concern Expression of Significant Others

(n = 236)	PSN Compliance		
	All others	Desired	Total
Intention to express concerns			
All others	88.4%	72.3%	85.2%
Desired	11.6%	27.7%	14.8%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $27.7\% - 14.8\% = 12.9\%$

Cross-Tabulation of Perceived Social Norm Measure Significant Others Expect the Patient to Express Concerns and Intention

(n = 236)	PSN People Who are Important Expect the Patient to Express Concerns		
	All others	Desired	Total
Intention to express concerns			
All others	90.6%	73.7%	85.2%
Desired	9.4%	26.3%	14.8%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $26.3\% - 14.8\% = 11.5\%$

Cross-Tabulation of Perceived Social Norm Measure Patients' Belief That Their Partner Thinks that He or She Should Express Concerns and Intention

(n = 204)^a	PSN People Partner		
	All others	Desired	Total
Intention to express concerns			
All others	94.6%	80.4%	86.8%
Desired	5.4%	19.6%	13.2%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $19.6\% - 13.2\% = 6.4\%$

^a N varies because there was also a "not applicable to me" answer category

Cross-Tabulation of Perceived Social Norm Measure Patients' Belief That Their Child(ren) Think(s) that He or She Should Express Concerns and Intention

(n = 177)^a	PSN People Child(ren)		
	All others	Desired	Total
Intention to express concerns			
All others	91.3%	81.2%	86.4%
Desired	8.7%	18.8%	13.6%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $18.8\% - 13.6\% = 5.2\%$

^a N varies because there was also a "not applicable to me" answer category

Cross-Tabulation of Perceived Social Norm Measure Patients' Belief That Their Sibling(s) Think(s) that He or She Should Express Concerns and Intention

(n = 185)^a	PSN Siblings		
	All others	Desired	Total
Intention to express concerns			
All others	92.3%	75.0%	85.9%
Desired	7.7%	25.0%	14.1%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: $25.0\% - 14.1\% = 10.9\%$

^a N varies because there was also a "not applicable to me" answer category

Cross-Tabulation of Perceived Social Norm Measure Patients' Belief That Their Friends Think that He or She Should Express Concerns and Intention

(n = 212)^a	PSN Friends		
	All others	Desired	Total
Intention to express concerns			
All others	91.5%	74.7%	84.9%
Desired	8.5%	25.3%	15.1%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: 25.3% - 15.1% = 10.2%

^aN varies because there was also a “not applicable to me” answer category

Cross-Tabulation of Perceived Social Norm Measure Patients' Belief That Other Cancer Patients Express Concerns and Intention

(n = 204)^a	PSN Other Cancer Patients		
	All others	Desired	Total
Intention to express concerns			
All others	89.3%	75.4%	85.7%
Desired	10.7%	24.6%	14.3%
% in the column	100.0%	100.0%	100.0%

Percentage to gain: 24.6% - 14.3% = 6.4%

^aN varies because there was also a “not applicable to me” answer category



CHAPTER 4:
THE EFFECTS OF PERSUASIVE MESSAGES
ON CANCER PATIENTS' ATTITUDES, NORMS
AND INTENTION TO EXPRESS CONCERNS

This paper is currently under review as Brandes, K., Linn, A.J., van Weert, J.C.M., Verdam, M.G.E., & Smit, E.G. The effects of persuasive messages on cancer patients' attitudes, norms and intention to express concerns.

Abstract

Cancer patients often do not intend to express their concerns during their consultations. This can be problematic because concern expression is associated with positive outcomes for patients such as better well-being. In this study we developed persuasive messages that are based on determinants that underlie patients' intention to express concerns. The aim of this study is to examine the effectiveness of these persuasive messages on cancer patients' attitudes, perceived social norm and intention to express concerns in consultations. We systematically tested the effects of the messages by using single targets (i.e., targeting one determinant), combined targets (i.e., targeting multiple determinants at once) and no targets. An experiment with 4 conditions (attitudes message, social norm message, combined message, control message) was used with pre-test and post-test measurements. The results showed small positive changes for patients who could potentially change, but there were no differences in effects between the messages. A second study was conducted to determine whether these effects could be attributed to exposure to the message or to the pre-test questionnaire. There were no differences between the group who received the message and the group who only received the pre-test questionnaire. This indicates that paying attention to concern expression might already increase patients' intention to express concerns.

Introduction

Expressing concerns during cancer consultations has been associated with many positive outcomes for patients such as reduced levels of anxiety and better well-being (de Haes & Bensing, 2009; Street, Makoul, Arora, & Epstein, 2009). Concern expression is an affective behavior and has been defined as clearly and explicitly verbalizing recent emotions during consultations (Bensing & Verhaak, 2004; Zimmermann et al., 2011). Although concern expression seems beneficial, cancer patients often do not express their concerns during consultations or do not express them in a direct and clear matter (e.g., 'I am worried') but rather as indirect cues (i.e., unclear verbal or non-verbal hints of concerns; Grimsbø, Ruland, & Finset, 2012; Heyn, Ruland, & Finset, 2012). Healthcare providers often find it difficult to notice and adequately respond to these indirect cues (Butow, Brown, Cogar, Tattersall, & Dunn, 2002). Patients might therefore benefit from interventions that support their concern expression.

The interventions that have been developed in the concern expression area consist of consultation preparation tools in the form of concern lists (e.g., Farrell, Heaven, Beaver, & Maguire, 2005; Ghazali, Roe, Lowe, & Rogers, 2015; Heaven & Maguire, 1998; Heyn et al., 2012; Hill, Amir, Muers, Connolly, & Round, 2003; Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008). Concern lists are lists with topics that patients might be concerned about (e.g., side-effects or treatment). Patients receive a concern list prior to their consultation and they can select the topics that are relevant to them. Most of these intervention studies assessed what topics patients select from concern lists (e.g., Ghazali et al., 2015) and/or the extent to which patients report to have discussed these topics with their provider (e.g., Hill et al., 2003). One study assessed the effects of a concern list on actual concern expression in a consultation (Heyn et al., 2012). These authors found that patients who received a concern list expressed more cues and concerns than patients in the control group. However, the vast majority of patients' expressions were cues, and, as indicated before, providers might not pick up on those cues which may result in inadequate discussion of concerns. More research is therefore needed into how concern expression can be supported via interventions.

One promising avenue to explore in developing concern expression interventions, is to use a behavioral theory such as the integrative model of behavioral prediction (IMBP; Fishbein, 2000) or the theory of planned behavior (TPB; Ajzen, 1991) as a basis for identifying relevant intervention targets (Fishbein, 2000; Fishbein & Cappella, 2006). Interventions that are based on behavioral theories are often more effective in changing health behaviors and intentions than interventions that are not (Avery, Donovan, Horwood, & Lane, 2013; Webb, Joseph, Yardley, & Michie, 2010). Both the IMBP and TPB postulate that individuals do or do not perform a behavior (in this case expressing concerns) based on their intention. According to these theories, individuals' intention

is formed on the basis of attitudes, perceived social norm and self-efficacy (Ajzen, 1991; Fishbein, 2000). In a recent empirical study (Brandes, Linn, Smit, & van Weert, 2016) the IMBP was taken as a starting point to examine the determinants of cancer patients' intention to express concerns. A survey was distributed among 236 cancer patients and cancer survivors and the results showed that their intention to express concerns is explained by their attitudes and perceived social norm. The authors concluded that a change in intention could be accomplished by targeting patients' attitudes (more specifically the affective component; *concern expression can be unpleasant*) and perceived social norm (more specifically the injunctive component, *significant others do not want patients to express concerns*) in a message. To examine the most optimal way how these messages can improve attitudes, perceived social norm and intention, it is important to test their single and combined effects (Dijkstra & de Vries, 2001; Michie & Abraham, 2004). Therefore, the aim of this study is to test whether a persuasive message targeting attitudes, perceived social norm or a combination is most effective in improving patients' attitudes, perceived social norm and, consequently, their intention to express concerns.

Persuasive Messages

Persuasive messages are described as communications that are theory-based and have the goal to change or reinforce a behavior or a behavioral intention (Fishbein & Cappella, 2006). Persuasive messages that aim to change intention are based on behavioral determinants that have causal relations with intention (i.e., in the case of intention to express concerns; attitudes and perceived social norm) and therefore give clear insights into which elements lead to a change in intention (i.e., can we attribute a possible change in intention to targeting the affective component of attitudes, the injunctive norm or both; Fishbein & Yzer, 2003; Michie & Prestwich, 2010). Because of these reasons, persuasive messages are often claimed to be more effective in changing intention and behavior than messages that are not based on behavioral determinants (Avery et al., 2013; Webb et al., 2010). Although the claim for the superior effects of these theory driven persuasive messages on intentions has often been proposed, it is difficult to support these claims with evidence because the effects on intentions vary and are inconclusive (Hardeman et al., 2002; Van den Putte & Dhondt, 2005). For example, a systematic review about the effectiveness of interventions based on the TPB (including persuasive messages) showed that only 42% of the interventions had a positive effect on intention and 33% had no effect on intention. Furthermore, the use of theory was unrelated to the direction of effects (i.e., positive, negative or no effects; Hardeman et al., 2002). Thus, the effects of persuasive messages can generate several changes in intention (positive, negative or no effect) and to establish under which circumstances these types of messages are effective, we need to apply them to different behaviors for different populations in different contexts.

In the context of cancer patients' concern expression, to our knowledge, persuasive messages based on behavioral determinants have not been developed and tested (Brandes et al., 2016). Moreover, we lack knowledge about what generates change in patients' communication behavior (Henselmans, de Haes, & Smets, 2012). Systematically testing the effectiveness of persuasive messages that target the determinants of patients' intention to express concerns can be a first step in identifying the utility of the IMBP and TPB as intervention formats for concern expression and in understanding which factors can lead to a change in concern expression.

Overview of Study and Research Questions

We targeted patients' attitudes (i.e., expressing concerns can be unpleasant) and perceived social norm (i.e., significant others do not want patients to express concerns) because these were identified as the most promising intervention targets to change intention (Brandes et al., 2016). To be able to thoroughly investigate the change generating processes of the persuasive messages on patients' attitudes, perceived social norm and intention, it is relevant to test the intervention targets together and separately (Michie & Abraham, 2004). Furthermore, to properly test these messages, a control message needs to be included that does not include these targets (Van den Putte & Dhondt, 2005). In this study we chose a message that just gives information about concerns and cancer. Thus, we included four conditions; (1) attitude message, (2) perceived social norm message, (3) combined message, and (4) control message. Although the importance of testing the single and combined effects of intervention targets has been stressed in various studies, most interventions do not follow this approach (Michie & Abraham, 2004). Therefore, it is unclear whether it is more effective to use a single intervention target or to combine multiple intervention targets. To assess the differences in effects between using single and combined intervention targets in the context of cancer patients' concern expression, we formulate the following research questions:

RQ 1: Which of the messages will be most effective in improving cancer patients' attitudes towards concern expression?

RQ 2: Which of the messages will be most effective in improving cancer patients' perceived social norm of concern expression?

RQ 3: Which of the messages will be most effective in improving cancer patients' intention to express concerns?

Studies have shown that past behavior (i.e., whether patients have expressed concerns in consultations before) can influence intention and should be controlled for to determine the effectiveness of a message (e.g., Fishbein & Cappella, 2006). Furthermore, individuals can also have attitudes towards

the message they are exposed to (e.g., whether they like the message or not). These attitudes can also influence the effects of a message (Van den Putte & Dhondt, 2005). Therefore, both past behavior and attitudes towards the message are taken into account as possible covariates.

Methods Study 1

Participants and Procedure

The participants were recruited in November- December 2014 via two cancer patient panels in the Netherlands (i.e., kanker.nl and PanelCom). Participants were eligible if they (1) were 18 years or older, (2) currently received treatment for cancer or had received treatment for cancer in the past and (3) still had consultations for their cancer (either treatment consultations or follow-up consultations). The experiment consisted of a pre-test measurement (T1) and a post-test measurement after two weeks, immediately after exposure to the message (T2). The ethical committee of the authors' university approved this study (2013-CW-74).

Study Design

This study consisted of an online experiment with 4 conditions (attitudes message, social norm message, combined message and control message) and within- between subject measures. This design was chosen to be able to analyze the results systematically (i.e., to examine the exact differences of using single targets, combined targets or no targets). At T1 participants completed a pre-test questionnaire which included questions about demographic and disease characteristics, past behavior and the dependent variables. At T2 participants were randomized to one of the videos and completed a post-test questionnaire about the dependent variables and their attitudes towards the message.

Materials

Three targeted messages were created in which intervention targets were manipulated; (1) a message targeting attitudes with an emphasis on the affective component of attitudes, namely on the way patients may feel after expressing concerns in a consultation (e.g., feeling relieved), (2) a message targeting perceived social norm with an emphasis on the way patients' significant others can respond after patients express their concerns (e.g., they support the patient) and (3) a combined message in which the targeted messages of 1 and 2 were combined. The control message was an informational message about cancer. All four messages started with the same short introduction about the different concerns patients can experience during cancer (this was approximately 50% of the total message). Appendix 4.1 shows the texts of all the different messages. As a format for the messages video-

testimonials were chosen because previous studies have indicated that messages with affective/emotional components can be best presented with narratives such as testimonials and with visuals (Van den Putte & Dhondt, 2005; Zebregs, van den Putte, Neijens, & de Graaf, 2015). We conducted two pre-tests; one for the scripts of videos and one for the character. Both pre-tests are described in Appendix 4.2.

Sample size

To estimate the required sample size to detect a meaningful difference between and within participants, a power calculation for a repeated measures within-between subject design was conducted with four groups and two measurement time points. The estimated effect size (*Cohen's f*) for the power calculation was set at .10 because meta-analyses in communication science have shown that the effect sizes in studies on the effectiveness of messages are typically small (O'Keefe, 2013). We assumed a correlation among the repeated measures of .70, and the alpha was set at .05. The power calculation showed that we needed 168 participants to achieve a power of 80% to detect an effect.

Measures

Demographic characteristics. Participants had to fill in their gender, age, living situation, whether they had children and their level of education.

Disease characteristics. Participants were asked to specify the date of their cancer diagnoses (which was later recoded into "time since diagnosis"), the type of cancer(s) they had, whether they were still undergoing treatment for their cancer(s), which treatments they currently received, which treatments they received in the past and their treatment goal (palliative or curative).

Attitudes. Participants' attitude towards expressing concerns in consultations was measured at T1 and T2 with six items (*unpleasant- pleasant, bad- good, not helpful- helpful, a disadvantage- an advantage, not stressful- stressful, not useful- useful*) on a 7-point semantic differential scale (Francis et al., 2004; Montano & Kasprzyk, 2008; T1: $\alpha = .91$, $M = 5.75$, $SD = 1.26$, T2: $\alpha = .91$, $M = 5.67$, $SD = 1.24$).

Perceived social norm. Perceived social norm was measured at T1 and T2 with eight items (Francis et al., 2004; Montano & Kasprzyk, 2008). Participants had to specify on a 7-point scale (1 = *strongly disagree* to 7 = *strongly agree*) to what extent their significant others (i.e., people who are important to them) *expect* or *want* them to express their concerns in a cancer consultation and whether they

complied with this. Furthermore, participants were asked to indicate whether they believed that certain important people in their environment want them to express concerns in a consultation (i.e., if applicable: their partner, their children, their siblings, their friends and other cancer patients; T1: $\alpha = .84$, $M = 5.09$, $SD = 1.15$, T2: $\alpha = .82$, $M = 5.05$, $SD = 1.12$).

Intention. Intention was measured at T1 and T2 with three items in which participants had to indicate on a 7-point scale (1 = *strongly disagree* to 7 = *strongly agree*) whether they intended to express concerns during their next cancer consultation (T1: $\alpha = .90$, $M = 5.12$, $SD = 1.63$, T2: $\alpha = .91$, $M = 5.17$, $SD = 1.55$; Francis et al., 2004; Montano & Kasprzyk, 2008).

Past behavior. Participants' concern expression in consultations in the past was measured with 1 item in which they had to indicate on a 7-point scale (1 = *strongly disagree* to 7 = *strongly agree*) whether they expressed their concerns towards their healthcare provider (T1: $M = 5.51$, $SD = 1.49$, T2: $M = 5.28$, $SD = 1.60$; Francis et al., 2004).

Attitude towards the video. Participants' attitude towards the video was measured at T2 after exposure to the video on a 7-point semantic differential scale with the same six items that were used to measure attitude towards concern expression in consultations but then with the focus on the video ($\alpha = .91$, $M = 4.92$, $SD = 1.07$).

Manipulation check. As a manipulation check we asked participants to indicate on a 7-point scale (1 = *strongly disagree* to 7 = *strongly agree*) whether they perceived that the message was about the character's feelings after expressing concerns or what the significant others of the character think of her expressing concerns in a consultation.

Analyses

To answer the research questions repeated measures ANOVAS were conducted for all the dependent variables with type of message as between-subject factor. If there was a significant difference, post-hoc comparisons with a Bonferroni correction were conducted.

Results Study 1

Response

The pre-test questionnaire was fulfilled by 226 participants. In total 190 participants (84.1%) completed both the pre- and the post-test. A non-response analysis showed that participants who only completed the pre-test did not differ from participants who completed the whole study in gender ($\chi^2 (1) = 1.11, p = .291$), age ($F (1, 224) = 2.87, p = .092$) and level of education ($\chi^2 (2) = 2.33, p = .312$).

Participants

The majority of the participants were female (52.6%), almost half of them were highly educated (45.3%) and they had a mean age just over 60 ($M = 60.61, SD = 9.76$). Most participants were diagnosed with either digestive-gastrointestinal cancer (22.1%) or urological cancer (21.6%) and common received treatments were surgery (35.3%) and chemotherapy (23.6%). Furthermore, 53.7% of the participants still received treatment for their cancer when they completed the study. Table 4.1 shows all the demographic and disease characteristics of the sample.

Randomization

A total of 190 participants were randomized to the four experimental groups; the attitudes group ($n = 50$), the social norm group ($n = 44$), the combined group ($n = 51$) and the control group ($n = 45$). The groups did not differ in gender ($\chi^2 (3) = 1.36, p = .715$), age ($F (3, 186) = .28, p = .837$) and level of education ($\chi^2 (6) = 2.81, p = .832$).

Covariates

Past behavior and attitudes towards the message were identified as possible covariates in previous studies. The conditions did not differ in past behavior ($F (3, 186) = .81, p = .487$) and attitudes towards the message ($F (3, 186) = 2.17, p = .093$). Past behavior and attitude towards the message did have significant correlations with all the dependent variables. We conducted the analyses with and without the covariates and the results remained the same. To retain sufficient power, we chose to present the results from the analyses without covariates.

Manipulation check

Participants who were randomized to the conditions that included an attitude message perceived this message to be more about the way you feel after expressing concerns ($M = 6.05, SD = 1.27$) than participants who did not receive an attitude message ($M = 4.76, SD = 2.11$). This difference was statistically significant ($F (1, 188) = 26.68, p < .001$). Participants who were randomized to

the conditions with a social norm message perceived this message to be more about how significant others think of patients expressing concerns ($M = 6.45$, $SD = 1.25$) than patients who did not receive a social norm message ($M = 3.86$, $SD = 1.79$). This difference was also statistically significant ($F(1, 188) = 133.43$, $p < .001$). Since the attitude and social norm messages were perceived as intended, we consider the manipulation to be successful.

Table 4.1

Demographics and Disease Characteristics of the Sample (N = 190)

Characteristic	N	%
<u>Gender</u>		
Male	90	47.4
Female	100	52.6
<u>Age</u>		
<i>M (SD)</i>	60.61 (9.76)	
Range	35-85	
<u>Educational level</u>		
Low	45	23.7
Middle	59	31.1
High	86	45.3
<u>Living arrangements</u>		
Alone	26	13.7
Partner	115	60.5
Partner and child(ren)	41	21.6
Child(ren)	5	2.6
Other	3	1.6
<u>Children</u>		
Yes	156	82.1
No	34	17.9
<u>Employed</u>		
Yes	74	38.9
No	116	61.1

Characteristic	N	%
<u>Type of cancer</u>		
Breast	39	18.3
Digestive-gastrointestinal	47	22.1
Haematological	29	13.6
Lung	3	1.4
Gynaecological	7	3.3
Urologic	46	21.6
Head and neck	5	2.3
Skin	9	4.2
Other	28	13.1
<u>Time since diagnosis (months)</u>		
<i>M (SD)</i>	52.83 (67.54)	
<u>Undergoing treatment</u>		
Yes	102	53.7
No	88	46.3
<u>Treatment intent</u>		
Curative	124	65.3
Palliative	57	30.0
Unknown	9	4.7
<u>Treatment</u>		
No treatment	5	1.3
Surgery	141	35.3
Chemotherapy	94	23.6
Radiotherapy	81	20.3
Immunotherapy	14	3.5
Hormone replacement therapy	26	6.5
Chemo radiation therapy	5	1.3
Goal directed therapy	10	2.5
Unknown	1	0.3
Other	5	5.5

Note. *n* varies for type of cancer and treatment due to the possibility to give multiple answers

Main analyses

For attitudes (RQ1), we found no significant time effect ($F(1, 182) = 1.37, p = .244$) and no differences in effects between conditions ($F(3, 182) = .30, p = .824$). For perceived social norm (RQ2), there was also no significant time effect ($F(1, 182) = 1.41, p = .236$) and no differences between conditions ($F(3, 182) = 2.26, p = .083$). For intention (RQ3), the analyses did show a significant time effect ($F(1, 182) = 4.49, p = .035$) but no significant differences between conditions ($F(3, 182) = .78, p = .507$).

The analyses only revealed a time effect for intention. To further explore and understand why there were no effects between the conditions, we created a median split between the participants who scored below the median at baseline (i.e., there was a fair possibility to detect a change, thus these participants had room for improvement) and those who scored above the median at baseline (i.e., there was little possibility to detect a change, thus these participants had no room for improvement). These analyses showed that the time effect for attitudes ($F(1, 182) = 29.25, p < .001$), perceived social norm ($F(1, 182) = 17.23, p < .001$) and intention ($F(1, 182) = 22.82, p < .001$) was different for participants who scored below and above the median at baseline across conditions. Participants' attitudes significantly increased in the group that scored below the median at baseline ($M_{\text{difference}} = .338, p = .002$) and significantly decreased in the group that scored above the median at baseline ($M_{\text{difference}} = -.523, p < .001$). This effect did not significantly differ between conditions ($F(3, 182) = .37, p = .772$). Participants' perceived social norm significantly increased in the group that scored below the median at baseline ($M_{\text{difference}} = .193, p = .024$) and significantly decreased in the group that scored above the median at baseline ($M_{\text{difference}} = -.351, p < .001$). This effect did not differ between conditions ($F(3, 182) = 1.89, p = .133$). Participants' intention significantly increased in the group that scored below the median at baseline ($M_{\text{difference}} = .315, p = .020$) and significantly decreased in the group that scored above the median at baseline ($M_{\text{difference}} = -.760, p = .005$). This effect did again not differ between conditions ($F(3, 182) = .10, p = .961$). Tables 4.2, 4.3 and 4.4 show the mean scores of the participants (below and above the median) at T1 and T2 on all the dependent variables.

Table 4.2*Mean Scores and Standard Deviations of the Participants (N = 190) at T1 and T2 on Attitudes*

	n	Attitudes T1	Attitudes T2
<u>Affective attitude message condition</u>			
Below the median at T1	24	4.97 (1.04)	5.44 (1.12)
Above the median at T1	26	6.88 (.19)	6.25 (.96)
Total	50	5.89 (1.22)	5.83 (1.12)
<u>Injunctive norm message condition</u>			
Below the median at T1	21	4.78 (.98)	5.02 (1.32)
Above the median at T1	23	6.78 (.25)	6.10 (1.36)
Total	44	5.82 (1.22)	5.58 (1.44)
<u>Combined message condition</u>			
Below the median at T1	23	4.48 (1.07)	4.86 (1.08)
Above the median at T1	28	6.23 (.30)	6.30 (.81)
Total	51	5.71 (1.35)	5.65 (1.18)
<u>Control message condition</u>			
Below the median at T1	28	4.82 (.92)	5.09 (1.20)
Above the median at T1	17	6.84 (.25)	6.48 (.74)
Total	45	5.59 (1.26)	5.62 (1.25)
<u>Total sample</u>			
Below the median at T1	98	4.77 (1.01)	5.11 (1.18)
Above the median at T1	92	6.80 (.26)	6.27 (1.00)
Total	190	5.75 (1.26)	5.67 (1.24)

Table 4.3

Mean Scores and Standard Deviations of the Participants (N= 190) at T1 and T2 on Perceived Social Norm

	n	Injunctive norm T1	Injunctive norm T2
<u>Affective attitude message condition</u>			
Below the median at T1	28	4.09 (1.09)	4.48 (1.27)
Above the median at T1	22	6.08 (.48)	5.70 (.77)
Total	50	4.97 (1.32)	5.02 (1.23)
<u>Injunctive norm message condition</u>			
Below the median at T1	20	4.26 (.95)	4.31 (1.26)
Above the median at T1	24	5.98 (.43)	5.67 (.67)
Total	44	5.20 (1.11)	5.05 (1.19)
<u>Combined message condition</u>			
Below the median at T1	25	4.47 (.87)	4.22 (1.13)
Above the median at T1	26	6.09 (.43)	5.71 (.77)
Total	51	5.30 (1.06)	4.98 (1.22)
<u>Control message condition</u>			
Below the median at T1	31	4.38 (.80)	4.96 (.82)
Above the median at T1	14	5.95 (.55)	5.64 (.48)
Total	45	4.87 (1.03)	5.17 (.79)
<u>Total sample</u>			
Below the median at T1	104	4.30 (.93)	4.53 (1.14)
Above the median at T1	86	6.03 (.46)	5.67 (.69)
Total	190	5.09 (1.15)	5.05 (1.12)

Table 4.4*Mean Scores and Standard Deviations of the Participants (N= 190) at T1 and T2 on Intention*

	n	Intention T1	Intention T2
<u>Affective attitude message condition</u>			
Below the median at T1	39	4.42 (1.48)	5.00 (1.60)
Above the median at T1	11	6.76 (.30)	6.09 (1.24)
Total	50	4.93 (1.64)	5.24 (1.59)
<u>Injunctive norm message condition</u>			
Below the median at T1	33	4.44 (1.65)	4.83 (1.82)
Above the median at T1	11	6.91 (.22)	6.03 (1.32)
Total	44	5.06 (1.79)	5.13 (1.78)
<u>Combined message condition</u>			
Below the median at T1	37	4.78 (1.45)	4.98 (1.54)
Above the median at T1	14	6.95 (.18)	5.55 (1.67)
Total	51	5.38 (1.57)	5.14 (1.58)
<u>Control message condition</u>			
Below the median at T1	38	4.75 (1.45)	5.11 (1.19)
Above the median at T1	7	6.90 (.25)	5.91 (1.36)
Total	45	5.09 (1.55)	5.24 (1.24)
<u>Total sample</u>			
Below the median at T1	147	4.60 (1.50)	4.99 (1.53)
Above the median at T1	43	6.88 (.24)	5.87 (1.40)
Total	190	5.12 (1.63)	5.19 (1.55)

Discussion Study 1

This study aimed to examine the effects of several persuasive messages (i.e., using single and combined targeting) on cancer patients' attitudes, perceived social norm and intention to express concerns. We had sufficient power to detect meaningful differences. However, we only found positive time effects for participants who scored below the median at pre-test on the outcome measures (i.e., their attitudes, perceived social norm and intention improved at T2 as compared to T1) and no differences in effects between the different messages. These results may imply that it does not matter which message patients with a potential to change receive as long as they receive some form of information about concerns and/or concern expression. As we measured attitudes, perceived social norm and intention at baseline, it could also be possible that we found an effect of our pre-test questionnaire, instead of a message effect. On the basis of the first data collection, we could not attribute our findings to the messages with certainty. Therefore, we performed a second study in which we randomized participants to a message condition or to a no exposure condition. The aim of the second study was to examine whether the time effects we found for participants who scored below the median at baseline in the first study were the result of exposure to a message or a pre-test questionnaire.

Methods Study 2

The method of study 2 was exactly the same as the method of study 1. Only the differences are described below.

Participants and Procedure

Participants were recruited in March and April 2015 from kanker.nl. To assure that we did not include participants from the first study, we only recruited among patients that registered themselves to kanker.nl after the first study was conducted. Furthermore, we also added a question at the beginning of the survey in which we asked participants whether they participated in a similar study in November- December 2014. If the answer to this question was "yes" ($n = 4$) they could not complete the second study.

Study Design

The second study consisted of a 1 factor (message or no message) design. Participants received a pre-test questionnaire online and two weeks later they were randomized to either the condition with a

message or the condition without a message. After exposure to the message, participants received the post-test questionnaire. Participants in the condition without the message only received the post-test questionnaire.

Materials

The message consisted of the intro message from study 1 in which the patient explains the different concerns that she experienced during cancer. The duration of this video message was 1 minute. This intro was also shown in all the conditions in study 1. Therefore, it could be that particularly this part of the message explained the effects that we found in study 1.

Sample Size

Power calculation showed that with an alpha of .05 and a correlation among the repeated measures of .70., we needed 84 participants to achieve a power of 80% to detect an effect (*Cohen's f* = .10) between the two conditions.

Measures

The same measures were used as in Study 1. The reliability and mean scores on the scales are described in Table 4.5.

Table 4.5

Mean Scores, Standard Deviations and Reliability of the Measures of the Second Study

	α T1	α T2	M (SD) T1	M (SD) T2
Attitudes	.88	.88	5.83 (1.08)	5.84 (1.07)
Perceived social norm	.68	.64	5.13 (1.18)	5.26 (1.05)
Intention	.89	.87	5.58 (1.42)	5.36 (1.39)
Past behavior			5.70 (1.48)	5.32 (1.56)
Attitude towards the message		.88		5.07 (1.00)

Note. Only the condition that was exposed to the video received the engagement with video questions.

Results Study 2

Response

The baseline survey was completed by 86 participants. In total 63 participants (73.3%) completed the entire study. A non-response analysis indicated that the participants who did and did not complete the entire study did not differ in gender ($\chi^2(1) = 0.07, p = .790$), age ($F(1, 84) = 3.29, p = .073$) and level of education ($\chi^2(2) = .04, p = .979$).

Participants

Most of the participants were female (68.3%), had a mean age of 56.94 years ($SD = 10.52$) and were highly educated (42.9%). The majority of the participants had breast cancer (24.3%) or digestive-gastrointestinal cancer (20.0%) and were treated with surgery (41.5%) or chemotherapy (22.0%). More than half of the participants (50.8%) was not undergoing treatment at the moment of the study. Table 4.6 shows all the demographic and disease characteristics of the participants.

Randomization

Sixty-three participants were randomized to either the message condition ($n = 33$) or the control condition without a message ($n = 30$). The two conditions did not differ in gender ($\chi^2(1) = 0.07, p = .796$), age ($F(1, 61) = .08, p = .774$) and level of education ($\chi^2(2) = .39, p = .823$).

Covariates

The two conditions did not differ in past behavior ($F(1, 61) = .71, p = .402$). Attitude towards the message was only measured in the message group. Correlations between past behavior, attitude towards the messages and the dependent variables showed significant relations between past behavior and attitudes and intention. Similar to study 1 adding the covariates to the analyses did not yield different results. To retain power, we used the analyses without the covariates.

Table 4.6*Demographics and Disease Characteristics of the Second Sample (N = 63)*

Characteristic	N	%
<u>Gender</u>		
Male	20	68.3
Female	23	21.7
<u>Age</u>		
M (SD)	56.94 (10.52)	
Range	27-76	
<u>Educational level</u>		
Low	15	23.8
Middle	21	33.3
High	27	42.9
<u>Living arrangements</u>		
Alone	10	15.9
Partner	36	57.1
Partner and child(ren)	15	23.8
Child(ren)	1	1.6
Other	1	1.6
<u>Children</u>		
Yes	49	77.8
No	14	22.2
<u>Employed</u>		
Yes	26	41.3
No	37	58.7
<u>Type of cancer</u>		
Breast	17	24.3
Digestive-gastrointestinal	14	20.0
Haematological	3	4.3
Lung	4	5.7
Gynaecological	9	12.9

Table continues on next page

Characteristic	N	%
Urologic	6	8.6
Head and neck	3	4.3
Skin	2	2.9
Other	12	17.1
<u>Time since diagnosis (months)</u>		
<i>M (SD)</i>	33.03 (34.88)	
<u>Undergoing treatment</u>		
Yes	31	49.2
No	32	50.8
<u>Treatment intent</u>		
Curative	48	76.2
Palliative	11	17.5
Unknown	4	6.3
<u>Treatment</u>		
No treatment	2	1.6
Surgery	51	41.5
Chemotherapy	27	22.0
Radiotherapy	23	18.7
Immunotherapy	3	2.4
Hormone replacement therapy	9	7.3
Chemo radiation therapy	1	0.8
Goal directed therapy	0	0.0
Unknown	2	1.6
Other	5	4.1

Note. *n* varies for type of cancer and treatment due to the possibility to give multiple answers

Main analyses

There was no significant time effect for attitudes ($F(1, 59) = .14, p = .712$), perceived social norm ($F(1, 59) = .64, p = .427$) and intention ($F(1, 59) = 1.61, p = .209$). There were also no significant differences between conditions for attitudes ($F(1, 59) = .83, p = .367$), perceived social norm ($F(1, 59) = .01, p = .914$) and intention ($F(1, 59) = 2.05, p = .158$).

Consistently with study 1, we added a median split to the analyses. For attitudes, a significant time effect was found for participants who scored below the median at baseline across conditions ($F(1, 59) = 7.08, p = .010$). Participants' attitudes significantly increased in the group that scored below the median ($M_{\text{difference}} = .402, p = .043$) and did not change in the group that scored above the median ($M_{\text{difference}} = -.303, p = .097$). For perceived social norm we also found a significant time effect for participants who scored below the median at baseline across conditions ($F(1, 59) = 5.97, p = .018$). Participants' perceived social norm significantly increased in the group that scored below the median ($M_{\text{difference}} = .447, p = .022$) and did not change in the group that scored above the median ($M_{\text{difference}} = -.227, p = .261$). For intention the time effect was not found ($F(1, 59) = 2.25, p = .139$). No differences were found between the conditions for attitudes ($F(1, 59) = 2.11, p = .152$), perceived social norm ($F(1, 59) = .03, p = .862$) and intention ($F(1, 59) = .06, p = .803$). Tables 4.7, 4.8 and 4.9 show the mean scores of the participants (below and above the median) at T1 and T2 on all the dependent variables.

Table 4.7*Mean Scores and Standard Deviations of the Second Sample (N = 63) at T1 and T2 on Attitudes*

	n	Attitudes T1	Attitudes T2
<u>Message condition</u>			
Below the median at T1	15	5.07 (.42)	5.16 (1.05)
Above the median at T1	18	6.76 (.29)	6.53 (.65)
Total	33	5.99 (.92)	5.90 (1.09)
<u>Control condition</u>			
Below the median at T1	14	4.60 (.87)	5.31 (1.06)
Above the median at T1	16	6.56 (.49)	6.19 (.90)
Total	30	5.64 (1.21)	5.78 (1.06)
<u>Total sample</u>			
Below the median at T1	29	4.84 (.71)	5.23 (1.04)
Above the median at T1	34	6.67 (.41)	6.37 (.78)
Total	63	5.83 (1.08)	5.84 (1.07)

Table 4.8*Mean Scores and Standard Deviations of the Second Sample (N = 63) at T1 and T2 on Perceived Social Norm*

	n	Perceived social norm T1	Perceived social norm T2
<u>Message condition</u>			
Below the median at T1	17	4.39 (.97)	4.85 (1.10)
Above the median at T1	16	6.02 (.52)	5.75 (.85)
Total	33	5.18 (1.13)	5.28 (1.07)
<u>Control condition</u>			
Below the median at T1	16	4.12 (.84)	4.56 (.70)
Above the median at T1	14	6.18 (.49)	5.99 (.80)
Total	30	5.08 (1.25)	5.23 (1.04)
<u>Total sample</u>			
Below the median at T1	33	4.26 (.91)	4.71 (.93)
Above the median at T1	30	6.09 (.51)	5.86 (.82)
Total	63	5.13 (1.18)	5.26 (1.05)

Table 4.9*Mean Scores and Standard Deviations of the Second Sample (N = 63) at T1 and T2 on Intention*

	n	Intention T1	Intention T2
<u>Message condition</u>			
Below the median at T1	14	4.93 (1.34)	4.55 (1.49)
Above the median at T1	19	6.90 (.22)	5.86 (1.10)
Total	33	6.06 (1.31)	5.30 (1.42)
<u>Control condition</u>			
Below the median at T1	26	4.76 (1.21)	5.26 (1.40)
Above the median at T1	4	6.92 (.17)	6.50 (.58)
Total	30	5.04 (1.35)	5.42 (1.38)
<u>Total sample</u>			
Below the median at T1	40	4.82 (1.25)	5.01 (1.46)
Above the median at T1	23	6.90 (.21)	5.97 (1.04)
Total	63	5.58 (1.42)	5.36 (1.39)

Discussion Study 2

In the second study we aimed to examine whether the time effects for participants who had a potential to change that were found in study 1 were caused by exposure to a message or to a questionnaire. In the second study we found the same time effects in both groups (i.e., the message group and no exposure group) for attitudes and perceived social norm. However, we did not find any effects on intention. In behavioral models intention is always presented after attitudes and perceived social norm. It is therefore more likely that messages will first influence attitudes and perceived social norm rather than intention (Fishbein & Yzer, 2003). As we had less power than we aimed for (i.e., 63 instead of 84 participants), it is possible that we had insufficient power to detect an effect on intention.

General Discussion

The first study aimed to examine whether persuasive messages were effective in improving cancer patients' attitudes, perceived social norm and intention to express concerns. We did not find any main effects from the messages on the dependent variables except for intention (i.e., a time effect across all the different message conditions). Furthermore, we did not find any differences between conditions indicating that it does not matter whether a message was targeting determinants of intention or just gave information. We added a median split to the analyses to further explore what might explain the lack of effects. The results showed a small improvement in all the dependent variables for patients who scored below the median at pre-test and a small decrease in the dependent variables for patients who scored above the median at pre-test. Because all four conditions received a message and a baseline questionnaire, it was unknown whether the effects could be attributed to receiving a message or a questionnaire. The aim of the second study was to answer the latter question. Patients were randomized to either a message condition or a no exposure condition. Again, no main effects were found and no differences between conditions. When we added the median split, similar effects as in study 1 were found for patients who scored below the median on attitudes and perceived social norm (i.e., their attitudes and perceived social norm increased). Contrary to study 1, we did not find a decrease in attitudes and perceived social norm for the patients who scored above the median. Further, we found no effects on intention, possibly due to insufficient power in study 2. Thus, both a pre-test questionnaire and a short message yielded small changes in the dependent variables for patients who scored below or above the median at pre-test (i.e., there was room for improvement in their attitudes, perceived social norm and intention). A possible explanation for the effects of the pre-test questionnaire can be that existing beliefs are activated (Ajzen & Fishbein, 2000; Ajzen, 2001). The questions might have primed participants' attention for their attitudes, norms and intentions and can therefore enhance the accessibility and salience of existing beliefs about concern expression. By increasing the accessibility and salience, individuals' perception of the importance of performing the behavior (i.e., expressing concerns) can increase and, consequently, attitudes, norms and intention can improve (Ajzen, 2001; Zhao et al., 2006)

An alternative explanation could be that the results are caused by a regression to the mean effect. A regression to the mean effect is a statistical phenomenon that can occur when repeated measures are completed by the same individuals. It is caused by random measurement error. When individuals have an extreme high or low score at baseline, it is more likely that their subsequent score will be closer to the "true mean". In the case of, for example, an extreme high mean score at baseline, this means that the subsequent score will decrease because it was not possible that the baseline mean score could

improve (Barnett, van der Pols, & Dobson, 2005; Verkooijen, Stok, & Mollen, 2015). Regression to the mean effects have been demonstrated in other studies that examined the effects of persuasive messages as well (Verkooijen et al., 2015). Although the regression to the mean effect can be an explanation for the results in the group that scored below the median at baseline (a small increase in the scores on the dependent variables at T2 compared to T1) and the group that scored above the median at baseline (a small decrease in the scores on the dependent variables at T2 compared to T1), it is more likely that this effect only exists for the group that scored above the median. Due to the high T1 scores on the dependent variables of this group (most of the times participants scored higher than a 6 on average on a 7-point scale), only a decrease in their scores was possible at T2. The patients in the group that scored below the median did have room to change (most of the times participants scored between 4 and 5 on average on a 7-point scale) and therefore it is more likely that their scores are not the result of a regression to the mean effect.

Overall, we did not find effects for any of the persuasive messages. A possible explanation could be that using persuasive messages based on the IMBP and the TPB is not the most optimal way to stimulate concern expression. We know from a previous study (Brandes et al., 2016) that not all the variance in intention to express concerns was explained by attitudes and perceived social norm and perhaps targeting other determinants than those of the IMBP (e.g., anticipated regret) will yield different results. Furthermore, we did not target underlying beliefs (e.g., beliefs that are elicited via qualitative research with cancer patients and that discriminate intenders from non-intenders), instead we targeted the specific content of patients' attitudes (i.e., feeling unpleasant) and perceived social norm (i.e., the feeling that significant others do not want the patient to express concerns). Underlying beliefs could address more specifically why concern expression is unpleasant or why patients have the feeling that significant others do not want them to express concerns. Perhaps targeting these underlying beliefs would have resulted in more positive effects. There are also studies, however, in which determinants were targeted more generally and these studies report positive effects on intention (e.g., Hill, Abraham, & Wright, 2007). More research is needed to explore whether targeting specific beliefs would yield different effects on patients' attitudes, perceived social norm and intention.

Another possible reason for the lack of effects in the present study could be that we exposed our participants only once to a relatively short message. Research has indicated that more intensive use of targeting with multiple exposures can lead to greater effects (Webb et al., 2010). This could specifically be the case when attitudes and norms are based on individuals' own experiences with performing the behavior because these are more difficult to change than attitudes and norms that are based on information that is provided by others (Fishbein & Yzer, 2003; Hornik & Woolf, 1999).

The patients in our study had been diagnosed for over 3 years on average and had relatively high scores on past behavior, therefore it is plausible to assume that their attitudes and perceived social norm are based on their own experiences in consultations. In such a case, multiple exposures could be needed to allow for adaptation of attitudes and norms (Kok et al., 2016). Future research could examine whether multiple exposures could be more effective in changing attitudes and norms that are based on patients' own experiences. Furthermore, a replication of this study is recommended with patients that are newly diagnosed to examine whether these results differ for patients who have not yet formed stable attitudes, norms and intentions to express concerns.

This study used information about positive emotional consequences (i.e., feeling relieved/ better after expressing concerns) and the approval of others (i.e., significant others want patients to discuss concerns) as techniques of targeting in the persuasive messages. These techniques are commonly used to changes attitudes, norms and intention, are feasible to use in short messages and showed positive effects on communication behaviors of cancer patients in previous studies (Hardeman et al., 2002; Henselmans et al., 2012; Kok et al., 2016). On the other hand, a meta-analysis on effective techniques used in health interventions shows that other techniques such as demonstration of the behavior can be very effective as well and perhaps this would have been a more suitable technique for concern expression (Webb et al., 2010). Demonstration of the behavior could, for example, be depicted in a video wherein a consultation is simulated in which a patient expresses concerns. In general, if we want to advance the field of targeting, more studies are needed to provide insights into which techniques are effective in changing certain types of health behaviors and intentions with specific populations (Michie et al., 2013). Future research could therefore further examine which (other) techniques can be used to positively change cancer patients' attitudes, perceived social norm and intention to express concerns.

To conclude, this study examined the effects of single and combined targeting in persuasive messages on cancer patients' attitudes, perceived social norm and intention to express concerns. There were no differences between the messages on the dependent variables for patients who had a potential to change. Further, we found the same effect for patients who only received a pre-test questionnaire. The pre-test questionnaire possibly caused an activation of patients' existing beliefs of concern expression which then lead to small positive changes in attitudes, perceived social norm and intention in the group of patients who had room for improvement. Thus, paying attention to concern expression, either by a message or a questionnaire, might already result in some positive effects for cancer patients. More research is recommended to identify effective techniques for persuasive messages, aside from providing information, which may yield larger changes in attitudes, norms and intentions.

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Appendix 4.1

The Persuasive Messages

Introduction messages that was used for all the messages:

Hello, my name is Ellen and I was diagnosed with cancer a year ago. After I was diagnosed, I experienced many concerns such as practical concerns about whether I would still be able to do my job, emotional concerns such as fear of dying, and physical concerns about the possible pain that I would experience as a result of this disease. I also experienced many concerns about my family and children, and how they would cope with my disease. I read in a magazine that many patients experience these concerns. For example, a third of the patients is worried about pain, work and dying. And half of the patients is worried about how their loved ones will cope with their disease.

Attitude message:

In the beginning of my disease trajectory, I found it very difficult to discuss my concerns with my doctor. I had doubts about whether I would feel unpleasant if I would do this and this withheld me from expressing my concerns. But I also noticed that my concerns were not going away and not discussing them made me feel worse. The concerns were constantly on my mind. Eventually, I decided to discuss my concerns with my doctor. My doctor responded with empathy and it felt good to talk about my concerns. After this conversation, I felt better. Because I discussed my concerns, I also felt relieved.

Perceived social norm message:

In the beginning of my disease trajectory, I found it difficult to estimate whether my loved ones would want me to express my concerns towards my doctor. I noticed that they wanted me to stay positive. Therefore, I found it difficult to discuss my concerns during a consultation because most of the times one my loved ones was present and I did not want my concerns to be a burden to them. This withheld me from expressing my concerns but the concerns were constantly on my mind. Eventually, I decided to discuss my concerns with my doctor. My loved ones thought this was a good decision and they supported me. I knew then they wanted me to express my concerns to my doctor.

Combined message:

In the beginning of my disease trajectory, I found it very difficult to discuss my concerns with my doctor. I had doubts about whether I would feel unpleasant if I would do this and whether my loved ones would want me to express my concerns towards my doctor. I noticed that they wanted me to stay positive. Therefore, I found it difficult to discuss my concerns during a consultation because most of

the times one my loved ones was present and I did not want my concerns to be a burden to them. This withheld me from expressing my concerns. But I also noticed that my concerns were not going away, and not discussing them made me feel worse. The concerns were constantly on my mind. Eventually, I decided to discuss my concerns with my doctor. My loved ones thought this was a good decision and they supported me. I knew then they wanted me to express my concerns to my doctor. In addition, my doctor responded with empathy and it felt good to talk about my concerns. After this conversation, I felt better. Because I discussed my concerns, I also felt relieved.

Control message:

I read that 100.000 people are diagnosed with cancer per year. The number of people who gets diagnosed with cancer increases every year with approximately 3%. The most important cause of this increase is that the population of the Netherlands grows and that people get older. The number of cancer patients increases the most in people that are 85 years or older. The most prevalent forms of cancer in the Netherlands are skin cancer, breast cancer, colon cancer, lung cancer and prostate cancer. These five forms of cancer together form two third of all the new diagnoses. The most diagnosed form of cancer differs per age group. For example, children are more frequently diagnosed with leukemia and older people with colon cancer.

Note. We translated the messages from Dutch into English to the best of our abilities. Some sentences might be longer or shorter than those in the original messages due to the translation. Some words that we used in the original messages also needed to be translated differently in English.

Appendix 4.2

Pre-tests

Four actors (two males and two females) were pre-tested among a panel of 23 healthy adults for trustworthiness, likeability and similarity. The results of the pre-test showed that one actress scored significantly higher on trustworthiness, likeability and similarity than the other actors and actress. Hence, this actress was chosen for all the videos. The scripts for the videos were pilot tested by five patients for understandability and adjusted accordingly. The scripts of the targeted messages contained four targeted sentences. To account for a possible exposure effect, two scripts and videos were developed for the combined message condition. One with all eight targeted sentences resulting in a video of 2:23 minutes and one with four targeted sentences (two about attitudes and two about norms) resulting in a video of 1:50 minutes (same length as the other videos). The introduction of the messages lasted 1 minute. When participants were randomized to the combined message condition, they received one of the two videos. ANOVA tests showed that there were no differences between the videos with respect to the dependent variables. Therefore, we combined the scores of the participants and treat them as one group (i.e., the combined message group) in further analyses.



PART 2:
STRESS- COPING PERSPECTIVE





CHAPTER 5:
UNDERSTANDING THE INTERPLAY
OF CANCER PATIENTS' INSTRUMENTAL
AND EMOTIONAL CONCERNS

This chapter is currently in revision as Brandes, K., van der Goot, M.J., Smit, E.G., van Weert, J.C.M., & Linn, A.J. Understanding the interplay of cancer patients' instrumental and emotional concerns.

Abstract

The objective was 1) to assess the congruency between the operationalization of concerns in the literature and patients' perspectives of concerns, and 2) to inform a theoretical framework in which the nature of concerns can be understood. Six focus groups were conducted with 39 cancer patients and survivors. In these focus groups participants were asked to indicate how they perceived concerns during and after their illness. Concerns were perceived as instrumental (e.g., receiving insufficient information) and emotional concerns (e.g., sadness). Patients frequently described their concerns as an interplay of instrumental and emotional concerns. Frequent combinations of instrumental and emotional concerns were, for example, *receiving insufficient information* and *uncertainty*, *receiving inadequate information* and *frustration*, *receiving insufficient information* and *insecurity*, *sadness* and *insufficient information*, and *fear* and *searching, finding and judging of information*. Instrumental concerns are often overlooked in the operationalization of concerns in research. A conceptual model is presented in which the nature of concerns is embedded into the stress-coping model. Additional research is needed in which the interplay and providers' responses are coded in actual consultations. The results of this study can be used to support providers in recognizing concerns that are expressed by patients in consultations.

Introduction

Half of the cancer patients experience clinical levels of psychological distress within one month after their diagnosis, and almost a third of the patients still experience such high levels of distress twelve months later (Carlson et al., 2004). High levels of distress are detrimental because they can impair patients' overall well-being (Street, Makoul, Arora, & Epstein, 2009). It is argued that adequate discussion of concerns by healthcare providers (e.g., adequately exploring and responding to concerns) offers patients support in coping with their concerns and, consequently, reduces levels of distress (Bensing & Verhaak, 2004; Street et al., 2009). However, concerns are not always adequately discussed in consultations, neither by patients nor providers (Finset, Heyn, & Ruland, 2013; Hill, Amir, Muers, Connolly, & Round, 2003). Patients have the tendency to express their concerns as indirect cues, for example by telling a story in which these cues are hidden. Providers find it difficult to recognize these cues and as a result the underlying concern might remain unaddressed (Butow, Brown, Cogar, Tattersall, & Dunn, 2002). It is therefore important to get a clear understanding of what comprises patients' concerns. Such information could assist providers in recognizing concerns, even when they are expressed as indirect or hidden cues. The current literature shows two gaps; 1) we lack knowledge about the congruency between the way concerns are operationalized in the literature and patients' perspectives of how they perceive concerns and 2) there is, to the best of our knowledge, no theoretical framework that helps to understand the complex nature of concerns. These gaps may be addressed by examining patients' perspectives of how they perceive concerns qualitatively. Such an examination can generate new ideas about concerns and therefore indicate whether concerns are operationalized in congruence with patients' perspectives and inform a theoretical framework (Britten, 2011).

Operationalization of concerns

Currently, we lack knowledge about the congruency between the operationalization of concerns in research and patients' perspectives. The importance of examining the congruency between researchers' operationalization of a concept and patients' perspectives is highlighted in a study about treatment decision making (Entwistle, Skea, & T O'Donnell, 2001). This study compared the narratives about treatment decisions of women who had a hysterectomy with scales that measure decision making roles. Women had to explain how they made decisions and then select a decision making role. The results showed that there were discrepancies between the narratives of women and the operationalization they selected, indicating problems with the validity of these scales.

Concerns are operationalized in different ways. There are studies that use concern checklists in which concerns are operationalized as "patient generated issues of importance" (Chaturvedi, Shenoy, Prasad,

Senthilnathan, & Premlatha, 1996; Farrell, Heaven, Beaver, & Maguire, 2005; Ghazali, Roe, Lowe, & Rogers, 2013; Heaven & Maguire, 1998). On the other hand there are problem lists in which concerns represent “the amount of burden a patient experiences about a topic” (Hoffman, Zevon, D’Arrigo, & Cecchini, 2004; Roth et al., 1998; Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008). Next to self-report studies, there are studies in which coding manuals such as the Roter Interaction Analysis System (RIAS) and the VR-CoDES are used to code concerns in consultations (Finset et al., 2013; Grimsbø, Ruland, & Finset, 2012; Heyn, Ruland, & Finset, 2012; Mellblom et al., 2014; Mellblom et al., 2016; Schouten & Schinkel, 2015; Vatne, Finset, Ørnes, & Ruland, 2010; Zimmermann, Del Piccolo, & Finset, 2007). The RIAS operationalizes a concern as “a condition or event that is serious, worrisome, distressing or deserving special attention” (Eide, Quera, Graugaard, & Finset, 2004; Roter & Larson, 2002), whereas VR- CoDES operationalizes a concern as “an unpleasant emotional state” (Del Piccolo et al., 2011; Zimmermann et al., 2011). In the present study we examine patients’ perspectives of how they perceived concerns with the aim to assess the congruency with different operationalizations in research. We strive to propose an operationalization that reflects patients’ perspectives best.

Theoretical frameworks of concerns

To the best of our knowledge, there is not a clear theoretical framework aiming to understand the complex nature of concerns. Such a theoretical framework is important to inform interventions, for example, to assist providers in recognizing concerns during consultations. To date, concerns are embedded in a few illness coping models (e.g., the stress coping model and the common-sense model of illness representations) but these models are not specifically developed to understand the nature of concerns. The aim of the stress- coping model (Bensing & Verhaak, 2004) is to provide a framework to understand how doctor-patient communication can lead to adequate stress-coping. In this model, it is argued that concerns reflect emotional needs. The nature of concerns is not specified in this model. It posits that if patients have emotional needs affective behaviors of a provider are needed to facilitate coping. If a patient on the other hand has an instrumental need instrumental behaviors are needed to facilitate coping (Bensing & Verhaak, 2004; Street & Millay, 2001). In the common-sense model of illness representations (Leventhal, Meyer, & Nerenz, 1980; Meyer, Leventhal, & Gutmann, 1985), concerns were initially not embedded nor specified. This model is developed to examine patients’ illness representations. In a subsequent published meta-analysis about the common-sense model (Hagger & Orbell, 2003) concern expression was added to the model as an instrumental coping strategy, indicating that concerns can also be instrumental. Thus, concerns are embedded differently in theory and none of these theories specify the nature of concerns. The present study therefore examines patients’ perspectives of how they perceived concerns with the aim to inform a theoretical framework about the nature of concerns and how this can affect doctor-patient communication.

Methods

Participants and procedure

Participants (cancer patients and survivors) were recruited via PanelCom (i.e., a patient panel) by email. Inclusion criteria were that participants had to be 18 years or older and currently diagnosed with cancer or have had cancer in the past. In total 221 panel members received an invitation, and 39 panel members responded to the email and agreed to participate. Table 5.1 shows the demographic and disease characteristics of the participants. We conducted four face-to-face focus groups (FFGs, $n = 30$) and two online focus groups (OFGs, $n = 9$). A combination of these two types of focus groups was chosen to be able to include participants who were not able to travel to the FFGs locations (e.g., because they felt too ill). In addition, both types of focus groups have advantages. For instance, in a FFG participants can see each other and contextual features such as body language can help participants to understand each other. But in an OFG, for example, participants can experience less barriers to discuss sensitive topics such as sexuality. Participants were assigned to a FFG based on their availability. After the FFG's, two OFGs were conducted simultaneously during two days.

We started the data collection with the four FFGs and these were moderated by two researchers (KB together with MG or AL) who also took notes. The FFGs were conducted in an open way, video-taped and transcribed verbatim. First, the researchers introduced themselves and explained the aim of the study. Participants were then asked to introduce themselves by stating their name, where they were from and why they wanted to participate in this study. After that, participants were asked to think back at the moment that they were diagnosed and to indicate what kind of concerns they had experienced from that moment until now. After the first FFG, the first author watched the video-tape, read the notes of both moderators and made a list of the concerns that were mentioned. This list was used in the second FFG as a starting point for discussion. Participants could then explain if they experienced similar concerns and were asked to come up with new concerns. This process was repeated in the different focus groups to make sure that the list was as complete as possible at the end of the data collection.

The OFGs started with a list of concerns derived from the FFGs. The OFGs were moderated by the first author. Participants logged in on a protected website with a username and password. The moderator posted statements and questions at the beginning of the day for all participants (e.g., what were your concerns during your disease trajectory?). During the day, based on the reactions of participants, the moderator posted follow-up statements and questions. Participants received an email when a new statement was posted by the moderator. The moderator also tried to facilitate discussion between participants by repeating statements of participants and asking whether other participants

could respond. The OFGs were held a-synchronously so that participants could respond on times that were convenient to them. All participants had to sign an informed consent form before the FFG or OFG started. Every participant received an incentive (fifteen euros) for their contribution and FFG participants also received travel reimbursement. At the end of all focus groups participants had to fill out a questionnaire eliciting demographic and disease characteristics. The study was approved by the ethical committee of the authors' university (2015-CW-31).

Table 5.1

Demographics and Disease Characteristics of the Sample (N = 39)

Characteristic	N	%
<u>Gender</u>		
Male	17	44
Female	22	56
<u>Age</u>		
M (SD)	59.74 (11.54)	
Range	28-80	
<u>Educational level</u>		
Low	2	5
Middle	13	33
High	24	62
<u>Living arrangements</u>		
Alone	9	23
Partner	23	59
Partner and child(ren)	5	5
Child(ren)	2	13
Other	0	0
<u>Children</u>		
Yes	27	69
No	12	31
<u>Employed</u>		
Yes	18	46
No	21	54

Characteristic	N	%
<u>Type of cancer</u>		
Breast	7	16
Digestive-gastrointestinal	7	16
Haematological	9	21
Lung	1	2
Gynaecological	3	7
Urologic	10	23
Head and neck	1	2
Skin	3	7
Other	2	5
<u>Time since diagnosis (months)</u>		
<i>M</i> (SD)	51.31 (37.08)	
<u>Still in treatment</u>		
Yes	14	36
No	25	64
<u>Treatment intent</u>		
Curative	27	69
Palliative	11	28
Unknown	1	3
<u>Treatment</u>		
No treatment	1	1
Surgery	24	29
Chemotherapy	22	27
Radiotherapy	20	24
Immunotherapy	4	5
Hormone replacement therapy	5	6
Chemo radiation therapy	0	0
Goal directed therapy	0	0
Unknown	0	0
Other	6	7

Note. *n* varies for type of cancer and treatment due to the possibility to give multiple answers

Analysis

The transcripts were coded and analyzed in Atlas.TI. The first step in the analytical process was open coding (Strauss & Corbin, 1998). Each focus group transcript was divided into fragments that represented a perspective of a concern and these fragments were coded. The transcript of the first FFG was coded on paper by two authors (KB and MG) to discuss the codes. The remaining five transcripts were coded by the first author. Doubts about interpretations during this process were discussed and resolved with the authors who were present at the FFGs (MG and AL). The codes emerged inductively, there were no a priori codes. After iterative coding for perspectives of concerns, the codes were discussed in the team and different structures were employed to present the data in a clear way. Eventually we have decided that the best way to structure the data, was to divide the concerns in instrumental concerns (i.e., concerns related to information) and emotional concerns (i.e., concerns related to emotions).

The second step was focused coding (Charmaz, 2006). Concerns were coded as instrumental concerns if they were about information (e.g., receiving insufficient information) and concerns were coded as emotional concerns if they contained a description of a feeling/ emotional situation (e.g., feeling sad). After coding perspectives of concerns as instrumental and emotional concerns, sub-categories were established. Instrumental concerns comprised four sub-categories of concerns: information overload, receiving insufficient information, receiving inadequate information, and difficulties with searching, finding and judging information. Emotional concerns comprised eight sub-categories: fear, loneliness, shame, frustration, denial, insecurity, uncertainty and sadness. Table 5.2 shows patients' descriptions of instrumental and emotional concerns and the respective sub-categories. After coding all the sub-categories and a first analysis of the data, we found that patients often discussed instrumental and emotional concerns in the same sentences and fragments. This made it complex to code them separately because in most utterances and fragments patients described an interplay of instrumental and emotional concerns. Thus, the focus of our analysis changed during the coding process to a deeper interest in the interplay of instrumental and emotional concerns.

The last step was therefore to look for patterns in interplays of instrumental and emotional concerns. We examined which codes of instrumental and emotional concerns were coded together in a sentence or fragment a patient. When a combination of instrumental and emotional concerns was identified, we explored how the interplay was described (i.e., was the instrumental concern accompanied by an emotional concern or vice versa).

Table 5.2*Patients' Instrumental and Emotional Concerns with Examples of the Sub-Categories*

Concerns	Examples
<u>Instrumental concerns</u>	
Information overload	Receiving too much information at once in a consultation which made it difficult for patients to remember what was being said. Specifically described in the context of bad-news consultations.
Receiving insufficient information	This concern was described in several contexts: 1) information that patients gathered themselves on the internet was not mentioned in the consultation, 2) little information was available because the patient, for example, had a rare form of cancer, 3) patients received no information at all about a certain topic and 4) lack of information on the internet about a certain topic.
Receiving inadequate information	Information turned out to be incorrect after a period of time (e.g., side-effects were downplayed). This was described for information that was received during a consultation (e.g., incorrect diagnosis) and information that was gathered on the internet (e.g., prognostic information).
Difficulties with searching, finding and judging of information	Difficulties in navigating the internet for information. Concerns about whether information on websites was approved by medical experts, find stories of patients with the same disease who were terminal and whether they were able to judge whether the information was applicable to their specific disease situation.
<u>Emotional concerns</u>	
Fear	Fear was described as an emotion that changes over time. In the beginning of the disease there was fear about survival but at the same patients adopted a survival mode. After treatments, fear became more prevalent and complex.
Loneliness	Loneliness was described in two contexts. First, patients could feel alone even though they had support from their partner and family. They had the feeling that their social environment did not fully understand what it means to have this disease. Second, patients felt alone because they do not have a partner. These patients had friends and family but did not want to be a burden to them and found it difficult to have no one to talk to at home.
Shame	Shame was mostly mentioned in relation to self-care. Some patients had to live with a stoma or had to apply self-catheterization which imposed feelings of shame, especially if patients needed help with applying self-care.
Frustration	Frustration was caused by situations (e.g., patients had to follow a fixed after-care program and they could not decide which activities they wanted to participate in), others (e.g., patients did not want to be seen and treated as patients by their social environment the entire time) and themselves (e.g., patients were in a constant battle with themselves because they wanted to keep the control over their lives but sometimes they were too ill to do that).

Table continues on next page

Concerns	Examples
<u>Emotional concerns</u>	
Denial	Patients in denial did not believe their diagnosis when they received it. Reasons for denial were that patients did not feel ill at all or believed that cancer was something that would never happen to them.
Insecurity	Insecurity refers to patients' feelings of vulnerability. For example, patients talked about insecurity in relation to bodily changes. They felt insecure because of hair loss and the way people looked at them when they wore a wig.
Uncertainty	Uncertainty refers to the doubtful situations. It was experienced, for instance, after cancer when patients had to go to the hospital for check-ups and they were uncertain whether the results were positive or not
Sadness	Sadness was discussed in two contexts. Sadness in the context of the patient and the patient's loved ones. Patients, for example, mentioned to feel sad when they noticed that they were losing their independency or had to learn to live with the limitations of their treatments (e.g., with a stoma). In relation to loved ones, sadness was experienced when patients saw the impact their disease had on the lives of their loved ones.

Results

Interplay of instrumental concerns and emotions

Concerns can be perceived as instrumental and emotional concerns which both have underlying sub-categories (see Table 5.2). Contrary to the suggestion in the stress-coping model (Bensing & Verhaak, 2004) and the common sense model of illness representations (Leventhal et al., 1980; Meyer et al., 1985) that instrumental and emotional needs/representations are two separate paths, there seems to be an interplay of instrumental and emotional concerns. Both types of concerns were mentioned repeatedly in the same sentences and fragments of patients. Different interplays were identified namely instrumental concerns that were accompanied by emotional concerns or emotional concerns that were accompanied by instrumental concerns.

Instrumental concerns accompanied by emotional concerns

Each of the instrumental concerns (i.e., information overload, receiving insufficient information, receiving inadequate information and difficulties with searching, finding and judging of information) was mainly described together with fear, frustration and uncertainty. Combinations that were coded frequently were the interplay of receiving inadequate information and frustration about unsuspected side-effects and the interplay of receiving insufficient information and uncertainty about the disease

trajectory. The interplay of inadequate information and frustration was described in the context of side-effects. Patients indicated that inadequate information is a concern that occurs over time. For example, patients received information during a consultation that turned out to be incorrect later on in their trajectory. Sometimes side-effects were downplayed in a consultation. For instance, in the case of two breast cancer survivors, providers told them that the chances of them experiencing capsular tissue were smaller than the factual statistics. This led to feelings of frustration when capsular tissue was nevertheless experienced. This is illustrated by one of the survivors who experienced capsular tissue after a breast reconstruction:

“At a certain moment I asked questions about problems with capsular tissue and prostheses because I also needed radiation. But noooo, that was not a problem, the chances of capsular tissue were very small. But it turned out that the chance of having capsular tissue in my particular case was 80%”.
(P13, female)

The interplay of insufficient information and uncertainty was often described in the context of patients who were going through a “wait and see period” (i.e., regular check-ups to see if the disease remains stable). Patients described that they received little information about treatment decisions during the “wait and see period” (e.g., what are the criteria for actually treating the cancer or continuing with the wait and see approach). This concern was accompanied by feelings of uncertainty about the disease trajectory. A patient with a chronic form of leukemia explained this:

“I have chronic leukemia, which is a very uncertain disease. I find it difficult, which test outcomes are relevant, when do they need to treat this disease, or when do they choose a wait and see approach. A lot is unknown. It’s uncertain and you wonder when the sword of Damocles will fall, when is it my turn, it’s difficult to estimate that”. (P17, female)

A distinct pattern was found for receiving insufficient information and feelings of insecurity about the body after cancer. Some patients indicated that they experienced insufficient information about how they would feel after cancer, when all the treatments are over. Patients explained that there was little information about what kind of complaints (e.g., fatigue) were normal to experience after treatment and how long these complaints would last. Alongside patients’ descriptions of receiving little information, they expressed feelings of insecurity. For example, a patient explained how she received little information about the period after cancer and how she felt insecure about her body after cancer:

“During treatments there is so much help, after the treatments there is nothing. There is no information about how you’ll feel. You analyze everything, every muscle in your body, every twinge. Why do I feel tired? Did the cancer return or I am tired just like everyone else is sometimes tired. You don’t trust your body any longer. You feel insecure, it’s horrible”. (P34, female)

Emotional concerns accompanied by instrumental concerns

Combinations in which emotional concerns were accompanied by instrumental concerns were found for all emotional concerns except denial (i.e., fear, loneliness, shame, frustration, insecurity, uncertainty and sadness) and for the instrumental concerns receiving insufficient information and difficulties with searching, finding and judging of information. It was notable that emotional concerns that were accompanied by instrumental concerns were most often described in the context of an emotional concern combined with difficulties in searching, finding and judging of information. Patients indicated to search for information to cope with a certain emotional concern. For example, patients experienced fear because they had side-effects after a treatment. To ease their mind about the nature of this side-effect, they would search for information on the internet. In some cases, however, patient found it difficult to decide on which websites they could find reliable information. A patient referred to this by explaining that she had concerns about using the internet to reduce her fear caused by side-effects that she experienced after her lung cancer treatment:

“So you’re anxious... and if you are searching for information on the internet, you can read information that will make you worry. Who says that the information on the internet is true? Which site provides honest information about my medical issues and which one provides nonsense?” (P31, female)

Another frequent described combination was uncertainty and concerns about insufficient information. For example, patients felt uncertain about their prognosis and wanted to know how long they could live with their disease. In some cases patients expressed their feeling of uncertainty to their doctor but sometimes the doctor could not give a clear prognosis. This uncertainty was discussed together with concerns regarding the lack of information that was available for their specific question. A patient referred to this as follows:

“So the question is whether your prognosis is always clear to your doctor. Because in my case it’s so unpredictable, they can only guess. It’s really a disillusion sometimes”. (P15, female)

A distinct pattern was found for sadness and receiving insufficient information. Sadness was often experienced in the context of patients’ loved ones. They felt sad because their children had difficulties

to continue their “carefree” lives (e.g., going out, having fun with friends) or they felt they were a burden for their partner (e.g., because the partner had less time for him/herself). Some patients indicated that they wanted information that could support their loved ones in coping with their disease. However, they perceived that there was insufficient information out there, for example both in consultations and on the internet, which made them feel even more concerned. A patient explained this by indicating that he experienced a lot of sadness when he saw how his disease made an impact on his wife and was concerned that there was little information available about after care for her:

“The influence of a cancer patient on his environment is enormous. The patient (patient refers to himself) is not always the biggest concern. My biggest concern was my wife. She had so many questions. I was the patient, I knew what was happening to me. But she didn’t know and had to go through it every day. All the emotions pile up and you have to cope with that. The question is how do you cope with that? But for her there was no after care and there is little information about that”.
(P23, male)

Discussion and conclusion

This study aimed to 1) examine the congruency between the ways concerns are operationalized in the literature and patients’ perspectives of concerns and 2) inform a theoretical framework in which the complex nature of concerns is specified. These aims were addressed by qualitatively exploring patients’ perspectives of how they perceived concerns during and after their disease. The results show that patients perceive concerns as instrumental (e.g., receiving insufficient information) and emotional concerns (e.g., sadness). More importantly, patients often discussed instrumental and emotional concerns in the same sentences and fragments, indicating that there is an interplay. Combinations of instrumental and emotional concerns were identified between receiving inadequate information and frustration, receiving insufficient information and uncertainty, and receiving insufficient information and insecurity. Conversely, emotional concerns were accompanied by instrumental concerns with combinations between fear and difficulties with searching, finding and judging of information, uncertainty and receiving insufficient information and sadness and receiving insufficient information.

The interplay of instrumental and emotional concerns is important to take into account when operationalizing concerns. In the literature concerns are often operationalized as negative emotions (e.g., Roter & Larson, 2002; Tuinman et al., 2008; Zimmermann et al., 2011). The current study shows that when patients were asked to reflect on how they perceived concerns, they also specified the instrumental nature of concerns. This indicates that solely focusing on the emotion when

measuring concerns might be too limited and possibly results in an incomplete picture of concerns. Korsvold and colleagues (2016) recently highlighted this issue as well. These authors used the VR-CoDES to code concerns in diagnostic consultations. They coded questions that contained an emotion but found little guidance in the current operationalization of concerns about whether they should code instrumental questions without a clear emotion. Eventually, many questions were coded because the overall nature of a diagnostic consultation is emotional for patients. This example stresses that the current ways of operationalizing concerns might not always be sufficient. We propose that both the instrumental and emotional component of a concern are taken into account when operationalizing and measuring concerns.

Such an operationalization can be integrated in studies that use concern check lists and problem lists. For example, by adding questions about whether patients experienced an instrumental concern, an emotional concern, or both about a certain topic and by further elaborating what types of instrumental and emotional concerns they experienced. This information could lead to a more in-depth understanding of which patterns of instrumental and emotional concerns occur in practice about certain topics. For the use of coding manuals such as the RIAS and the VR-CoDES, it would mean that, in addition to coding emotional concerns, researchers also have to closely assess whether there are instrumental concerns. The RIAS offers some guidance in coding instrumental concerns. Under instrumental behaviors, there is a category of questions about psychosocial behaviors in which questions about concerns are embedded (Roter & Larson, 2002). However, expressions of concerns are not conceptualized as a distinct instrumental behavior. This could be added to the manual. Coding instrumental concerns could further support the interplay found in our study and inform which combinations of instrumental and emotional concerns are frequently expressed together in consultations.

This study aimed to propose a theoretical framework in which the complex nature of concerns can be understood. Currently concerns are embedded in coping models (Bensing & Verhaak, 2004; Leventhal et al., 1980; Meyer et al., 1985) that specify two separate paths for instrumental and emotional needs/representations. The results of our study show that concerns are perceived by patients as an interplay of instrumental and emotional concerns, indicating that the nature of concerns cannot be understood as either instrumental or emotional. We propose a conceptual model (see Figure 5.1) in which we have embedded the complex nature of concerns in the stress-coping model (Bensing & Verhaak, 2004). We chose the stress-coping model as a basis because we wanted to elaborate further on how the nature of concerns can possibly affect doctor-patient communication and coping. The interplay of how patient perceived concerns suggests that patients may also express their emotional concerns as requests for information or their instrumental concerns as emotions. Furthermore, the conceptual

model suggests that providers could use both responses (affective and instrumental) for both types of concerns. For example, when patients express an emotional concern, providers may also be able to adequately reduce this emotional concern with an instrumental reaction rather than an emotional reaction. These responses could then lead to both types of coping behaviors (problem oriented and emotional coping). This model is suggested as a starting point to examine concerns and doctor-patient communication more dynamically rather than as a linear process in which a certain expression requires a certain response to have an impact on a certain coping behavior. More empirical research investigating the dynamic relations is needed to support this conceptual model.

There are some limitations that need to be addressed. The time since diagnosis in this study was quite high (on average 51 months). Research shows that concerns can develop over time and that certain concerns are more prevalent right after diagnosis than further along in the disease trajectory (Hill et al., 2003). Therefore, it is possible that we found patterns of interplays in our sample that are only prevalent further in the disease trajectory. For example, concerns about inadequate information were mentioned to be experienced after a while when patients realized that they were experiencing long-term side-effects that were not mentioned in prior consultations. A replication of this study with patients who were more recently diagnosed could provide insights into the interplay of instrumental and emotional concerns at the beginning of the disease.

To conclude, cancer patients perceive concerns as an interplay of instrumental concerns and emotions. Additional research is needed in which these results are taken into account in measuring concerns and coding consultations to provide further empirical evidence for this interplay.

Practice implications

Providers encounter difficulties in recognizing patients' concerns in consultations because they are often expressed as hidden cues in stories of patients. By recognizing the interplay in consultations and coding this in future research, we can identify frequent combinations of instrumental concerns and emotions during actual consultations. This information could support providers in recognizing patients' instrumental concerns and emotions and to respond adequately.

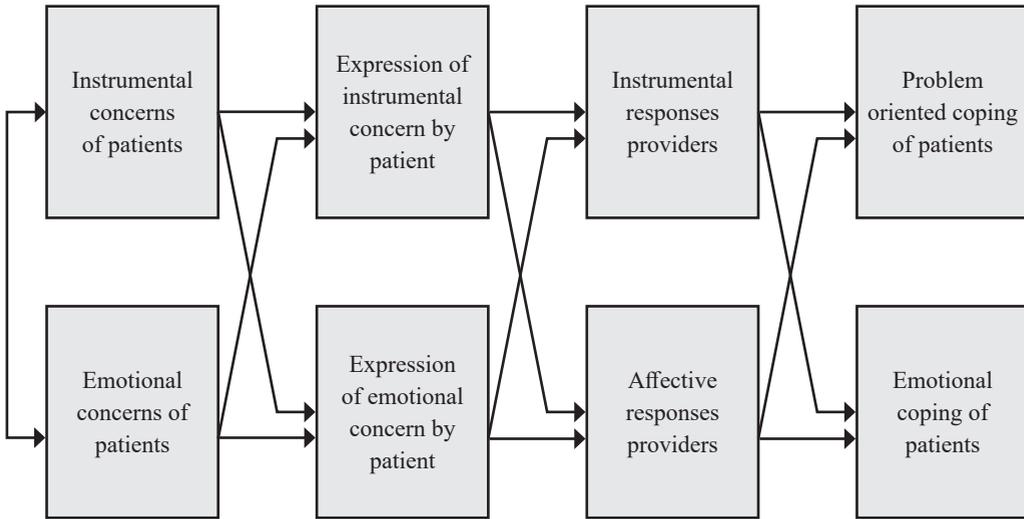


Figure 5.1. Conceptual model (based on the stress-coping model) addressing the interplay of instrumental and emotional concerns of patients and how this can affect communication in the consultation and coping.

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CHAPTER 6:
A FRAMEWORK FOR DEVELOPING
INTERVENTIONS TO SUPPORT CANCER
PATIENTS IN EXPRESSING INSTRUMENTAL
AND EMOTIONAL CONCERNS

This chapter is currently submitted for publication as Brandes, K., Linn, A.J., van Weert, J.C.M., van der Goot, M.J., & Smit, E.G. A framework for developing interventions to support cancer patients in expressing instrumental and emotional concerns.

Abstract

Little is known about how cancer patients can be supported in expressing their concerns during consultations. The few interventions that have been developed to support concern expression, hardly distinguish between patients' instrumental (i.e., concerns related to information) and emotional (i.e., concern related to emotions) concerns and the different topics of patients' concerns (i.e., medical, psychosocial and practical topics). The present study focuses on structuring patients' needs for support regarding instrumental and emotional concerns for medical, psychosocial and practical topics. By doing so, this study aims to present a framework with practical guidelines for developing interventions to support concern expression. Six focus groups ($N = 39$) were conducted among cancer patients and survivors. Patients' needs for support regarding instrumental and emotional concerns and the topics were classified with behavior change techniques and ways for delivering those techniques (i.e., by using interpersonal or mediated communication). The results show that patients wanted practical and emotional support, behavioral practice/rehearsal, help with preparation, instructions on how to perform the behavior, feedback on behavior, prompts/cues, a different structure for the consultation and tailoring. Most of these techniques needed to be delivered via (mediated) interpersonal communication. Needs sometimes differed for instrumental and emotional concerns. For example, patients wanted to discuss emotional concerns with other people than their doctor (e.g., peers and their social environment). Implications for intervention development are discussed.

Introduction

When patients are diagnosed with cancer an insecure time starts with many concerns (Beach & Dozier, 2015; Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premlatha, 1996). In a recent focus group study (Brandes, van der Goot, van Weert, Smit, & Linn, in revision), patients were asked which concerns they experienced during their disease trajectory. Based on patients' perceptions, concerns could be classified as either instrumental concerns (i.e., information overload, receiving insufficient information, receiving inadequate information and difficulties with searching, finding and judging of information) and emotional concerns (i.e., fear, loneliness, shame, frustration, denial, insecurity, uncertainty and sadness). These concerns comprise a variety of topics such as medical topics (i.e., disease, treatment, side-effects, pain, prognosis, heredity of cancer, decision making and hospital), psychosocial topics (i.e., social environment, life after cancer, end-of-life and religion and spirituality) and practical topics (i.e., daily-life, self-reliance and finances). It is important that patients express their concerns during consultations because healthcare providers can help to reduce concerns (de Haes & Bensing, 2009; Street, Makoul, Arora, & Epstein, 2009). In turn reduced concerns have been associated with positive outcomes for patients such as lower levels of anxiety and better psychological well-being (Street et al., 2009). Despite these possible benefits, concerns are often not adequately discussed in consultations (Grimsbø, Ruland, & Finset, 2012; Heyn, Ruland, & Finset, 2012).

Inadequate discussion of concerns is on the one hand caused by difficulties that providers experience with noticing and addressing concerns (Butow, Brown, Cogar, Tattersall, & Dunn, 2002; Farrell, Heaven, Beaver, & Maguire, 2005; Hill, Amir, Muers, Connolly, & Round, 2003). On the other hand, patients experience barriers to expressing concerns. These barriers can be related to the healthcare providers' behavior (e.g., the patient thinks that the healthcare provider will not respond with empathy), the logistics of the consultation (e.g., lack of time for discussing concerns in a consultation; Brandes, Linn, Smit, & van Weert, 2015), and agenda setting (e.g., putting concerns on the consultation agenda; Henselmans et al., 2012). Thus, both providers and patients might benefit from interventions to support them to adequately discuss concerns. Because most research in the concern expression literature has been focused on interventions for providers (Zimmermann, Del Piccolo, & Finset, 2007), the focus of this paper will solely be on support for the patient.

The studies that have been conducted so far to support patients with expressing concerns during consultations have mainly focused on supporting patients to prepare their consultations more sufficiently with the help of concern lists, i.e., lists with topics of concern from which the patient can select the topics that he or she is concerned about (e.g., Ghazali, Roe, Lowe, & Rogers, 2013;

Heaven & Maguire, 1998). Concern list studies show that concerns about medical topics (e.g., information about side-effects) are mostly adequately discussed, but concerns about psychosocial topics (e.g., family) and emotions are hardly ever discussed, let alone in an adequate way (Farrell et al., 2005; Hill et al., 2003). It could be that patients need additional support, next to preparation tools, to express all types of concerns (i.e., instrumental and emotional concerns about all topics). To our knowledge, there are neither studies that have made a distinction between instrumental and emotional concerns in the development of patient interventions to stimulate concern expression nor studies that have examined whether different interventions are needed to facilitate discussion of different topics. The focus of the current paper is therefore to qualitatively explore patients' needs for support for expressing instrumental and emotional concerns about medical, psychosocial and practical topics during consultations. By doing so, we aim to present a framework with practical guidelines for developing concern expression interventions.

To be able to create a framework for patients' needs for support, behavior change techniques and ways for delivering those techniques are taken into account, using the behavior change taxonomy (Michie et al., 2013). This taxonomy includes 93 different behavior change techniques and is a tool that helps to present intervention content to facilitate a change in behavior, in this case expressing concerns, in a standardized way (Abraham & Michie, 2008; Michie et al., 2013). A behavior change technique can, for example, comprise instructions on how to perform the behavior (i.e., advising or agreeing on how a person should express concerns) or practical social support (i.e., asking someone to help with the expression of concerns during a consultation). We use the behavior change taxonomy to structure the content of patients' needs for support so that the content can be presented in a clear matter for those who wish to develop an intervention for expressing concerns. Next to the content of an intervention, the way by which the content is delivered (i.e., interpersonal or mediated communication) can also contribute to the effectiveness of an intervention and whether the intervention is accepted by the target group (van Gemert-Pijnen et al., 2011; Webb, Joseph, Yardley, & Michie, 2010). Whether a behavior change technique needs to be delivered via interpersonal or mediated communication is also taken into account in this study. Interpersonal communication refers to face-to-face interaction. Mediated communication refers to communication that is facilitated by the use of a medium (e.g., offline via a booklet, or online via a website or discussion platform; Walther, 1996).

Methods

Participants

Participants for the focus groups were recruited via a cancer patient panel of the authors' university PanelCom (see www.panelcom.nl). The inclusion criteria were that participants had to be 18 years or older and were currently diagnosed with cancer or have had cancer in the past. A total of 221 panel members who were registered as cancer patients or cancer survivors received an invitation email, 39 of them agreed to participate (see Table 6.1 for the demographic and disease characteristics of the sample). The focus groups were conducted face-to-face (four groups, $n = 30$) and online (two groups, $n = 9$) to be able to include participants who indicated that they were too ill to travel to the focus group location. Participants for the face-to-face focus groups (FFGs) and online focus groups (OFGs) had to sign an informed consent form. Each participant received fifteen euros for their contribution and the FFG participants also received a travel reimbursement. After each focus group participants filled out a questionnaire eliciting demographic and disease characteristics. The ethical committee of the authors' university approved this study (2015-CW-31).

Procedure

First, the FFGs were conducted and participants were assigned to the different focus groups based on when they were available. After the FFGs, the two OFGs were held during two days and participants were randomly assigned to these OFGs. The focus groups comprised of two topics. The first topic had the aim to explore patients' perceptions of concerns during their disease trajectory which is described in a different paper (Brandes et al., in revision). The second topic had the aim to examine patients' needs for support to discuss concerns. This paper describes this second topic.

Table 6.1*Demographics and Disease Characteristics of the Sample (N = 39)*

Characteristic	N	%
<u>Gender</u>		
Male	17	44
Female	22	56
<u>Age</u>		
M (SD)	59.74 (11.54)	
Range	28-80	
<u>Educational level</u>		
Low	2	5
Middle	13	33
High	2	62
<u>Living arrangements</u>		
Alone	9	23
Partner	23	59
Partner and child(ren)	5	5
Child(ren)	2	13
Other	0	0
<u>Children</u>		
Yes	27	69
No	12	31
<u>Employed</u>		
Yes	18	46
No	21	54
<u>Type of cancer</u>		
Breast	7	16
Digestive-gastrointestinal	7	16
Haematological	9	21
Lung	1	2
Gynaecological	3	7
Urologic	10	23

Characteristic	N	%
Head and neck	1	2
Skin	3	7
Other	2	5
<u>Time since diagnosis (months)</u>		
<i>M</i> (SD)	51.31 (37.08)	
<u>Still in treatment</u>		
Yes	14	36
No	25	64
<u>Treatment intent</u>		
Curative	27	69
Palliative	11	28
Unknown	1	3
<u>Treatment</u>		
No treatment	1	1
Surgery	24	29
Chemotherapy	22	27
Radiotherapy	20	24
Immunotherapy	4	5
Hormone replacement therapy	5	6
Chemo radiation therapy	0	0
Goal directed therapy	0	0
Unknown	0	0
Other	6	7

Note. *n* varies for type of cancer and treatment due to the possibility to give multiple answers

Face-to-face focus groups. The FFGs were moderated by two researchers (KB with MG or AL), video-taped and transcribed verbatim. At the start of a FFG, the researchers introduced themselves and explained the two topics of the study. Then the participants were asked to introduce themselves and to share the reasons for their participation in the study. Next, the researchers asked participants to elaborate on the first topic (i.e., their perceptions of concerns during their disease trajectory). Last, participants were asked to discuss the second topic (i.e., their needs for support in discussing concerns). The researchers summarized what kind of concerns patients indicated when they discussed the first topic and then asked what kind of support they needed to discuss these concerns with their healthcare providers. This question was asked in an open way in each FFG. After participants brainstormed about their needs for support, we showed them two examples of interventions (i.e., two Question Prompt Lists; QPLs) that have been developed to support patients in expressing their information needs. QPLs are structured lists with questions, they differ from concern lists in the way information needs are formulated (i.e., as questions instead of concerns). Both QPLs had the same content, only their presentation format differed (i.e., a hardcopy booklet and a website). QPLs were shown because both a hardcopy and an online version were available in Dutch. By showing a hardcopy and online tool, participants could further elaborate whether they prefer online or offline mediated communication tools and which one was most easy to use. At the end of each FFG one of the researchers summarized the participants' needs for support and asked whether there were any additions.

Online focus groups. The OFGs were moderated by the first author and were conducted on a password protected website. The OFGs lasted for two days, a day per topic (i.e., the first day was about participants' perceptions of concerns and the second day about their needs for support). The OFGs were held a synchronically which means that participants could respond to the questions that were posted and to each other during the entire day. The OFGs had a similar structure as the FFGs except for the open question about participants' needs for support. Instead, a list with ideas for support that were derived from the FFGs was posted online. Participants were then asked to what extent they agreed with these ideas, whether they had other support needs that were not mentioned on the list and why they had those needs. During the OFGs the moderator tried to facilitate discussion between the participants by repeating statement of participants and asking others to respond. The moderator also asked follow-up questions during the OFGs to stimulate participants to elaborate on their answers. We did not show the examples of the Question Prompt Lists in the OFGs because it was not possible to show the hardcopy booklet. At the end of each OFG, the moderator summarized the needs for support and asked whether there were any additions.

Analysis

The transcripts were coded and analyzed in Atlas T.I. The framework method was used to analyze the data (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Ritchie, Lewis, Nicholls, & Ormston, 2013). This method was employed because the aim of this study was to propose a framework in which participants' needs for support to discuss concerns could be structured. The framework method is developed with the purpose to structure data with a priori codes but the method is also flexible, leaving room for emerging themes (Gale et al., 2013). Our a priori codes consisted of behavior change techniques and relevant modalities to address those technique. To code the behavior change techniques, the behavior change taxonomy (v1) was used (Michie et al., 2013). When specific needs for support emerged that could not be coded with the behavior change taxonomy, a new suitable code was given. For each behavior change technique, we coded whether patients suggested to use interpersonal or mediated communication (online or offline). Furthermore, the reasons for using the techniques and the way it needs to be delivered were also coded. Two authors (KB and AL) coded one focus group to discuss the codes. The other five focus groups were coded by the first author. Doubts about the codes were discussed with the other authors and were resolved through discussion. After iterative coding of the behavior change techniques and ways for delivery, they were linked to the instrumental and emotional concerns. In some cases it was not possible to identify whether suggestions were specifically made for instrumental or emotional concerns. In that case we present that finding as a need for support that could address both instrumental and emotional concerns. As a last step, we coded the different topics within instrumental and emotional concerns; medical topics (i.e., disease, treatment, side-effects, pain, prognosis, heredity of cancer, decision making and hospital), psychosocial topics (i.e., social environment, life after cancer, end-of-life and religion and spirituality) and practical topics (i.e., daily-life, self-reliance and finances). This resulted in a framework (Table 6.2) that shows which behavior change techniques (via interpersonal or mediated communication) can support patients in expressing instrumental concerns and emotions about medical, psychosocial and practical topics.

Table 6.2

Framework for Cancer Patients' Need for Support to Stimulate the Expression of Instrumental and Emotional Concerns about Medical, Psychosocial and Practical Topics

		Patients' need for support	Behavior change technique	Interpersonal or mediated communication
<u>Instrumental concerns</u>				
Medical topics (i.e., disease, treatment, side-effects, pain, prognosis, heredity of cancer, decision making and hospital)	1	A coach	Practical social support	Interpersonal communication
	2	A concern list	Behavior practice and rehearsal + help with preparation + prompts/cues	Mediated communication: booklets (offline), websites (online)
	3	Practicing consultations with a family member	Behavior practice and rehearsal	Interpersonal communication
	4	Videos of patients' experiences and consultations	Instruction on how to perform the behavior	Mediated communication: video on website
	5	Evaluation of consultation	Feedback on behavior	Interpersonal communication (e.g., a coach) and mediated communication (a question list)
	6	Tailored information	Tailoring	Interpersonal and mediated communication

		Patients' need for support	Behavior change technique	Interpersonal or mediated communication
<u>Instrumental concerns</u>				
Psychosocial topics (i.e., social environment, life after cancer, end-of-life and religion and spirituality)	1	A coach	Practical social support	Interpersonal communication
	2	A concern list	Behavior practice and rehearsal + help with preparation + prompts/cues	Mediated communication: booklets (offline), websites (online)
	3	Videos of patients' experiences and consultations	Instruction on how to perform the behavior	Mediated communication: video on website
	4	Different consultation structure (complementary consultation with a nurse)	Restructuring the physical environment	Interpersonal communication
	5	Evaluation of consultation	Feedback on behavior	Interpersonal communication (e.g., a coach) and mediated communication (a question list)
	6	Tailored information	Tailoring	Interpersonal and mediated communication

Table continues on next page

		Patients' need for support	Behavior change technique	Interpersonal or mediated communication
<u>Instrumental concerns</u>				
Practical topics (i.e., daily-life, self-reliance and finances)	1	A coach	Practical social support	Interpersonal communication
	2	A concern list	Behavior practice and rehearsal + help with preparation + prompts/cues	Mediated communication: booklets (offline), websites (online)
	3	Videos of patients' experiences and consultations	Instruction on how to perform the behavior	Mediated communication: video on website
	4	Different consultation structure (complementary consultation with a nurse)	Restructuring the physical environment	Interpersonal communication
	5	Evaluation of consultation	Feedback on behavior	Interpersonal communication (e.g., a coach) and mediated communication (a question list)
	6	Tailored information	Tailoring	Interpersonal and mediated communication

	Patients' need for support	Behavior change technique	Interpersonal or mediated communication
<u>Emotional concerns</u>			
Medical topics (i.e., disease, treatment, side-effects, pain, prognosis, heredity of cancer, decision making and hospital)	1 A coach	Practical social support	Interpersonal communication
	2 A concern list	Behavior practice and rehearsal + help with preparation + prompts/cues	Mediated communication: booklets (offline), websites (online)
	3 Videos of patients' experiences and consultations	Instruction on how to perform the behavior	Mediated communication: video on website
	4 Different consultation structure (complementary consultation with a nurse)	Restructuring the physical environment	Interpersonal communication
	5 Bring someone from social environment to the consultation (e.g., spouse, children or a friend)	Emotional social support	Interpersonal communication
	6 Evaluation of consultation	Feedback on behavior	Interpersonal communication (e.g., a coach) and mediated communication (a question list)
	7 Tailored information	Tailoring	Interpersonal and mediated communication

Table continues on next page

		Patients' need for support	Behavior change technique	Interpersonal or mediated communication
<u>Emotional concerns</u>				
Psychosocial topics (i.e., social environment, life after cancer, end-of-life and religion and spirituality)	1	Online patient/survivor forums	Emotional social support	Interpersonal communication
	2	Contact with patients/survivors in person	Emotional social support	Interpersonal and mediated communication
	3	A concern list with referral to patient associations	Behavior practice and rehearsal + help with preparation + prompts/cues	Mediated communication: booklets (offline), websites (online)
	4	Different consultation structure (complementary consultation with a nurse)	Restructuring the physical environment	Interpersonal communication
	5	A trust person	Restructuring the physical environment	Interpersonal and mediated communication
	6	Evaluation of consultation	Feedback on behavior	Interpersonal communication (e.g., a coach) and mediated communication (a question list)
	7	Tailored information	Tailoring	Interpersonal and mediated communication

		Patients' need for support	Behavior change technique	Interpersonal or mediated communication
<u>Emotional concerns</u>				
Practical topics (i.e., daily-life, self-reliance and finances)	1	Online patient/survivor forums	Emotional social support	Mediated communication
	2	Contact with patients/survivors in person	Emotional social support	Interpersonal and mediated communication
	3	A concern list with referral to patient associations	Behavior practice and rehearsal + help with preparation + prompts/cues	Mediated communication: booklets (offline), websites (online)
	4	Different consultation structure (complementary consultation with a nurse)	Restructuring the physical environment	Interpersonal communication
	5	A trust person	Restructuring the physical environment	Interpersonal and mediated communication
	6	Evaluation of consultation	Feedback on behavior	Interpersonal communication (e.g., a coach) and mediated communication (a question list)
	7	Tailored information	Tailoring	Interpersonal and mediated communication

Results

Patients' needs for support to stimulate discussion of concerns were classified in behavior change techniques and ways for delivering those techniques (interpersonal or mediated communication). We linked these findings to patients' instrumental concerns (e.g., receiving insufficient information) and emotional concerns (e.g., fear) if possible (Brandes et al., in revision). Then we looked for different needs within instrumental and emotional concerns for medical, psychosocial and practical topics. We coded seven different existing behavior change techniques (i.e., *practical social support*, *emotional social support*, *behavioral practice/rehearsal*, *instruction on how to perform the behavior*, *feedback on behavior*, *prompts/cues*, and *restructuring the physical environment*). We found that many patients indicated a need for help with the preparation of a consultation, which sometimes could be coded as behavioral practice/rehearsal (e.g., practicing a consultation with a relative) and sometimes could not be coded as an existing behavior change technique (e.g., preparing via a concern list). Therefore, we added *help with preparation* as a separate technique. In addition, patients often mentioned the need for *tailoring* in interventions (e.g., tailor specific information in interventions to the specific characteristics of the patient). We added *tailoring* as a technique as well in our analyses (see Table 6.3 for an overview of the existing BCTs, their initial definitions and how we coded these BCTs in this paper).

Table 6.3*Coding Scheme with Behavior Change Techniques, their Definitions and Examples*

Behavior Change Technique (BCT)	Original definition derived from the BCT taxonomy ^a	Example from the BCT taxonomy ^a	Interpretation of the BCT in light of the focus group data	Example from a code of the focus group data
Practical social support	Advise on, arrange or provide practical help for performance of the behavior	Ask the partner of the patient to put their tablet on the breakfast tray	Advise on, arrange or provide practical help for patients' concern expression in consultations	A coach who helps the patient before and during a consultation with concern expression
Emotional social support	Advise on, arrange or provide emotional social support for performance of the behavior	Ask the patient to take a partner or friend with them to their colonoscopy appointment	Advise on, arrange, or provide emotional social support for concern expression	Bring someone from the social environment (e.g., spouse) to the consultation
Help with preparation	-	-	Advise on, arrange, or provide help for the patient to prepare for concern expression in a consultation	A concern list that patients can fill out prior to their consultation
Behavioral practice/rehearsal	Prompt practice or rehearsal of the performance one or more times in a context or at a time when performance of the behavior may not be necessary	Prompt asthma patients to practice measuring their peak flow in the nurse's consultation room	Prompt practice or rehearsal of concern expression outside the consultation room	Practicing concern expression with a family member
Instruction on how to perform the behavior	Advise or agree on how to perform the behavior	Advise the person how to put on a condom on the model of a penis correctly	Advise or agree on how to express concerns in a consultation	Videos of patients who express concerns in a consultation

Table continues on next page

Behavior Change Technique (BCT)	Original definition derived from the BCT taxonomy ^a	Example from the BCT taxonomy ^a	Interpretation of the BCT in light of the focus group data	Example from a code of the focus group data
Feedback on behavior	Monitor and provide informative or evaluative feedback on performance of the behavior	Inform the person of how many steps they walked each day	Provide evaluative feedback on how the communication of the consultation went	A list of questions at the end of the consultation to evaluate both the communication of the provider and the patient
Prompts/cues	Introduce or define social stimulus with the purpose of prompting or cueing the behavior	Put a sticker on the bathroom mirror to remind people to brush their teeth	Introduce stimuli with the purpose of prompting or cueing concern expression during a consultation	The concern list that patients can bring with them to a consultation
Restructuring the physical environment	Change or advise to change the physical environment in order to facilitate performance of the wanted behavior	Arrange to move the vending machine out of the school	Change or advise to change the structure of consultations in order to facilitate concern expression	Splitting the consultation in two consultations; one with the doctor and one with a nurse or trust person
Tailoring	-	-	Provide advice, information or feedback that is adjusted to the personal characteristics and situation of the patient (e.g., the specific concerns of the patient)	The possibility on a website for patients to tailor the content of their information to their specific concerns (e.g., categories of concerns that patients can select)

Note. Preparation and tailoring were behavior change techniques that emerged from the focus group data. Both could not be coded as an existing BCT from the taxonomy.

^aThese definitions and examples were derived from the BCT taxonomy (Michie et al., 2013). The entire BCT taxonomy coding scheme can be accessed via <http://www.bct-taxonomy.com/>

Instrumental Concerns

Practical social support. The most frequently preferred technique for dealing with instrumental concerns about medical topics was *practical social support* (i.e., advising or agreeing on how a person should express concerns). Interpersonal communication was suggested as the best modality for delivering *practical social support*. In the context of interpersonal communication patients indicated that they would like to have a coach. Ideally this coach would also accompany the patient to the consultation so that he or she can assist the patient to express the concerns. Afterwards they could discuss the answers of the provider. Important to note was that the coach should be objective and not be emotionally involved, so that he or she would be able to remember information better. The coach could be someone who works at the hospital or a cancer survivor. On the one hand patients thought that it would be good to have a coach who has a medical background and knows the hospital system (e.g., a nurse). That way, the coach would be able to understand the medical information and perhaps provide additional information to reduce medical concerns of the patient. On the other hand, some patients were skeptical and suggested that the coach should be someone from outside the hospital system. They thought that such a person would be impartial (i.e., the person does not know the doctor) and might be better to stand up/advocate for them during a consultation. Patients indicated that a coach for these particular needs could only be offered face-to-face and not online. The quote below illustrates how patients see the role of the coach:

“If you have the need for a person to accompany you to the specialist who is not emotionally involved, you should be able to “hire” someone. So the person should be trained and you speak with him or her before the consultation with the specialist and afterwards in a special room you discuss what was said” (P3, female).

Help with preparation. Patients further indicated that, in order to stimulate instrumental concern expression in a consultation, *help with preparation* may be an important technique. Patients indicated that it would be helpful if there were lists with possible topics of instrumental concerns about medical, psychosocial and practical topics. These lists need to be based on former patients’ experiences. Ideally they would be provided both offline (e.g., in the form of a booklet) and online on a website. Patients explained that the preferences for online and offline tools can differ. For example, some patients expressed a strong preference for an online tool because they frequently use the internet, but some patients also preferred to have a hardcopy tool that they could easily bring with them to the consultation. Most patients who preferred online tools explained that they could also imagine that patients who were not acquainted with the internet would prefer a hardcopy version. Hence, they suggested that when a concern list is offered both offline and online, patients can select the version

that suits their needs best. Patients also indicated that it would be important that these lists have “closed categories” and that patients can open a category when they feel ready to be exposed to the (potential) concerns that are grouped into that specific category. Patients suggested that a booklet could have tabs with colors and topics and similarly these topics would be folders on a website or on an app which patients can then unfold. Ideally such a tool would be accompanied with a “referral manual” (i.e., an overview with whom patients can discuss certain concerns best). Patients indicated that the instrumental concerns about all topics in a booklet or on the website (the QPL examples) could be discussed with a doctor, but concerns about psychosocial topics such as family would rather be discussed with a peer (i.e., another patient or survivor). Some patients explained that they rather discuss those topics with someone who went through a similar disease trajectory. The referral manual should therefore give advice about which people and organizations patients can contact to discuss particular topics with (e.g., specialized psychosocial care for cancer patients for psychosocial topics). Patients indicated that they would prefer such a concern list at the beginning of the disease. Especially in the beginning of the disease, a patient does not know what will happen during the disease trajectory and therefore might not express relevant concerns or might not prepare well enough for a consultation. A patient illustrated this:

“If you don’t know what the question is, how can you ask it?” (P18, male).

A possible pitfall of the concern list was that it might prime the attention for certain concerns that were not prevalent in patients. For example, one of the QPLs that we showed (the booklet) exposed patients to all the questions at once rather than letting the patient select a category that he or she wanted to be exposed to. Thus, working with closed categories on concern lists could prevent the evocation of concerns that are not prevalent in patients at a particular moment. Aside from the suggestion to use closed categories, patients also proposed that the concern list could be used in combination with the coach. The coach could help them with the preparation of their consultation by prioritizing what is relevant and referring the patient to the right person to discuss a concern with.

Behavioral practice/rehearsal. *Behavioral practice/rehearsal* was mentioned in the context of interpersonal communication. One patient indicated that it was helpful for her to practice the discussion of instrumental concerns about medical topics with a family member. She sometimes practiced with her daughter who had to impersonate the doctor. This way she could get a better idea whether she voiced her instrumental concerns in a clear and decent way.

Instruction on how to perform the behavior. Some patients also suggested the technique *instruction on how to perform the behavior* for instrumental concerns about all topics. Patients explained that

the coach could have a role in this. For example, if there would be a coach who helps patients to prepare for a consultation, this person could also give the patient instructions on how to communicate during a consultation. One patient came up with another idea, namely that there could be a website for consultation preparation in which videos are embedded with patients who are discussing concerns with a doctor. These videos can show patients how to communicate but can also create awareness in patients about what their role can be during a consultation and that they are capable of expressing concerns.

Feedback on behavior. Patients indicated that *feedback on behavior* could be helpful to support their instrumental concern expression. This was mostly discussed in the context of interpersonal and mediated communication. For example, for interpersonal communication patients indicated that a person (e.g., the aforementioned coach) could provide them feedback on how they communicated during a consultation. For mediated communication, patients suggested that it could be useful if providers work with a computer program at the end of the consultation to evaluate the communication. A patient mentioned that such a program could contain questions about the communication of both the patient and the provider so that they could give each other feedback. This feedback could then also help patients to discuss their concerns in the future. The quote below shows the description of this program of the patient:

“My practice uses a beautiful computer program. There are five questions that are asked every time after a consultation. It’s purely an evaluation, like are we on the right track, how did our talk go?”
(P8, female).

Prompts/cues. *Prompts/cues* refer to certain stimuli that can prompt the behavior of a patient at the time and place where the behavior needs to be performed. The concern lists with the categories of concerns that were mentioned by patients can act as *prompts/cues*. The lists can help patients to remember and express certain concerns during the consultation.

Restructuring the physical environment. Patients also made suggestions for *restructuring the physical environment*. This technique is considered as making changes in the environment in order to facilitate the behavior. Thus, in the case of expressing concerns to the doctor, we interpreted this as changes in the consultation room and/or consultation structure. These changes could be delivered via interpersonal communication. First, patients suggested that consultations might need to be structured differently. For example, it was suggested that a nurse could complement doctors for discussing psychosocial and practical topics. They found the nurse a more suitable person to discuss these particular topics with. For instance, because they perceived nurses to be more empathic and

more involved with their personal lives. Further, patients thought that nurses would have more time to elaborate on concerns. Some of these patients suggested that perhaps a doctor could put focus on providing medical information (e.g., scan and blood results and treatment plan) and on answering instrumental concerns about the same medical topics, followed by another consultation with a nurse around psychosocial and practical topics.

Tailoring. Patients also discussed *tailoring* as an important technique for interventions. *Tailoring* referred to providing information that was tailored/adjusted to the patient's personal characteristics and situation. Patients indicated that they valued tailored communication highly. It was important to them to be seen as an individual and not as a part of a larger group of patients who have the same type of cancer. *Tailoring* was discussed in the context of interpersonal and mediated communication and for all the different topics and can be perceived as an overarching technique that can be applied to previously mentioned techniques. For example, patients mentioned *tailoring* in the context of their consultation. In this context they preferred individually tailored information from their providers in every stage of their disease (e.g., when providers communicate treatment information, patients would prefer that their personal situation is taken to account when the pros and cons of a treatment are discussed). In addition, this information can be tailored by the provider that is most suitable to discuss the information with (e.g., the doctor or the nurse). Patients may then be able to communicate their concerns more specifically. Further, *tailoring* was discussed in the context of the concern lists. If such a list works with categories of information that patients can unfold, patients can tailor a list of concerns to their specific situation which can facilitate their concern expression. It could also enable patients to retrieve tailored information for the specific concern that they are experiencing.

Emotional concerns

Emotional social support. *Emotional social support* was mentioned in relation to support for discussing emotional concerns (e.g., fear of dying). Patients suggested interpersonal and mediated communication as the way for delivering emotional social support. *Emotional social support* was mentioned in the context of discussing emotional concerns about all topics. Patients explained that the company of someone from their social environment (i.e., family, spouses, children and friends) helped them to discuss emotional concerns with their doctor. They mostly agreed that they would only discuss emotional concerns about medical topics with their doctor. If the emotional concerns were about psychosocial and practical topics they wanted to discuss them with other people such as their social environment and peers (i.e., other patients and cancer survivors). Patients sometimes distinguished between their social environment and peers on the basis of topics. For example, certain psychosocial topics such as fear of dying, psychological changes due to cancer and how to deal with your social environment when you are ill, were rather discussed with peers. Most patients indicated

that they did not want to worry their social environment because they already had been through so much since they became ill. Another reason was that only peers could understand certain emotional concerns because they went through the same disease process. Needs for *emotional social support* to facilitate discussion of emotional concerns comprised contact with patients and cancer survivors via patient associations (both offline and online) and online patient platforms. Specifically for the discussion of emotional concerns such as fear and loneliness and sensitive psychosocial topics such as end-of-life and sexuality, some patients indicated to prefer the anonymity of an online platform. The next quote about discussing emotional concerns on an online platform highlights this:

“Sometimes you want to talk to someone you don’t know. Then you will not have all the emotions that you have when you discuss something with someone you do know. For example, I do this when I wonder how much time I have left...” (P31, female).

Help with preparation. Similar to instrumental concerns, patients indicated that *preparation* was needed in the form of concerns lists for the discussion for emotional concerns. Booklets and websites were mentioned with the same note that patients should be able to choose whether they receive it online or offline so that it suits their needs best. Patients would use a concern list for emotional concerns partly to prepare for their consultation (i.e., put emotional concerns about medical topics on the agenda) and to find out who they can contact for emotional concerns about more sensitive topics such as psychosocial and practical topics.

Instruction on how to perform the behavior. One patient also indicated that the videos that were suggested for *instruction on how to perform the behavior* of instrumental concerns could be used for emotional concerns. She thought that it would be useful if patients became aware that they could express an emotional concern to their doctor if they wanted to.

Feedback on behavior. *Feedback on behavior* was also mentioned for emotional concerns in a similar way as it was for instrumental concerns in the context of mediated communication. The computer program that was described to evaluate the communication of the consultation, could also be used to evaluate emotional concern expression.

Prompts/cues. *Prompts/ cues* for emotional concerns were described in the same context as for instrumental concerns. They refer to the categories of concerns that patients can use to create their concern list with, which then can function as a prompt/cue in a consultation to stimulate patients’ emotional concern expression.

Restructuring the physical environment. Similar to the suggestions for *restructuring the physical environment* for the expression of instrumental concerns, patients explained that they would prefer changes in the structure of the consultation for the expression of emotional concerns. Also for emotional concerns it was suggested that a part of the consultation could be with the doctor, emotional concerns about medical topics could be expressed during this part and the emotional concerns about other topics could be discussed in the other part of the consultation with the nurse. However, some patients also stressed that they would rather have a “trust person” in the hospital (the trust person is quite similar to the coach described under instrumental concerns, but some patients used “trust person” as a concept in this context). This trust person should be someone else who is especially hired for this function. It could be a social worker, someone with a psychology background or a former patient. The trust person should be a part of the patient’s care from the beginning on. He or she should be there for the emotional part of the patient’s disease trajectory. The trust person should be available to discuss emotional concerns face-to-face but also via the phone or email. A patient explains this:

“There should be a trust person for every specialist. He or she can also accompany the patient to the consultation and send the patient a report of the consultation. After each consultation with the specialist the patient has a talk with the trust person to discuss emotions. The patient should also be able to contact the trust person from home because sometimes you can’t wait with your emotions. The patient needs to be able to rely on the trust person for all emotions” (P34, female).

Tailoring. *Tailoring* was also suggested for emotional concerns both in the context of interpersonal and mediated communication. Just like patients preferred tailored information for instrumental concerns, they also preferred tailored information for their emotional concerns. Patients could seek such tailored information in their social environment, online with peers or during a consultation. In addition, the concern list was also mentioned for emotional concerns and could be used as a tool for patients to tailor their list with emotional concerns prior to their consultation and/or to retrieve specific information about the emotional concerns that they are experiencing.

Discussion

This study aimed to propose a framework with practical guidelines for concern expression interventions by exploring patients’ needs for support in discussing instrumental and emotional concerns about medical, psychosocial and practical topics. Patients’ needs for support were structured with behavior change techniques and ways for delivering these techniques (interpersonal or mediated communication). Patients indicated to want interventions that focus on *practical social support*,

emotional social support, help with preparation, behavioral practice/rehearsal, instruction on how to perform the behavior, feedback on behavior, prompts/cues, restructuring the physical environment and tailoring.

One of the most frequently mentioned techniques was social support and this could best be delivered via interpersonal communication. Patients differentiated between *practical social support* for instrumental concerns (e.g., a coach that helps the patient before and during the consultation with concern expression) and *emotional social support* for emotional concerns (e.g., the company of a family member during a consultation). Within emotional social support patients further differentiated between the different people with whom they wanted to discuss certain emotional concerns. For example, some patients indicated that they were reluctant to discuss emotional concerns with a doctor. Especially if these emotional concerns were about psychosocial and practical topics. In line with this finding, research shows that patients more often select medical topics from consultation preparation tools than psychosocial and practical topics (Ghazali, Roe, Lowe, & Rogers, 2015; Rogers, Audisio, & Lowe, 2015). The finding may also shed light on the lack of effects in studies with concern lists on discussion of emotional concerns during consultations (Farrell et al., 2005; Hill et al., 2003) or why emotional concerns in general are discussed to a lesser extent in consultations than information needs (Brandes et al., 2014; Jansen et al., 2010). Rather than discussing emotional concerns with a doctor, some patients preferred to discuss them with peers because they understand exactly what the patient is going through. Furthermore, some patients explained that they especially preferred peer support online because this gives them a sense of anonymity to discuss sensitive emotional concerns. Expressing emotional concerns by frequent participation in online social support groups has been associated with positive patient outcomes such as less depressive feelings (Batenburg & Das, 2014). In addition, studies have also shown that participation in online environments (e.g., online discussion groups) can empower patients to communicate in a consultation. For example, patients can feel more confident in a consultation or can better clarify their needs and concerns (Van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009; van Uden-Kraan et al., 2008). Incorporating emotional online social support from peers might therefore be a promising avenue for interventions for concern expression.

Next to social support, patients wanted interventions to help them with *preparation* and *behavioral practice/ rehearsal*. These interventions should contain *prompts/cues*. One of frequently mentioned examples was the concern list. This list could help patients to prepare for their consultation and it contained prompts for during the consultation (i.e., if a patient brings a concern list to the consultation, the concerns on the list can act as prompts and reminders). Further, they explained that such a list needs to have a referral manual so that patients can find information with whom they can

discuss an instrumental or an emotional concern about a certain topic best. There are interventions available that have a referral possibility such as the distress thermometer where patients can indicate topics of concern and then get a list of different providers (e.g., a doctor, a nurse, a psychologist or a physiotherapist) that can possibly help them. Peers are also included on this list (Hoffman, Zevon, D'Arrigo, & Cecchini, 2004; Roth et al., 1998; Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008). Perhaps such an intervention could be expanded by giving specific advice about who to contact for each specific topic of concern.

Instruction on how to perform the behavior was a technique that was discussed in light of online videos in which patients could see how other patients expressed instrumental and emotional concerns during a consultation. PatientTIME is a Dutch study in which online videos were developed to show patients how to communicate during a consultation (van Bruinessen et al., 2016). The authors indicate that the videos possibly made patients more critical about the communication in a consultation (e.g., their expectations of the communication of their provider increased). Thus, although patients want these types of videos, there could be negative effects. More research is therefore needed into how to develop and distribute these videos in the most optimal matter. Furthermore, patients preferred a coach to show them how to communicate concerns during a consultation. A study that used coaches to help patients to prepare for their consultation had positive effects on patients' communication barriers, and patients' and providers' satisfaction with the communication of the consultation (Sepucha, Belkora, Mutchnick, & Esserman, 2002). Future studies could explore the effects of a coach on concern expression during a consultation.

Tailoring was indicated for both instrumental and emotional concerns. The importance of *tailoring* was stressed by many patients both in the context of mediated communication (e.g., the ability to find information online that is tailored to the specific situation of the patient) and interpersonal communication (e.g., receiving tailored information from the provider). Patients also discussed *tailoring* in line with the concern list (i.e., the ability to self-tailor the communication in a consultation). Heyn and colleagues (2012) tested the effects of a concern list that could be tailored to the needs of the patient on cues and concern expression during the consultation. The intervention group in this study expressed more cues and concerns than the control group, however, the number of clear expressed concerns remained low (0.6 concerns per consultation versus 2.4 cues per consultation). Cues are often more difficult for providers to recognize and to respond to (Butow et al., 2002). Thus, *tailoring* can be a promising technique for concern expression interventions but more research is needed to assess how clear expressions of concerns can be prompted.

Patients also indicated that they wanted a different structure for consultations to stimulate the expression of both instrumental and emotional concerns. For instrumental concerns patients suggested a complementary consultation with a nurse to discuss more psychosocial and practical topics. For emotional concerns patients also indicated they wanted a trust person and this person did not necessarily had to be a nurse. Some patients even stressed that it had to be someone who was not involved in their medical care. Arguments for changing the structure were that patients thought that a nurse or a trust person would be more empathic and would have more time for concerns. These arguments are in line with findings from a previous study where empathy and perceived lack of time were influential barriers for patients to express their concerns to their doctor (Brandes et al., 2015). It would be worth to explore whether this proposed consultation structure is effective in increasing concern expression. A systematic review on consultations in a GP setting has shown that nurses spend more time with their patients which would resolve one of the barriers that patients perceive for expressing concerns (Horrocks, Anderson, & Salisbury, 2002). Perhaps similar findings would occur in an oncology setting. Furthermore, a study that compared the communication of nurses and doctors shows that nurses structure their consultation on the basis of patients' contributions while doctors mostly structure a consultation based on their own medical agenda (Collins, 2005). Thus, it could be that nurses are indeed better able to lead a consultation in which the focus has to be on the concerns of the patient.

We also coded whether the intervention content can be best delivered via interpersonal or mediated communication. Although many interventions to facilitate concern expression are delivered via mediated communication such as booklets (e.g., Hill et al., 2003), websites (e.g., Tuinman et al., 2008) and apps (e.g., Ghazali et al., 2015), the patients in our study most frequently mentioned the need for interpersonal communication, either directly or mediated (i.e., the possibility to interact with another person online). (Mediated) interpersonal communication was mentioned in light of tailoring (providing information that matches patients' characteristics and situation), the changes in the consultation structure (the consultations with a nurse or trust person), emotional social support (support from social environment and peers) and practical social support (the help of a coach). This finding can be explained by the richness of (mediated) interpersonal communication, it gives the possibility to engage in a two-way interaction and to receive feedback. People have the tendency to discuss an emotional concern as soon as it occurs, a process that is referred to as the social sharing of emotions. The person does that in order to receive feedback that can help to deal with that emotional concern right away (Rimé, 2009). Further, there may also be a higher possibility that the feedback that patient receives from another person is more tailored to the specific situation of the patient. This was also something that was highly valued by patients. Thus, instead of interventions to help to express

their concerns in a future consultation, patients most often came up with interventions that could help them express their concerns right away, possibly to receive feedback right away. Future studies could focus on incorporating (mediated) interpersonal communication, for example a coach prior to or during the consultation, into concern expression interventions.

There are some limitations to this study that need to be addressed. Most of our sample consisted of highly educated middle aged patients. This group of patients is known to be very verbal during consultations (Street, Gordon, Ward, Krupat, & Kravitz, 2005). It could be that they have other needs for support to facilitate concern expression than patients who are, for example, less educated. Further, most patients had been diagnosed for quite some time (on average 51 months) and may therefore not fully remember what they wanted for type of support right after their diagnosis. Patients had a high need for (mediated) interpersonal communication interventions but research has also shown that online and offline preparation tools can be very beneficial for patients who are recently diagnosed (Dimoska, Tattersall, Butow, Shepherd, & Kinnersley, 2008). We did ask patients to reflect on the moment of their diagnosis and to recall what their needs were at that particular time. However, more research into patients' different needs for support for concern expression right after diagnosis and later on in their trajectory is warranted.

To conclude, patients have different needs for support to stimulate their expression of instrumental and emotional concerns. Furthermore, these needs also differ for medical, psychosocial and practical topics. Preparation tools such as concern lists can be beneficial to stimulate discussion of instrumental concerns and emotional concerns about medical topics with a doctor. Patients also indicated a high need for tailoring in interventions, information about concerns should, ideally, always be tailored the personal characteristics and situation of the patient. Interpersonal communication also plays an important role in facilitating concern expression. For instrumental concerns patients would like a coach to support them prior to and during a consultation. They would also like separate consultations with a nurse to discuss psychosocial and practical topics. For emotional concerns patients want emotional social support from their peers both in an online and offline context. Further, patients indicate that they would like a trust person in the hospital who is not involved in their medical care to discuss emotional concerns with. Future studies could use these recommendations to develop specific interventions for specific elements of concern expression and/or specific topics.

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CHAPTER 7:
SUMMARY AND
GENERAL DISCUSSION

Summary

Cancer is a life-threatening disease that evokes many concerns. When these concerns accumulate, they can lead to psychological distress. This can influence patients' suffering and overall well-being. Optimal communication between a patient and a provider is a good way to prevent this accumulation of concerns. A crucial element for achieving optimal communication between patients and providers, is that the patient clearly expresses his/her concerns during a consultation. However, this does not always happen as patients might express their concerns as indirect cues or hints. These cues and hints are more difficult for a provider to detect and to respond to than clear expressed concerns. Patients may benefit greatly from communication interventions that aim to improve their concern expression. To determine how concern expression can be improved, it is important to consider which factors explain and support concern expression. The aim of this dissertation is therefore to investigate how concern expression can be improved by examining what explains and supports concern expression.

Two research questions were proposed accordingly:

- 1) What explains cancer patients' concern expression during consultations?
- 2) What supports cancer patients' concern expression during consultations?

Both research questions were examined from two different theoretical perspectives; a behavior change perspective, using the integrative model of behavioral prediction (part 1 of the dissertation), and a stress-coping perspective, using the stress-coping model (part 2 of the dissertation). A behavior change perspective was chosen because it provides a systematic approach for examining the factors that underlie concern expression, and how interventions can be developed accordingly. This systematic approach can give clear insights into what affects a change in intention and behavior. The stress-coping perspective was chosen because it potentially offers other insights into concern expression than the behavior change perspective. Where the behavior change perspective ends with changing behavior (i.e., concern expression), the stress-coping perspective proposes what can happen after concerns are expressed in a consultation (i.e., provider responses and coping). Furthermore, the stress-coping perspective also includes factors that can explain concern expression, namely patients' needs before a consultation (i.e., instrumental and emotional needs). These different types of needs may also play a role in explaining and supporting concern expression. Thus, by combining these two perspectives, this dissertation strives to examine as thoroughly as possible how patients' concern expression can be improved.

Summary of main findings

Part 1

Chapter 1 described the introduction of this dissertation. In **chapter 2** we have examined the influential barriers to expressing concerns in oncology consultations. Concern expression was operationalized as “the expression of recent or current emotions” (Zimmerman et al., 2011). Knowledge is lacking about the exact influential barriers for expressing concerns and whether the potential barriers actually occur in practice. If patients indicate that a situation can possibly be a barrier (e.g., a provider does not respond with empathy) but this situation never occurs in a consultation (i.e., the provider always responds with empathy), this barrier may be less influential than a potential barrier that does often occur in practice. Thus, to examine influential barriers, we measured both possible barriers and their occurrence in practice. First, we conducted a pre-study that consisted of two online focus groups with sixteen cancer patients and cancer survivors. In these online focus groups, patients were asked to describe their barriers to expressing concerns. Patients indicated to perceive sixteen different barriers to expressing concerns, eleven of those barriers were also described in literature about general patient participation. Based on existing literature, the barriers were classified in three domains; barriers related to the behavior of the provider (e.g., not responding with empathy), barriers related to the logistics of the consultation (e.g., perceived lack of time) and barriers related to the legitimacy of concern expression (e.g., the perception that expressing concerns will deteriorate the relation with the provider). After the pre-study, we distributed an online survey in which we asked to what extent these 16 barriers may be perceived as possible barriers and to what extent they occurred in practice. A composite score between these two measures (i.e., the possible barrier score multiplied by the proportion of perceived occurrence of the barrier) was created for each barrier to determine its influence. In total, 236 cancer patients and survivors completed the survey. The results showed that influential barriers were related to providers’ behavior (i.e., not inviting concern expression, not responding with empathy, and not providing the right information to deal with concerns) and the logistics of the consultation (i.e., perceived lack of time and not being able to choose the provider). Thus, the most influential barriers are mainly barriers that patients cannot overcome themselves. These barriers are related to providers’ communication behavior and the logistics of the consultation.

Chapter 3 investigates which determinants of the integrative model of behavioral prediction (IMBP) have the strongest relation with patients’ intention to express concerns and what specific content of these determinants needs to be targeted in an intervention to affect a change in intention. The same survey data was used as in **chapter 2** and concern expression was therefore operationalized

in the same way. The survey included questions about the determinants and was filled out by 236 cancer patients and cancer survivors. To determine what specific content of a determinant needs to be targeted, a percentage to gain analysis was conducted. This analysis shows to what extent intention can be improved if a specific part of a determinant is targeted in an intervention that is 100% successful. For example, if attitude is an important determinant for patients' intention to express concerns, a percentage to gain analysis for each item of the attitude scale can be conducted to analyze with what percentage intention can be improved if that item is successfully targeted in an intervention. The results showed that patients' attitudes and perceived social norm were related to their intention to express concerns. Next, we examined with the percentage to gain analysis what content of the determinants needs to be targeted to affect a change in intention. For attitudes this was the affective component (i.e., the feeling that concern expression can be unpleasant) and for perceived social norm this was the injunctive component (i.e., the feeling that significant others do not support concern expression). Thus, **chapter 3** suggests that patients' affective attitudes and injunctive norm are potential intervention targets.

In **chapter 4** the intervention targets that were identified in **chapter 3** were targeted separately as well as together in persuasive video messages. The aim was to investigate which of the messages (i.e., an attitude message, a perceived social norm message, a combined message and a control message) was most effective in changing cancer patients' attitudes, perceived social norm and intention. Concern expression was operationalized in the same way as in **chapter 2 and 3**. This chapter consists of two online experiments. In the first experiment, a total 190 cancer patients and cancer survivors participated. Participants first filled out a pre-test questionnaire about their attitudes, perceived social norm and intention to express concerns. Two weeks later they were randomized to one of the message conditions and completed a post-test questionnaire with similar questions as the pre-test questionnaire. None of the messages showed a change in one of the determinants. In a subsequent analysis, we analyzed the data again to assess the differences between participants who had a potential to change and those who had no potential to change (participants who scored below or above the median). The results showed that attitudes, perceived social norm and intention improved over time for participants who had a potential to change, although there were no differences between the message conditions. A second experiment was conducted to test whether the time effect of experiment 1 could be attributed to the fact that participants were exposed to a message or to a pre-test questionnaire. Participants were either randomized to a condition with a message (the intro message about concern expression that was used in all the messages of experiment 1) or to a condition without a message (i.e., only a pre-test and post-test questionnaire). In total 63 cancer patients and cancer survivors participated (none of these participants participated in experiment 1). The results showed again an effect over time for attitudes

and perceived social norm for participants who had a potential to change, and again there were no differences between the conditions. This implies that both the message and the pre-test questionnaire affected (small) changes in the determinants of intention to concern expression. Thus, the results of **chapter 4** suggest that paying attention to concern expression (with a message or a questionnaire) might already support patients with a potential to change in expressing concerns.

Chapters 2, 3 and 4 formed **Part 1** of the dissertation and were designed from a behavior change perspective. This approach provided valuable insights into what explains and supports (intention to) concern expression. However, the systematic approach that is often described in behavior change theory, was not more effective in changing patients' determinants to express concerns than exposure to a control message or a pre-test questionnaire. In other words, the theory based messages were not superior in changing the determinants compared to a control message or receiving just the pre-test questionnaire. A possible explanation could be the strict demarcation of behavior that the IBMP proposes (i.e., the action, the time and the place, which was measured in our studies as "expressing concerns during your next consultation with your doctor"). It might be that this demarcation is too one-dimensional for measuring intention to express concerns. Concern expression could, for example, involve expressing concerns about a variety of topics (i.e., medical, psychosocial and practical topics). Furthermore, we operationalized concern expression as the expression of recent or current emotions. The operationalization we used was devised by researchers and it could be that patients perceive concern expression differently. For example, patients might perceive concern expression as the expression of all their needs and not solely as the expression of their emotions. These nuances were not taken into account. The stress-coping perspective proposes that patients' needs and perceptions can possibly influence their communication during consultations. In the second part of the dissertation we therefore decided to change the perspective. Instead of using a demarcated approach for measuring concern expression, we decided to start "open" by qualitatively assessing how patients perceive concerns and what kind of support they need. Therefore, the second part of dissertation is focused on what explains and what supports concern expression from a stress-coping perspective.

Part 2

Chapter 5 explains patients' concern expression by exploring how concerns can be operationalized based on patients' perceptions of concerns and by proposing a framework in which the nature of patients' concerns can be understood in relation to the communication during a consultation. Six focus groups (four face-to-face focus groups and two online focus groups) with 39 cancer patients and cancer survivors were conducted. Patients were asked to describe the concerns they perceived during their entire disease trajectory. The transcripts of the focus groups were analyzed with open coding.

After a structure was determined (i.e., similar to the classification of patients' needs in the stress-coping model; either instrumental or emotional concerns), the data was recoded. Results indicated that patients' concerns could be classified as instrumental concerns (e.g., concerns about receiving insufficient or inadequate information) and emotional concerns (e.g., feelings such as sadness or fear). The results of **chapter 5** show that instrumental and emotional concerns mostly occur together, suggesting that there is a constant interplay between them. The results therefore suggested that an operationalization of concerns should include the instrumental nature of concerns next to the emotional nature of concerns. This interplay may also have implications for communication in the consultation; in contrast to the stress-coping model in which linear relations are suggested (i.e., an instrumental need should be addressed with an instrumental response and an emotional need should be addressed with an emotional response), a framework is proposed with a dynamic model in which both responses are related to both types of concerns.

Chapter 6 aims to propose a framework with practical guidelines for developing communication interventions to support concern expression. Taken into account that concerns can be both instrumental and emotional, we assessed whether patients' needs for support are also different for instrumental and emotional concerns. In addition, we investigated whether these needs differed for different topics of concerns (i.e., medical, psychosocial and practical topics). The same focus group data was used as in **chapter 5**. Patients' needs for support were coded for instrumental and emotional concerns, and for medical, psychosocial and practical topics. The needs were then structured according to behavior change techniques (derived from the behavior change taxonomy) and whether these techniques should be addressed with interpersonal or mediated communication. Patients indicated needs for support for the expressions of both instrumental and emotional concerns in the form of the following techniques; practical social support, emotional social support, behavioral practice and rehearsal, preparation, instructions on how to perform the behavior, feedback on behavior, tailoring, prompts/cues, and a different structure for the consultation. The need for interpersonal and mediated communication differed per technique. For example, for the social support techniques patients mostly preferred interpersonal communication and for the preparation techniques mostly mediated communication. Patients wanted concern lists with prompts (i.e., lists with possible topics of concern that they may encounter during their trajectory) to practice and prepare for their consultations for the expression of instrumental concerns. Further, they preferred videos that depicted concern expression in consultations. Patients also stressed the importance of tailoring for concern expression (e.g., information tailored to the specific characteristics and situation of the patient). They also indicated a wish for practical social support in the form of a coach and/or a separate consultation with a nurse to discuss psychosocial and practical topics. For emotional concerns patients also

suggested the concern lists, videos and tailoring. Further, some patients explained that they would rather not discuss their emotional concerns with a provider, but instead they would prefer to discuss them with a significant other (e.g., a spouse or a family member) or with a peer (i.e., another patient or a cancer survivor). For very sensitive topics such as end-of-life decisions they preferred to talk to a peer in an online environment. Patients also indicated a different structure for consultations. For example, after a consultation with a provider, there could be a complementary consultation with a nurse or trust person for psychosocial and practical topics, and emotional concerns. Thus, needs for support differed for instrumental and emotional concerns and these different needs should be taken into account in intervention development for concern expression. **Chapter 7** of this dissertation describes the general discussion.

General discussion

Concern expression by a patient during an oncology consultation is related to positive outcomes such as reduced levels of distress. However, patients often experience difficulties with expressing their concerns. It is therefore important to understand how cancer patients' concern expression during a consultation can be improved. This dissertation aimed to gain insight into how cancer patients' concern expression during a consultation can be improved by examining what explains (RQ1) and supports (RQ2) concern expression. The two research questions form the structure of the general discussion.

What explains cancer patients' concern expression during consultations?

The three studies described in chapter 2, 3 and 5 investigated what explains concern expression from both a behavior change and stress-coping perspective. These chapters focused on the influential barriers to expressing concerns, the determinants of intention to express concerns and the nature of concerns (i.e., instrumental or emotional).

Influential barriers to expressing concerns

This dissertation shows that the communication of the provider plays a crucial role in explaining why some patients do and others do not express concerns. Chapter 2 highlights that influential barriers to expressing concerns were mostly related to providers' communication behavior (i.e., not inviting concern expression, not responding with empathy, and not providing the right information to reduce concerns). This finding is in line with previous studies in which barriers of patients' overall participation in consultations were examined (e.g., Sepucha, Belkora, Mutchnick, & Esserman, 2002).

Further, these results indicate that both instrumental communication (e.g., information provision) and emotional communication (e.g., responding with empathy) of the provider are relevant for patients' concern expression. In a recent study, the importance of both instrumental and emotional communication as a response to patients' emotional concerns was highlighted. When a provider only responds with empathy to an expressed emotional concern, a patient could possibly sink deeper into the emotion. The emotion then needs to be explored and it is important that a provider provides relevant information, for example a plan of action that helps the patient to deal with the emotion (Back & Arnold, 2014). This is also underlined in chapter 5 in which we describe that concerns can be both instrumental and emotional and therefore both types of responses of a provider are warranted.

Chapter 2 and 5 show that barriers that are related to the logistics of a consultation are influential. More specifically, the findings of chapter 2 show that barriers related to perceived lack of time and provider choice can prevent patients from expressing their concerns. These barriers have also been described in studies about patient participation (e.g., van Bruinessen et al., 2013; Sepucha et al., 2002). Thus, it seems that patients experience similar barriers to expressing concerns as to general patient participation. Patients of the focus groups in chapter 5 explained that they know that their consultations are short and that there are many other patients in the waiting room. This can give them the feeling that there is no time to discuss their concerns (this finding is not described in the results of chapter 5 but extracted from the focus group data). Being able to choose a provider can be explained by the level of concordance that patients perceive with their provider. If patients feel that they are concordant with their provider, their trust in their provider is often higher. This can also result in feeling more comfortable to express concerns (Street, O'Malley, Cooper, & Haidet, 2008). Being able to choose a provider was also highlighted in our focus groups (chapter 6) in which some patients indicated to rather discuss certain concerns that are not related to a medical topic with a nurse instead of a doctor. It could be that patients want to choose with which specific provider they want to discuss certain concerns.

Determinants of intention

Perceived social norm had the strongest relation with intention to express concerns. The results of chapter 3 show that it was particularly the injunctive norm (i.e., the feeling that significant others do not want the patient to express concerns) that could be an intervention target. Most patients go to a consultation together with a significant other (e.g., a spouse, a child or a friend) and it could be that the support of that significant other is important for patients to determine whether they want to express their concerns. Research shows that significant others, such as spouses, often experience a lot of emotional distress when their loved one is diagnosed with cancer (Northouse et al., 2007). Patients

notice this emotional distress and might therefore want to protect their significant other from more distress, for example by not wanting to share their concerns in front of them (Zhang & Siminoff, 2003). While these studies are mostly based on the situation at home, our results suggest that the same patterns can occur during a consultation. The results of chapter 5 also describe that patients perceive many concerns in relation to their significant others. Patients in the focus groups explained that they did not want to be a burden to their significant others, which also implies that they sometimes wanted to protect them. This might be an explanation for the lack of effects for the perceived social norm message in chapter 4 in which the protection of significant others was not fully captured. More intensive family interventions might be needed to offer a solution for expressing concerns. For example, a study about family counseling sessions showed that patients who received counseling, reported better communication with their spouses as compared to the control group who did not receive counseling sessions (Northouse et al., 2007). These types of counseling interventions might have similar effects on expressing concerns in front of spouses during a consultation.

Patients' affective attitudes were also identified as a potential determinant that explains their intention to express concerns. This result confirms findings from a previous study which showed that patients' attitudes explained why some patients are reluctant to express concerns (Okuyama et al., 2008). Since concern expression was defined as an emotional behavior in this study, it seemed rather logical that the affective component of the attitude was most influential. The affective component of an attitude comprises feelings and emotions towards the behavior (Fabrigar & Petty, 1999). Concern expression is defined with more nuances in chapter 5. In this chapter we conclude that concern expression can be both instrumental and emotional (this definition was based on the instrumental and emotional nature of patients' concerns). Possibly other intervention targets could have been identified if we used this definition in chapter 3.

The nature of concerns

Concern expression can further be explained by the nature of the concerns. The nature of concerns (i.e., how patients perceive concerns) can influence how patients communicate their concerns. Further, the nature of concerns can possibly affect which concerns are discussed or not and which explanatory factors play a role. In chapter 5 it is described that patients' concerns can have an instrumental or an emotional nature (instrumental and emotional concerns respectively). This finding seems to contradict most research about concerns in which it is suggested that concerns are emotional of nature (Zimmermann, Del Piccolo, & Finset, 2007). These instrumental and emotional concerns mostly occur together indicating that there is a constant interplay of concerns. This finding is important for the way in which concern expression should be coded and measured. Studies have

shown that when patients talk for several utterances, they are more likely to express an emotional concern (e.g., Bensing, Verheul, Jansen, & Langewitz, 2010). Before such an emotional concern is expressed, it could be that patients already expressed an instrumental concern. In such a scenario the instrumental concern led up to the emotional concern. Coding programs such as Observer (Noldus, Trienes, Hendriksen, Jansen, & Jansen, 2000) offer the possibility to code these details and could be used to code the interplay of instrumental and emotional concerns. Further, we proposed a framework suggesting that instrumental and emotional concerns can be expressed via instrumental and emotional communication of the patient and that providers can therefore respond with both instrumental and emotional responses to both types of concern expression. Because the focus in research has mostly been on the emotional part of concern expression and the instrumental part is not always taken into account, it could be that, according to our definition in chapter 5, the actual number of expressed concerns is higher than currently presented in research (e.g., Grimsbø, Ruland, & Finset, 2012; Heyn, Ruland, & Finset, 2012). In order to explain and research concern expression as comprehensive as possible, it is recommended to take both the instrumental and emotional nature of concerns into account.

In sum, both the behavior change perspective and the stress-coping perspective provided novel insights into what explains concern expression. Explanatory factors for the emotional part of concern expression are barriers related to providers' behavior and the logistics of the consultation, affective attitudes and the injunctive norm. Concern expression can further be explained by the nature of patients' concerns (i.e., an interplay of instrumental and emotional concerns).

What supports cancer patients' concern expression during consultations?

Two studies, described in chapter 4 and 6, examined what supports concern expression from a behavior change and stress-coping perspective. These chapters focused on messages based on the determinants of intention, and a qualitative exploration of patients' needs for support to express their concerns.

Messages based on the determinants of intention

In chapter 4 the effects of persuasive messages were tested on patients' attitudes, perceived social norm and intention to express concerns. The results showed that the attitudes, perceived social norm and intention slightly improved over time for patients who had a potential to change. This effect did not differ between the different message conditions and the condition without message. Hence, both exposure to a message (it did not matter whether determinants were targeted or not) and a pre-test questionnaire had a small effect. A possible explanation for the effect of the pre-test questionnaire is

that it activated existing beliefs. If these existing beliefs are activated, they can become more salient. The salience of these beliefs can increase the perceived importance of expressing concerns which in turn influences attitudes, perceived social norm and intention (Ajzen & Fishbein, 2000; Zhao et al., 2006). Thus, paying attention to concern expression (via a message or a questionnaire) might lead to small effects for patients who have the potential to change. Other possible explanations for the lack of effects of the messages could be the single exposure to the message and the behavior change techniques that were used in these messages. Most of our patients were diagnosed for a longer period of time with cancer and patients were only exposed to a message once. It could therefore be that they had formed a stable attitude and perceived social norm towards concern expression. For such stable attitudes and perceived social norms, multiple exposures to the message are probably needed to yield a change (Kok et al., 2016). Further, to target attitudes and perceived social norm, we used information about the consequences of expressing concerns (for attitudes) and information about the approval of others (for perceived social norm). These informational techniques may have been too weak to change the determinants. Studies have shown that other techniques such as instructions on how to perform the behavior are also powerful techniques (Webb, Joseph, Yardley, & Michie, 2010). Thus, focusing on other techniques than providing information to target attitudes and perceived social norm might yield more effects. More research is needed to confirm this assumption.

Concern lists

In chapter 6, patients indicated the importance of using lists with possible topics of concerns. A possible explanation for the desire for these lists is that they give the patient the feeling that these topics can be discussed in a consultation. Another explanation is that patients often forget what they want to discuss and such a list can act as a reminder (Dimoska, Tattersall, Butow, Shepherd, & Kinnersley, 2008). A concern list can be an affordable and feasible way to support patients' concern expression. Providers, however, play a crucial role in the success of such lists. There is little research available about the exact effects of concern lists on patients' communication during the consultation but research on question lists (i.e., structured lists with questions that patients might have during their disease trajectory) shows that providers' endorsement of the list increases its effectiveness on patients' communication during the consultation (Brandes, Linn, Butow, & van Weert, 2015). However, providers can experience barriers in using and endorsing such lists. For example, providers think that these lists might not be feasible to use because they can increase the time of a consultation (Jacobs et al., 2015). While studies have shown that consultation time often does not increase (Brandes et al., 2015), providers are not always aware of this. It therefore seems important to take the barriers of providers into account when concern lists are developed. If these barriers can be removed, concern lists might succeed in supporting patients' concern expression.

Interpersonal and mediated communication

Patients also indicated that they have a need for support through interpersonal communication. Interpersonal communication (e.g., practical social support from a coach) was more often mentioned in the focus groups in chapter 6 than mediated communication support, with the exception of mediated communication that facilitates interaction with another person such as a forum. This was especially the case for the discussion of emotional concerns. This finding may also shed light on the lack of findings in chapter 4 in which we examined the effects of a mediated communication intervention and defined concerns as emotions. The need for interpersonal communication interventions, in particular for emotional concerns, can be explained by the social sharing of emotion theory which posits that if emotions are intense, they need to be discussed with another person (Rimé, 2009). A mediated communication intervention like the one in chapter 4 does not provide this possibility.

In order to facilitate interpersonal communication about concerns, a different structure for the consultation was proposed for discussing both instrumental and emotional concerns. Participants of the focus groups suggested that the consultation with a doctor to discuss medical topics would be followed by a consultation with a nurse or a trust person to discuss their emotional concerns. The need for a different consultation structure can be explained by the findings from chapter 2 in which patients indicated to experience logistical barriers in expressing their concerns. Perceived lack of time during a consultation was one of those barriers. Research shows that nurses spend more time with their patients which can possibly remove this barrier (Horrocks, Anderson, & Salisbury, 2002)

Another important finding was that patients often do not want to discuss emotional concerns with a provider but rather discuss them with a peer because they went through the same disease process. For the expression of emotional concerns about sensitive topics such as end-of-life, patients sometimes also prefer the anonymity of an online environment. Online environments have the advantage that patients can find peers more easily. These peers experience the same emotional concerns and patients can express their emotional concerns about sensitive topics without restrictions or having to think about what kind of impact they will have on their family (Derks, Fischer, & Bos, 2008; Zakowski et al., 2003). Furthermore, research shows that active patient participation on online platforms (e.g., by expressing emotional concerns) can positively influence a variety of outcomes such as less depressive feelings (Batenburg & Das, 2014) and feeling more empowered to communicate in consultations (Van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2009; van Uden-Kraan et al., 2008). Stimulating mediated interpersonal communication about concerns with peers therefore seems a promising avenue for intervention development alongside face-to-face interpersonal communication interventions.

Some suggestions that were mentioned in chapter 6 already exist and are offered through the Dutch healthcare system or online. But some patients were not aware of these options. For example, there are concern lists available online such as the distress thermometer (Tuinman, Gazendam-Donofrio, & Hoekstra-Weebbers, 2008), but not all patients were familiar with this option. Some patients indicated that they knew it and that it was sometimes used during their disease trajectory by a provider (most of the times a nurse). However, the use of the distress thermometer was not consistent and providers often did not tell patients that they could access the thermometer themselves as well.

Furthermore, there is good psychosocial care available in the Netherlands for cancer patients but some patients in the focus groups indicated that they were not aware of this. Providers can play an important role in referring their patients to psychosocial care or asking patients at several time points in their disease trajectory whether they have a need for psychosocial care. Next to psychosocial care, patients suggested the need for a coach who assists them before, during and after the consultation. The Netherlands has several programs in hospitals that relate to this coaching principle. There are, for instance, projects in which medical students accompany a patient to a consultation and discuss the consultation with them afterwards. There are also professional coaches, who patients can hire to help them to prepare for their consultation and who can accompany them. In addition, there is a national organization (Care for Cancer) that consists of nurses that can support patients during their disease trajectory. Providers should actively assess whether patients have a need for these initiatives and refer them accordingly.

It was also noteworthy that patients indicated to want interventions such as concern lists and videos that sometimes appeared not to be effective in experiments (e.g., our video in chapter 4). A possible explanation can be that patients were asked to indicate in the focus groups what kind of support they wanted for their entire disease trajectory. Especially with the concern lists and videos with instructions on how to participate, patients indicated that they can be very helpful right after the diagnosis. Most experiments (including the studies in this dissertation), however, are conducted later in the disease trajectory using samples of patients and survivors who have been diagnosed for quite some time. Another possible explanation might be that patients reported to prefer videos that depict actual consultations in which a patient expresses concerns (instruction on how to perform the behavior) and we used a story-telling template (i.e., a testimonial).

In sum, the systematic approach that is proposed in behavior change theory did not support concern expression to a greater extent than an information message. It did seem that paying attention to concern expression (via a message or a questionnaire) supported patients who had a potential to change. Following the stress-coping approach we differentiated between the needs for support for

instrumental concerns and emotional concerns. Patients expressed a need for support via concern lists to help them to prepare for their consultation. Patients also reported to prefer interventions such as a coach (instrumental concerns) and a trust person (emotional concerns), and mediated communication interventions with the possibility to interact with someone such online contact with a peer (emotional concerns). Furthermore, next to supporting concern expression in consultations, the results of this dissertation also show that it is important to focus on supporting concern expression outside the consultation room (e.g., online with peers or at home with family).

Implications for theory

Two theoretical perspectives were used in this dissertation to gain as much insight as possible into what explains and supports concern expression. When comparing the utility of both perspectives, they often complement each other. Many of the findings from part 1 of the dissertation (behavior change perspective) could later be explained by the findings of part 2 (stress-coping perspective). For example, we found that the affective attitude was an important determinant for patients' intention to express concerns to their doctor. During the focus groups of part 2, we came to understand that some patients feel uncomfortable to discuss certain concerns with their doctor such as emotional concerns about psychosocial topics. The two perspectives can further complement each other because of their different focuses. The behavior change perspective is focused on the factors that explain concern expression, and the stress-coping perspective is mostly focused on what can happen after concerns are expressed. It is, however, difficult to fully compare both perspectives, partly because we adopted different methods for both perspectives. For the behavior change perspective, we relied on a survey and an experiment while for the stress-coping perspective, we relied on focus groups. These focus groups give a lot of context and explanations that are impossible to derive from quantitative data. Furthermore, there were no empirical tests conducted in the second part of the dissertation. Hence, the explanatory findings and the needs for support have to be experimentally tested in future research in order to truly determine which of these approaches is effective in improving concern expression. We, however, do believe that a combination of theoretical perspectives and different research methods gives an in-depth understanding of concern expression.

Both theories can play a role in explaining and supporting concern expression in consultations. The IMBP proposes guidelines on how to develop an intervention to improve a behavior (Fishbein, 2000; Fishbein & Yzer, 2003; Fishbein & Cappella, 2006). Although we followed these guidelines, the messages that we developed according to this approach did not affect patients' attitudes, perceived social norm, and intention to express concerns. An explanation can be that the IMBP does not provide information about which behavior change technique can be selected best to target a determinant.

This information is relevant because matching the right techniques with the right determinants might possibly enhance the effects of an intervention (Kok et al., 2016; Michie, Johnston, Francis, Hardeman, & Eccles, 2008). A behavior change technique refers to the “active ingredient” in an intervention that needs to yield the change in the determinant (e.g., giving information or demonstrating how a behavior should be performed; Michie et al., 2013). Recent studies (both published after our data collection) have tried to link theoretical determinants and behavior change techniques to each other on the basis of prior research (Kok et al., 2016; Michie et al., 2016). Michie et al. (2016) have conducted several reviews and consensus coding rounds of behavior change interventions to determine which behavior change technique can target a certain determinant of behavior (e.g., attitude) best (the entire framework is not published yet). Kok et al. (2016) have based their framework on the intervention mapping approach which describes what kind of methods can be used to target certain determinants and underlying beliefs. More experimental studies are needed in which the theoretical determinants and behavior change techniques are tested together in a systematic way to strengthen empirical evidence for which techniques work for which determinants.

Chapter 5 proposes a new framework on how the nature of patients’ concerns can affect the communication between a patient and a provider in a consultation. Patients’ concerns could be understood as an interplay of instrumental concerns and emotions. Contrary to the stress-coping model in which concern expression is seen as an emotional behavior, we therefore suggest that concern expression can be both instrumental and emotional. As a consequence, providers can also respond with both instrumental and affective responses. This should be tested empirically to examine whether the interplay of concerns actually affects provider-patient communication in the way that is proposed in the model.

Implications for measuring concerns and concern expression

Concern expression is mostly measured by coding the number of concerns that are expressed in a consultation. Commonly used coding manuals are the VR-CoDES (Del Piccolo et al., 2011; Zimmermann et al., 2011) and the Roter Interaction Analysis System (RIAS; Roter & Larson, 2002). In these manuals concern expression is operationalized as an expression of an emotion indicating that concern expression is an emotional behavior. Although concern expression is coded in RIAS as an affective or socio-emotional behavior, the manual includes categories under instrumental behaviors that comprise questions and recommendations about psychosocial topics. In these categories, questions related to concerns are embedded. Such questions can also be coded as concern expression because the RIAS states that utterances must be coded mutual exclusive from another and when there is doubt between an emotional or instrumental behavior, the emotional behavior should be coded.

Thus, when questions contain an emotional concern (e.g., fear), they could be coded as emotional behaviors while the behavior might actually be instrumental. This dissertation indicates that concerns are perceived by patients as an interplay of instrumental and emotional concerns. This impacts the way concerns are coded with these manuals. If patients perceive instrumental concerns about medical, psychosocial and practical topics as concerns, the expressions of instrumental concerns is also a part of their concern expression and therefore needs to be included in existing coding manuals. Such instrumental concerns can be recognized by coders by paying attention to patients' utterances in which they indicate concerns about information overload, insufficient information, inadequate information, and difficulties with searching, finding and judging of information. Coding these concerns in addition to emotional concerns could result in a comprehensive overview of expressed concerns during consultations.

Next to coding, concerns are also measured with self-report measures which mostly consist of concern lists (e.g., Farrell, Heaven, Beaver, & Maguire, 2005; Ghazali, Roe, Lowe, & Rogers, 2015; Heaven & Maguire, 1998; Hill, Amir, Muers, Connolly, & Round, 2003; Tuinman et al., 2008). In these studies patients are asked to indicate the topics that they are concerned about. The interplay of concerns can be integrated into these lists by asking per topic whether patients experience an instrumental concern, and emotional concern, or both. Currently, concern lists are provided online (Ghazali et al., 2015; Tuinman et al., 2008) which allows to build in a structure so that patients can indicate per topic whether they have an instrumental or an emotional concern (e.g., the topic is work and the patient has an emotional concern). When the topic and type of concern are selected, patients can indicate specifically which instrumental or emotional concern they experience (e.g., the patient feels insecure about going back to work). Measuring concerns this way will give a more comprehensive overview of patients' concerns during cancer. In addition, when researchers want to measure concern expression in surveys, both expressions of instrumental and emotional concerns about different topics should be measured. This way we will be able to fully understand what types of concerns patient do or do not express and why.

Implications for clinical practice

The results of this dissertation on how patients' concern expression can be improved provide implications for clinical practice. Previous research suggests that patients' concern expression is an important element of patient-provider communication in a consultation, but providers' communication is equally important (Bensing & Verhaak, 2004; de Haes & Bensing, 2009; Street, 2001). Patients indicate that the communication of their provider is one of most influential barriers to expressing concerns. Previous research shows that providers can stimulate concern expression

by showing empathy, inviting concern expression, listening actively and asking open-ended questions (Back & Arnold, 2014; Ryan et al., 2005). According to this dissertation, patients report that these communication skills are not always present in consultations. Both instrumental provider communication (i.e., providing information) and emotional provider communication (i.e., inviting concern expression and responding with empathy) are important for expressing concerns. This combination of instrumental and emotional communication also underlines the findings of chapter 5 where we explain that patients' concerns are an interplay of instrumental and emotional concerns. Both instrumental and emotional communication of a provider is therefore needed to address these concerns and this should be addressed in communication skills trainings for providers (van Vliet & Epstein, 2014).

This dissertation also suggests that patients' concern expression can be hindered by the structure of consultations. More time and the preference to have different consultations with different providers were suggested to improve the circumstances in healthcare for concern expression. Results of chapter 6 indicate that both suggestions can be addressed by having a separate consultation with a nurse after the consultation with a doctor. Patients believe that a nurse has more time to listen to them and that they feel more comfortable to discuss instrumental concerns about psychosocial and practical topics with a nurse. Research also shows that nurses more often let the needs and concerns of the patient form the basis of their consultation (Collins, 2005). Evaluating the effectiveness of these separate consultations is important to understand whether this actually affects concern expression and other important outcomes such as patient satisfaction.

Further, the results of this dissertation indicate that clinical practice may also benefit from deploying coaches and trust persons. Coaches and trust persons are important for supporting patients in preparing their consultation, joining them to the consultation and discussing their emotions. There are studies that evaluated the effectiveness of a coach on patient participation in oncology consultations (e.g., Brandes et al., 2015; Rodenbach et al., in press; Sepucha et al., 2002; van Weert et al., 2016). These studies, for example, show that a preparation session with a coach prior to a consultation can increase the discussion of difficult topics such as prognosis (Rodenbach et al., in press), reduce communication barriers and enhance the satisfaction with a consultation of both the patient and the provider (Sepucha et al., 2002). Similar coaching initiatives exist in the Netherlands (e.g., Care for Cancer). However, these coaching initiatives are often unknown to patients. Since the effects of coaching interventions seem promising, more effort should be made in the healthcare system to inform patients about these possibilities.

Also mediated communication is important to consider in clinical practice. Patients indicated that they would benefit from online tools that can help them to prepare for their consultation (e.g., by preparing a consultation agenda with concerns). Such tools can also be beneficial for providers because it can give them a better understanding of what is going on with their patient (Tuinman et al., 2008), and help them to tailor the communication in the consultation to the concerns of the patient (Linn, van Weert, Smit, Perry, & van Dijk, 2013; Street, 2003). Different tools are available in the Netherlands that respond to this need for support of patients. For example, there is the distress thermometer to assess different topics of concern in patients (Tuinman et al., 2008). Further, patients preferred tools which can give them tailored advice about which provider can help them with which type of concerns. The OncoKompas is a Dutch tool that offers this service for cancer survivors. This tool gives tailored advice about how survivors can seek help from supportive care services for problems they are experiencing (e.g., physical or emotional problems; Duman-Lubberding et al., 2016). These tools were found to be feasible and can be accessed online, yet patients do not always manage to find them (as indicated by chapter 6). Providers can play a crucial role in referring patients to these services. More research is needed into how these types of services can be addressed in the healthcare system and how they can be brought to patients' attention best.

Limitations and directions for future research

This dissertation has some limitations that need to be addressed. First, in none of the chapters actual concern expression during a consultation was measured. In the first part of the dissertation we relied on intention, and in the second part we used qualitative data where patients talked about concern expression. Therefore, it is unknown whether the factors that were identified influence actual concern expression. In future research the explanatory factors that were identified in this dissertation could be measured before a consultation and, subsequently, the consultation could be audiotaped and coded in order to determine the number of expressed concerns (taken the distinction between instrumental and emotional concerns into account). Similarly for the support chapters, the recommendations that have been made should be tested in clinical practice and consultations need to be recorded and coded to assess the effects on concern expression.

Second, for all studies we recruited patients and survivors from patient association websites and patient panels which could have resulted in samples that are not completely representative of the general cancer patient population. Our samples mostly consisted of highly educated and middle-aged patients, these demographic characteristics have been associated with higher levels of participation during consultations (Street, Gordon, Ward, Krupat, & Kravitz, 2005). It could therefore be that the factors that explained and supported their concern expression are different for patients who are, for

example, less educated or older. Further, most patients had been diagnosed for a few years when they participated in our studies. Concerns change over time (Hill et al., 2003), thus it could be that patients in our studies had other concerns than patients who have been recently diagnosed. We did ask patients to reflect back on the moment that they were just diagnosed but it is unsure whether patients fully recalled the concerns that they experienced during that time. More research about concerns and concern expression is therefore needed among samples with recently diagnosed cancer patients, older patients and patients who are less educated.

Last, in the first part of this dissertation the determinants around concern expression were measured in a one-dimensional way. Concern expression was defined as the expression of an emotional state and patients were then asked to fill out questions about the determinants. In the second part of the dissertation, we concluded that concerns were not solely emotions but also instrumental concerns. Which also implies that concern expression can be a request for information. The results of the first part of the dissertation can only be interpreted in the context of the definition of concern expression that we used. It is unclear whether the same determinants of intention and influential barriers would be identified if we included the instrumental concerns in our definition as well. Further, concerns can be experienced about a variety of topics (i.e., medical, psychosocial and practical topics) and these topics were not distinguished in our measures. We therefore do not know with what type of topics in mind patients filled out the surveys in part 1 of the dissertation. In part 2 we conclude that patients would discuss concerns about medical topics with their doctor but to a lesser extent psychosocial and practical topics. Including these topics in measuring determinants of both instrumental and emotional concern expression could provide more in-depth insights into which determinants play a role for which type of concern expression about a certain topic.

Conclusion

If patients express their concerns in a consultation, providers can address them. This can potentially lead to positive outcomes such as reduced levels of distress and better well-being. Patients, however, often experience difficulties with expressing their concerns and concerns remain unaddressed. Little was known about what explains and supports cancer patients' concern expression in consultations. The results of this dissertation indicate that patients' concern expression can be explained by the nature of concerns (i.e., whether concerns are instrumental or emotional), barriers (i.e., providers' communication behavior and the logistics of the consultation), attitudes (i.e., the feeling that concern expression can be unpleasant) and perceived social norm (i.e., the feeling that significant others do not support concern expression). Patients' concern expression can be supported via concern lists, consultation coaches, trust persons, tailored interventions, a different consultation structure and better instrumental and emotional communication from a provider. For the development of concern expression interventions, it is essential to select the right techniques to address potential intervention targets. Furthermore, patients' different needs for support for instrumental and emotional concerns need to be taken into account. Such interventions could possibly lead to improved concern expression and, consequently, better health outcomes for patients.

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Chapter 2: Patients' Reports of Barriers to Expressing Concerns During Cancer Consultations

Brandes, K., Linn, A.J., Smit, E.G., & van Weert, J.C.M.

Study concept and design: KB, AL, ES and JvW. Acquisition of the data: KB. Data analysis and interpretation: KB. Manuscript preparation: KB. Critical review: AL, ES and JvW.

Chapter 3: Unraveling the Determinants of Cancer Patients' Intention to Express Concerns

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Study concept and design: KB, AL, ES and JvW. Acquisition of the data: KB. Data analysis and interpretation: KB. Manuscript preparation: KB. Critical review: AL, ES and JvW.

Chapter 4: The Effects of Persuasive Messages on Cancer Patients' Attitudes, Norms and Intention to Express Concerns

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Study concept and design: KB, AL, JvW and EG. Acquisition of the data: KB. Data analysis and interpretation: KB and MV. Manuscript preparation: KB. Critical review: AL, JvW, MV and EG.

Chapter 5: Understanding the Interplay of Cancer Patients' Instrumental and Emotional Concerns

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Study concept and design: KB, MvdG, ES, JvW and AL. Acquisition of the data: KB, MvdG and AL. Data analysis and interpretation: KB and MvdG. Manuscript preparation: KB. Critical review: MvdG, ES, JvW and AL.

Chapter 6: A Framework for Developing Interventions to Support Cancer Patients in Expressing Instrumental and Emotional Concerns

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DUTCH SUMMARY

(NEDERLANDSE SAMENVATTING)

Uit een recente rapportage van KWF Kankerbestrijding blijkt dat 64% van de (ex-) patiënten met kanker zorgen ervaart over psychosociale zaken, zoals angst, onzekerheid, en verminderd zelfvertrouwen. Wanneer dit soort zorgen zich opstapelen, kunnen ze het ziekteproces en welzijn van de patiënt negatief beïnvloeden. Door optimale communicatie tussen de patiënt en zijn of haar zorgverlener kan de opstapeling van zorgen verminderd, of soms zelfs voorkomen, worden. Patiënten kunnen bijdragen aan optimale communicatie door actief te participeren en hun zorgen te uiten tijdens het consult. Zorgverleners kunnen bijdragen door goed te luisteren, de zorgen van de patiënt te exploreren en met empathie te reageren. Dit kan leiden tot positieve resultaten voor de patiënt, zoals minder psychosociale klachten en een beter welzijn. Een van de redenen voor de suboptimale communicatie is dat veel patiënten hun zorgen niet expliciet maar impliciet uiten. Impliciete uitingen zijn moeilijker te herkennen door zorgverleners dan expliciete. Daarnaast wachten veel zorgverleners tot de patiënt uit zichzelf zijn of haar zorgen inbrengt tijdens het consult. Om interventies te kunnen ontwikkelen die patiënten kunnen ondersteunen bij het uiten van hun zorgen tijdens gesprekken met hun zorgverlener, is het van cruciaal belang om eerst te begrijpen waarom sommige patiënten hier geen en anderen hier wel moeite mee hebben. Het doel van dit proefschrift is dan ook om inzicht te krijgen in onderliggende redenen van het al dan niet uiten van zorgen tijdens een consult en mogelijkheden om dit te verbeteren.

Twee onderzoeksvragen staan hierbij centraal:

1. Wat weerhoudt patiënten met kanker ervan om hun zorgen te uiten tijdens consulten met hun zorgverleners?
2. Wat stimuleert patiënten met kanker om hun zorgen te uiten tijdens consulten met hun zorgverleners?

De eerste onderzoeksvraag werd beantwoord in **hoofdstuk 2, 3 en 5** en de tweede onderzoeksvraag in **hoofdstuk 4 en 6**. Zorgen werden in het eerste deel van dit proefschrift als recent ervaren emoties gedefinieerd.

Twee perspectieven

De twee onderzoeksvragen zijn onderzocht vanuit twee verschillende theoretische perspectieven, namelijk het *behavior change* perspectief (deel 1 van het proefschrift) en het *stress coping* perspectief

(deel 2 van het proefschrift). Het *behavior change* perspectief is gekozen omdat het een systematische benadering biedt om onderliggende redenen van het (al dan niet) uiten van zorgen te onderzoeken. Daarnaast geeft het handvatten om interventies te ontwikkelen gebaseerd op deze onderliggende redenen. Binnen het *behavior change* perspectief is het *integrative model of behavioral prediction* als uitgangspunt genomen. In dit model wordt verondersteld dat gedrag wordt verklaard door intentie, die voorkomt uit attitudes, sociale norm en eigen effectiviteit. Verder veronderstelt het model dat als mensen hun intentie in gedrag willen omzetten, zij de juiste vaardigheden moeten hebben en geen barrières ervaren. Het *stress coping* perspectief is gekozen omdat het aanvullende inzichten kan bieden op de inzichten vanuit het *behavior change* perspectief. Hierin wordt de communicatie in een consult gerelateerd aan de mate waarin de patiënt kan omgaan met zijn of haar ziekte (*coping*). Volgens het *stress-coping model* kan ziekte gerelateerde stress bij patiënten leiden tot twee soorten behoeftes: een instrumentele en een emotionele. Een instrumentele reactie van de zorgverlener op een instrumentele uiting (gebaseerd op de instrumentele behoefte) van de patiënt leidt tot probleemgerichte coping. Een affectieve reactie van de zorgverlener op een emotionele uiting (gebaseerd op een emotionele behoefte) van de patiënt leidt tot emotionele coping. Door deze twee perspectieven te combineren wordt in dit proefschrift geprobeerd om tot een dieper inzicht te komen ten aanzien van wat patiënten weerhoudt en stimuleert om hun zorgen te uiten.

Deel 1

De data voor **hoofdstuk 2 en 3** werden gelijktijdig verzameld in dezelfde steekproef. In **hoofdstuk 2** werd onderzoek gedaan naar de algemene barrières omtrent zorgen uiten in een consult met een arts. In **hoofdstuk 3** werd onderzoek gedaan naar de determinanten die de intentie tot zorgen uiten kunnen verklaren. In een voorstudie van **hoofdstuk 2** zijn 16 verschillende barrières geïdentificeerd, die konden worden onderverdeeld in drie categorieën: barrières gerelateerd aan de communicatie van de zorgverlener (bijvoorbeeld het gevoel hebben dat een arts niet met empathie reageert op een geuite zorg), barrières gerelateerd aan de logistiek van een consult (bijvoorbeeld het gevoel hebben dat er te weinig tijd is) en barrières gerelateerd aan de legitimiteit van zorgen bespreken (bijvoorbeeld de gedachte dat zorgen bespreken de relatie met de arts kan verslechteren). In totaal participeerden 236 (ex-)patiënten met kanker aan een online vragenlijst onderzoek om inzicht te krijgen in hoe bepalend deze barrières waren. De resultaten van deze studie laten zien dat de meest bepalende barrières gerelateerd waren aan de communicatie van de zorgverlener (niet reageren met empathie, de patiënt niet uitnodigen om zorgen te bespreken en niet de juiste informatie verstrekken om de zorg weg te nemen) en de logistiek van het consult (het gevoel hebben dat er te weinig tijd is en niet de mogelijkheid hebben om zelf een zorgverlener te kiezen). Deze studie laat zien dat de medewerking van artsen en beleidsmakers van belang is om barrières van patiënten op te lossen. In **hoofdstuk 3** werd onderzocht welke ruimte voor verbetering er is bij de patiënt zelf. Dit werd

gedaan door te onderzoeken welke determinanten (attitude, sociale norm en zelf-effectiviteit) een relatie hebben met de intentie van patiënten om zorgen te uiten en op welke determinanten interventies zich het beste kunnen richten. De resultaten van dit hoofdstuk lieten zien dat de attitude van de patiënt ten aanzien van het uiten van zorgen en de sociale norm gerelateerd waren aan de intentie om zorgen te bespreken. Verder bleek dat vooral het affectieve element van de attitude van de patiënt belangrijk was: het gevoel dat zorgen uiten onplezierig kan zijn. Voor sociale norm was het injunctieve element belangrijk: het gevoel dat naasten niet positief staan tegenover het bespreken van zorgen met de zorgverlener. In interventies waarin beoogd wordt de intentie tot zorgen uiten te bevorderen, lijkt het van belang om aandacht te besteden aan de affectieve attitude en de injunctieve norm van patiënten.

Op basis van de resultaten van **hoofdstuk 3** zijn in **hoofdstuk 4** videoboodschappen ontwikkeld waarin de affectieve attitude en injunctieve norm van patiënten werden aangesproken. Om de effectiviteit van de videoboodschappen te onderzoeken, werden vier videoboodschappen ontwikkeld: een boodschap die zich richtte op attitudeverandering, een boodschap die zich richtte op het veranderen van de sociale norm, een hiervan gecombineerde boodschap en een controle boodschap (deze boodschap bevatte alleen algemene info over kanker). Het doel van de studie was te identificeren welke boodschap het meest effectief was in het veranderen van de attitude en de sociale norm en uiteindelijk de intentie tot het uiten van zorgen. In dit hoofdstuk zijn twee online experimenten uitgevoerd. In het eerste experiment participeerden 190 (ex-) patiënten met kanker. Uit de resultaten bleek dat geen enkele videoboodschap effect had op de attitude, sociale norm of intentie van de hele groep. Uit een sub analyse bleek dat de attitude, sociale norm en intentie van patiënten waarbij ruimte was voor verandering (patiënten die lager scoorden dan de mediaan op de schaal van de determinant in de voormeting) verbeterden. In een tweede experiment werden patiënten willekeurig toegewezen aan ofwel een algemene videoboodschap (de introboodschap die in alle vier de videoboodschappen van experiment 1 zat), ofwel een conditie zonder boodschap (in dit geval vulden patiënten alleen twee keer de vragenlijst in) om te ontrafelen of de bevindingen van experiment 1 toe te wijzen waren aan de voormeting (vragenlijst effect) of aan blootstelling aan een video. In totaal participeerden 63 (ex-) patiënten met kanker in deze studie. In lijn met het eerste experiment, lieten ook deze resultaten zien dat attitude en sociale norm verbeterden bij patiënten waarbij ruimte was voor verandering. Wederom waren er geen verschillen tussen de twee condities. Dit impliceert dat zowel de blootstelling aan een videoboodschap als aan een voormeting kan leiden tot kleine verbeteringen in de attitudes, sociale norm en intentie tot het uiten van zorgen van patiënten. **Hoofdstuk 4** suggereert daarmee dat het besteden van aandacht aan het uiten van zorgen al ondersteuning kan bieden aan patiënten waarbij ruimte is voor verandering.

Deel 2

In **hoofdstuk 5** werd beoogd meer inzicht te krijgen in de aard van de zorgen van patiënten en hoe de beschrijving van zorgen vanuit patiëntperspectief geplaatst kan worden in het *stress coping model*. Om patiënten open te laten praten over hun zorgen, werden zes focus groepen gehouden (vier *face-to-face* focusgroepen en twee online focusgroepen). In totaal deden 39 (ex-) patiënten met kanker aan het onderzoek mee. De resultaten lieten zien dat (ex)patiënten met kanker verschillende typen zorgen beschrijven, namelijk instrumentele (bijvoorbeeld zorgen gerelateerd aan het krijgen van te weinig of onjuiste informatie) en emotionele (bijvoorbeeld gevoelens zoals verdriet en angst) zorgen. Daarbij bleek dat instrumentele en emotionele zorgen vrijwel altijd in samenhang beschreven werden, wat suggereert dat er een continue wisselwerking is. Deze continue wisselwerking impliceert dat instrumentele zorgen zowel op instrumentele als emotionele wijze geuit kunnen worden. Hetzelfde geldt voor emotionele zorgen. Anders dan het *stress-coping model* suggereert, lijkt zowel een instrumentele als een affectieve reactie van de zorgverlener op het uiten van een instrumentele, dan wel emotionele zorg van de patiënt, tot adequate *coping* te kunnen leiden. Op basis van deze bevindingen werd een eerste aanzet gedaan voor een theoretisch raamwerk waarin de veronderstelde relaties beschreven en gevisualiseerd worden.

De data voor **hoofdstuk 6 en hoofdstuk 5** werden gelijktijdig verzameld. Het doel van **hoofdstuk 6** was om een raamwerk te presenteren met praktische richtlijnen voor interventies die patiënten, die daar behoefte aan hebben, kunnen ondersteunen in het bespreken van hun zorgen met hun zorgverlener. Voor dit raamwerk werd onderzocht wat voor behoeftes patiënten hadden voor ondersteuning bij het bespreken van hun instrumentele en emotionele zorgen. Daarnaast is nagegaan of de behoeftes verschilden voor het bespreken van zorgen over medische, psychosociale en praktische onderwerpen. Een taxonomie van gedragsveranderingstechnieken werd gebruikt om de verschillende manieren waarmee aan de behoeftes voor ondersteuning tegemoet gekomen kan worden, te structureren. Verder werd gestructureerd of er een voorkeur was voor interpersoonlijke en/of gemedieerde interventies. In de context van het bespreken van instrumentele zorgen bleek uit de antwoorden van patiënten dat zij behoefte hebben aan praktische sociale ondersteuning, hulp bij de voorbereiding op een consult, oefenen van zorgen uiten, instructies hoe gecommuniceerd kan worden, feedback op de communicatie, informatie op maat en een andere structuur voor de communicatie. De behoefte aan interpersoonlijke of gemedieerde communicatie verschilde per techniek. Voor praktische sociale ondersteuning wilden patiënten voornamelijk interpersoonlijke communicatie in de vorm van een coach die hen kon bijstaan tijdens en na een consult. Voor de voorbereiding van het consult en instructies hoe gecommuniceerd kan worden, wilden patiënten voornamelijk gemedieerde communicatie. Patiënten gaven bijvoorbeeld aan behoefte te hebben aan zogenaamde

zorgenlijsten (gestructureerde lijsten met onderwerpen waar zorgen over kunnen ontstaan tijdens het ziekte-traject die kunnen helpen bij het bepalen welke zorgen men wil bespreken). In de context van ondersteuning bij het uiten van emotionele zorgen werden grotendeels dezelfde technieken genoemd als bij instrumentele zorgen. Deze bevinding is in lijn met die van hoofdstuk 5, waaruit bleek dat er een continue wisselwerking is tussen instrumentele en emotionele zorgen. Er waren ook enkele verschillen. In de context van emotionele zorgen gaven patiënten, in plaats van praktische sociale ondersteuning, aan dat zij emotionele sociale ondersteuning wilden, bijvoorbeeld door iemand uit hun directe omgeving mee te nemen naar een consult. Een aantal patiënten gaf aan dat ze hun emotionele zorgen niet (altijd) met hun behandelend arts wilden bespreken. Zij gaven de voorkeur aan een naaste of een lotgenoot (dat wil zeggen een andere patiënt of iemand die in het verleden kanker heeft gehad). Zeer gevoelige onderwerpen zoals beslissingen rondom het levenseinde, werden door een aantal patiënten liever besproken op een online platform met lotgenoten dan met naasten en/of zorgverleners. **Hoofdstuk 6** suggereert dat de behoeftes voor ondersteuning voor het bespreken van instrumentele en emotionele zorgen grotendeels met elkaar overlappen, maar soms ook kunnen verschillen. Het is van belang deze nuances in acht te nemen bij de ontwikkeling van interventies.

Conclusie proefschrift

De resultaten van dit proefschrift dragen bij aan de kennis over het communiceren van zorgen in oncologie consulten. Dit proefschrift laat zien dat de attitudes en sociale norm van patiënten voor een deel bepalen of patiënten de intentie hebben om zorgen te uiten tegenover hun zorgverlener. Nader onderzoek is nodig om na te gaan hoe deze determinanten het best aangesproken kunnen worden in interventies. Naast de attitude en sociale norm van de patiënt zelf, ervaren patiënten ook barrières voor het uiten van hun zorgen die te wijten zijn aan de communicatie van hun arts (bijvoorbeeld het niet reageren met empathie) en de logistiek van het ziekenhuis (bijvoorbeeld het gevoel hebben dat er weinig tijd is). Dit impliceert dat het ook van belang is dat zorgverleners op een adequate wijze reageren als een patiënt zorgen uit. Wanneer dit niet gebeurt, is er het risico dat patiënten geen zorgen meer willen of durven te bespreken en kunnen interventies die gericht zijn op het ondersteunen van patiënten, ook niet goed werken.

In dit proefschrift wordt ook duidelijk dat patiënten behoeftes aankaarten voor interventies die grotendeels al beschikbaar zijn. Bijvoorbeeld zorgenlijsten, coaches en websites met informatie-opmaat over het omgaan met verschillende zorgen bestaan reeds. Het gegeven dat niet alle patiënten deze interventies kenden, laat zien dat er nog veel aandacht nodig is voor hoe deze goed onder de aandacht van patiënten gebracht kunnen worden. Zorgverleners en beleidsmakers kunnen hier een rol in spelen door patiënten actief te wijzen op wat voor hulp er beschikbaar is voor hun zorgen.



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CURRICULUM VITAE

Kim Brandes was born on the second of August 1986 in Vlissingen, the Netherlands. After obtaining a bachelor in economics at the Inholland University of Applied Sciences Rotterdam in 2009, she continued studying in the bachelor of communication science at the University of Amsterdam. In 2013 she completed a master of science degree in health psychology at the University of Sydney. In the same year she wrote a PhD project proposal for the NWO Graduate Program competition of the Amsterdam School of Communication Research (ASCoR). Her PhD project proposal, which was about explaining and supporting cancer patients' concern expression, was selected for funding. Kim worked on the project as a PhD student at ASCoR between 2013 and 2016. During her PhD Kim received a travel grant from the Dutch Cancer Society (KWF) for a research visit at University College London. In January 2017 Kim will start to work as a postdoctoral researcher at both the Heart Centre for Children and the School of Women's and Children's Health of the University of New South Wales (Sydney, Australia). During her postdoc she will investigate the impact of routine psychosocial assessment for families of infants with complex heart disease.

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