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Communicating about concerns in oncology

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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 posible 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-Weebers, 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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