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

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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	%
Gender		
Male	17	44
Female	22	56
Age		
M (SD)	59.74 (11.54)	
Range	28-80	
Educational level		
Low	2	5
Middle	13	33
High	2	62
Living arrangements		
Alone	9	23
Partner	23	59
Partner and child(ren)	5	5
Child(ren)	2	13
Other	0	0
Children		
Yes	27	69
No	12	31
Employed		
Yes	18	46
No	21	54
Type of cancer		
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
Time since diagnosis (months)		
M (SD)	51.31 (37.08)	
Still in treatment		
Yes	14	36
No	25	64
Treatment intent		
Curative	27	69
Palliative	11	28
Unknown	1	3
Treatment		
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
Instrumental concerns				
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
Instrumental concerns				
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
Instrumental concerns				
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	nterpersonal 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
Emotional concerns				
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
Emotional concerns				
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
Emotional concerns				
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.

[a] These 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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