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DOI

[10.1111/ecc.13138](https://doi.org/10.1111/ecc.13138)

Publication date

2019

Document Version

Final published version

Published in

European Journal of Cancer Care

License

Article 25fa Dutch Copyright Act

[Link to publication](#)

Citation for published version (APA):

Linn, A. J., van der Goot, M. J., Brandes, K., van Weert, J. C. M., & Smit, E. G. (2019). Cancer patients' needs for support in expressing instrumental concerns and emotions. *European Journal of Cancer Care*, 28(6), [e13138]. <https://doi.org/10.1111/ecc.13138>

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Cancer patients' needs for support in expressing instrumental concerns and emotions

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Funding information

This project was funded by the Netherlands Organisation for Scientific Research (NWO), grant number: 022.003.037.

Abstract

Introduction: The aim of our study was to provide an overview of intervention guidelines on how to address patients' practical needs for support in expressing instrumental concerns and emotions regarding medical, psychosocial and practical topics.

Methods: Six focus groups of cancer patients and survivors ($N = 39$) were organised. An interview guide was created that consisted of three topics: (a) concerns, (b) needs for support, and (c) a Concern Prompt List. Using the framework method, the transcripts were coded and analysed in Atlas T.I.

Results: Patients prefer to receive practical and emotional support, help with preparation, prompts/cues, instructions on how to perform the behaviour (i.e., express their concerns or emotions), feedback, a different structure for the consultation and tailoring. Most of these techniques should preferably be delivered via interpersonal communication. Needs sometimes differ for instrumental concerns and emotions. Only some needs for support were exclusively related to instrumental concerns or emotions. The typical needs for support were not solely linked to the medical, psychosocial and practical topics.

Conclusion: Different needs to express instrumental concerns and emotions throughout the disease trajectory are categorised. These needs provide input for developing interventions to support concern expression.

KEYWORDS

behaviour change techniques, cancer, concern expression, concerns, intervention, patients

1 | INTRODUCTION

Cancer patients experience many concerns during their disease trajectory (Beach & Dozier, 2015). These concerns are composed of instrumental concerns and emotions, and may involve medical, psychosocial and practical topics (Brandes, Van der Goot, Smit, Van Weert, & Linn, 2017). The accumulation of these concerns may lead to detrimental outcomes, such as high levels of distress and depression, which may be prevented if these concerns are discussed during a consultation (Street, Makoul, Arora, & Epstein, 2009). However, concerns are often not discussed adequately (Heyn, Ruland, & Finset, 2012).

On the one hand, inadequate or lack of discussion of concerns is due to difficulties that providers experience with noticing and addressing concerns (Farrell, Heaven, Beaver, & Maguire, 2005; Hill, Amir, Muers, Connolly, & Round, 2003). On the other hand, patients experience barriers to expressing concerns, such as a perceived lack of time during the consultation and problems with putting concerns on the agenda (Brandes, Linn, Smit, & van Weert, 2015; Henselmans et al., 2012). To tackle these problems, interventions for providers were developed, such as communication skills training to elicit and address patients' concerns (e.g., Butow et al., 2008; Zimmermann, Piccolo, & Finset, 2007). Patient interventions focus on concern

lists that may be used as an aid before a consultation (e.g., Ghazali, Roe, Lowe, & Rogers, 2015; Hill et al., 2003). The effects of provider and patient interventions vary and are inconclusive. A possible reason for the inconclusiveness is that these interventions do not incorporate different techniques to enhance the expression of patients' instrumental concerns and emotions about different topics. To develop more effective concern expression interventions, it is important to examine whether patient interventions should include different techniques. The current study examined patients' needs for support in expressing instrumental concerns and emotions about medical, psychosocial and practical topics during consultations. We present an overview based on our results consisting of cancer patients' needs for support in expressing instrumental concerns and emotions.

2 | METHODS

2.1 | Participants

We purposefully worked with maximum variation in sampling (Braun & Clarke, 2013, p. 56); that is, we sought diversity in sex, age and types of cancer as well as stages in the disease trajectory to include needs that arise in different types of cancer and at different moments in the trajectory. Participants for the focus groups were recruited via a patient panel (PanelCom, www.panelcom.nl). The inclusion criteria for participants were: (a) 18 years or older, and (b) currently diagnosed with cancer or had cancer in the past. A total of 221 panel members who were registered as cancer patients or cancer survivors received an invitation email and 39 of them agreed to participate (17.6%). Table 1 summarises the demographic and disease characteristics of the sample, which helps elucidate the range of participants who reported the need for support. Most participants were women (56%) and highly educated (62%). Four focus groups were performed face-to-face (FFG) ($n = 30$). Two online focus groups (OFGs) were performed to include participants who were too ill to travel, to allow participants to take their time to construct a more in-depth reaction and to remove possible barriers to the discussion of sensitive topics ($n = 9$; Stewart & Williams, 2005). This combination of FFGs and OFGs was used before in other health communication research (e.g., Schouten, Vlug-Mahabali, Hermanns, Spijker, & van Weert, 2014). Participants signed an informed consent form. The ethical committee of the authors' university approved this study (2015-CW-31).

2.2 | Procedure

The FFGs were performed first and participants were assigned to the different FFGs based on availability. The two OFGs were held during 2 days. Participants were randomly assigned to these OFGs. This study was part of a larger project to develop a concern expression patient intervention. With the objective of this larger project in mind, we developed an interview guide that consisted of three topics: (a) concerns, (b) needs for support, and (c) a Concern Prompt List. The first topic was developed to obtain an overview of the concerns

patients have experienced during their illness. The findings regarding these concerns have been published elsewhere (Brandes et al., 2017). The second topic aimed to gather ideas for a communication tool that supports concern expression. The third topic was developed to further explore patients' preferences regarding a specific communication tool: a Concern Prompt List. The present article focuses on the data derived from topics 2 and 3. The interview guide is presented in Table 2.

Two researchers moderated, videotaped and transcribed verbatim the FFGs. At the start of an FFG, the researchers introduced themselves, explained the three topics of the study, and asked participants to introduce themselves and share their reasons for participation. The researchers summarised the types of concerns patients indicated (topic 1) and then asked what kind of support they needed to discuss these concerns with their providers (topics 2 and 3). At the end of each FFG, one of the researchers summarised the participants' needs for support and asked whether there were any additions.

The third author moderated the OFGs, which were performed on a password protected website during 2 days. The OFGs were held asynchronously, which means that participants could respond to the questions and reactions that were posted on that particular day. The OFGs had a similar structure as the FFGs except for the open question about participants' needs for support. Instead, a list of ideas for support derived from the FFGs was posted online. Participants were asked whether they agreed with these ideas, whether they had other needs that were not mentioned on the list, and why they had these needs. During the OFGs, the moderator facilitated the discussion by repeating the participants' statements, asking others to respond and asking follow-up questions. At the end of each OFG, the moderator summarised the needs for support and asked whether there were any additions.

2.3 | Analysis

The transcripts were coded and analysed in Atlas T.I. by means of the framework method (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Ritchie, Lewis, Nicholls, & Ormston, 2013). This method was developed to structure data with a priori codes, but the method is also flexible to allow for emerging themes (Gale et al., 2013). To present an overview of patients' needs for support for interventions to stimulate concern expression in a standardised manner our a priori codes consisted of Behaviour Change Techniques (BCT) as outlined in Michie et al.'s BCT taxonomy (Abraham & Michie, 2008; Michie et al., 2013). This extensive taxonomy of 93 consensually agreed upon distinct BCTs helps researchers code behaviour change intervention components and informs the development of new interventions. A BCT is defined as "an observable, replicable and irreducible component of an intervention designed to alter or redirect causal processes that regulate behaviour; that is, a technique is proposed to be an 'active ingredient' (e.g., feedback, self-monitoring and reinforcement)" (Michie et al., 2013, p. 82). The taxonomy is widely used in health settings, and effective BCTs were identified for interventions

TABLE 1 Demographics and disease characteristics of the sample (N = 39)

Characteristic	N	%
Gender		
Men	17	44
women	22	56
Age		
M (SD)	59.74 (11.54)	
Range	28–80	
Educational level		
Low	2	5
Middle	13	33
High	24	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
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

(Continues)

TABLE 1 (Continued)

Characteristic	N	%
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.

to increase physical activity, sexual health behaviours and diabetes preventive behaviours (Michie, West, Sheals, & Godinho, 2018).

We started with double coding of one of the FFGs by two authors to sharpen the definition and codes, as presented in the BCT taxonomy. In this phase, the two authors independently reviewed the transcript and identified the different BCTs and ways for delivery (online or offline), as suggested by the patients. The instrumental and emotional concerns were coded, and the different topics (medical topics: e.g., disease, treatment, side effects, pain, prognosis, heredity of cancer, decision-making and hospital; psychosocial topics: e.g., social environment, life after cancer, end-of-life, religion and spirituality; and practical topics: e.g., daily life, self-reliance and finances) within the instrumental and emotional concerns were coded. The two authors also checked whether each BCT was suggested for instrumental concern and/or emotions. A new code was given when specific needs for support emerged that could not be coded with the existing BCTs. Doubts about the codes were discussed with the team members. For example, in some cases, it was not possible to identify whether suggestions were specifically made for instrumental concerns or emotions. Based on the discussion between the team members, we presented this finding as a need for support that could address instrumental concerns and emotions. Discussions were held between team members until no doubts about the coding existed and full consensus was reached. Because of this full consensus, we were confident that one author (KB) could reliably code the other focus groups. Table 3 shows the BCTs, their original definitions, and phrases in our material. Table 4 shows our coding for each need for support related to the BCTs and what type of communication (interpersonal or mediated) participants suggested.

3 | RESULTS

Six of the BCTs listed in the BCT taxonomy (Michie et al., 2013) were present in our data (see Table 3). We added two other BCTs, namely: help with preparation for consultations and tailoring. We describe these eight BCTs below. The results (with accompanying quotes) are summarised in Table 4.

TABLE 2 Interview guide

Topic	Initial question and technique used to elicit responses
Topic 1: Concerns Aim: Obtain an overview of the concerns patients have experienced during their illness.	Initial question: Which concerns did you experience during your disease? Technique: Place large sheets of paper on the table and divide the group in half. When both groups have made their own inventory of concerns, the inventory will be discussed.
Topic 2: Needs for support Aim: Find out which ideas patients have for a communication tool (content and form) that supports concern expression.	Initial question: Now we have an inventory of your concerns. We would like to ask you to think about what you think could help patients to discuss these concerns during a consultation. Technique: Place large sheets of paper on the table and divide the group in half. Ask if the groups can describe on paper the communication tool they have in mind. When both groups have made their own inventory of concerns, the inventory will be discussed.
Topic 3: Concern Prompt List Aim: Find out the most pleasant way of offering a CPL, according to patients.	Initial question: What do you think of the hardcopy/online intervention materials? In what form would you like to receive the CPL and why? When would you prefer to receive the CPL? (how far before the consultation and where within the disease trajectory) Why? From whom would you prefer to receive the CPL? Why?

Practical social support, delivered via interpersonal communication, was mentioned for instrumental concerns about medical topics. Patients indicated that they preferred a coach. This coach could be someone who works at the hospital or a cancer survivor. Ideally, this coach would accompany the patient to consultations to assist the patient in expressing instrumental concerns. Notably, the coach should be objective and not emotionally involved to better remember the information.

Emotional social support, delivered via interpersonal or mediated communication, was mentioned in relation to discussing emotions (e.g., fear of dying) on all topics. Patients explained that someone from their social environment (e.g., a spouse or family member) could help them discuss emotions with their doctor. Patients agreed that they preferred to discuss emotions about medical topics with their doctor and psychosocial and practical topics with other people from their social environment and/or peers. Patients distinguished between their social environment and peers on the basis of topics. For example, certain psychosocial topics, such as fear of dying, were rather discussed with peers. Patients indicated that they did not want to worry their social environment, and only peers could understand certain emotions because they went through the same disease process. *Emotional social support* could consist of contact with patients and cancer survivors via (offline and online) patient associations and online patient platforms. Specifically, for the discussion of emotions such as fear and loneliness and sensitive psychosocial topics such as end-of-life and sexuality, some patients indicated a preference for the anonymity of an online platform.

Help with preparation for consultations, via mediated communication tools, was identified as a need for discussing instrumental concerns and emotions about all topics. Patients indicated that it would be helpful if there were lists with possible concerns for potential discussion during consultations. Ideally, the lists would be provided online and offline. Patients also indicated that it would be important that these lists have “closed categories” so that patients can open a

category when they feel ready to be exposed to certain (potential) concerns. For the offline version, patients suggested a booklet with tabs. Patients also suggested that this tool would be, most ideally, accompanied by a “referral manual.” According to the patients, this referral manual could give advice about which people and organisations patients could contact to discuss particular topics (e.g., specialised psychosocial care for cancer patients).

Prompts/cues are certain stimuli that prompt the expression of instrumental concerns and emotions of a patient at the time and place where this behaviour must be performed. The concern lists with the categories of concerns and emotions that were mentioned by patients could act as *prompts/cues*. The patients agreed that these lists could help them remember and express certain instrumental concerns and emotions during the consultation.

Instructions on how to perform instrumental concerns and emotions was suggested by some patients as an interpersonal communication technique to help them express their instrumental concerns and emotions about all topics. Patients explained that a coach could play a role in this process. Some patients mentioned that this coach could help them prepare for a consultation by giving instructions on how to communicate during a consultation. One patient suggested a website for consultation preparation that included embedded videos with patients discussing concerns with a doctor. The patient explained that these videos could show patients how to communicate and create awareness about what the patients' role may be during a consultation.

Patients indicated that *feedback on how patients expressed their instrumental concerns and emotions* via interpersonal and mediated communication, could be helpful to support their instrumental concern expression. For example, for interpersonal communication, patients indicated that a person (e.g., the aforementioned coach) could provide them with feedback on how they communicated during a consultation. For mediated communication, patients suggested that it could be useful if providers worked with a computer program at

TABLE 3 Coding scheme with BCTs, their definitions and examples

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 of a code in the focus group data
Practical social support	Advise on, arrange or provide practical help for performance of the behaviour	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 behaviour	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
Prompts/cues	Introduce or define social stimulus with the purpose of prompting or cueing the behaviour	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	A concern list that patients can bring with them to a consultation
Instruction on how to perform the behaviour	Advise or agree on how to perform the behaviour	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
Feedback on behaviour	Monitor and provide informative or evaluative feedback on performance of the behaviour	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
Restructuring the physical environment	Change or advise to change the physical environment in order to facilitate performance of the wanted behaviour	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 BCTs that emerged from the focus group data. Both could not be coded as an existing BCT from the taxonomy.

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

TABLE 4 Cancer patients' need for support to stimulate the expression of instrumental concerns and emotions about medical, psychosocial and practical topics

Need for support	BCT	Interpersonal or mediated communication	Instrumental concerns and/or emotions	Topics	Quote from a patient
A coach	Practical social support	Interpersonal communication	Instrumental concerns and emotions	Medical, psychosocial and practical topics	"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, woman).
Bring someone from social environment to the consultation (e.g., spouse, children or a friend)	Emotional social support	Interpersonal communication	Emotions	Medical topics	"After what I've been through... (patient referring to having received his diagnosis when he was alone), it's so important to bring someone to support you and who helps you with your emotions about the diagnosis and everything that follows (patient referring to treatment information)" (P1, man).
Contact with patients/survivors	Emotional support	Interpersonal communication and mediated communication (e.g., via a patient website)	Emotions	Psychosocial and practical topics	"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, woman).
A concern list (with referral options to patient associations)	Help with preparation + prompts/cues	Mediated communication: booklets (offline) and websites (online)	Instrumental concerns and emotions	Medical, psychosocial and practical topics	"If you don't know what the question is, how can you ask it?" (P18, man).
Videos of patients' experiences and consultations	Instruction on how to perform the behaviour	Mediated communication: video on website	Instrumental concerns	Medical, psychosocial and practical topics	"There should be a website with videos in which patients' experiences with consultations are depicted. Like a website created by patients for patients" (P17, woman).
Evaluation of consultation	Feedback on behaviour	Interpersonal communication (e.g., a coach) and mediated communication (a question list)	Instrumental concerns and emotions	Medical, psychosocial and practical topics	"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, woman).
Different consultation structure	Restructuring the physical environment	Interpersonal communication	Instrumental concerns and emotions	Psychosocial and practical topics	"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. 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 go to the trust person for all emotions" (P34, woman).
Tailoring of information and intervention components to personal circumstances and characteristics	Tailoring	Interpersonal and mediated communication	Instrumental concerns and emotions	Medical, psychosocial and practical topics	"The danger is to receive general information about your disease, that you're just part of the statistics. That you're not an individual person but a part of the mass. It doesn't say anything about me. This should be addressed" (P13, woman).

the end of the consultation to evaluate the communication. A patient mentioned that this program could contain questions about the communication of the patient and the provider to give each other feedback. According to this patient, this feedback would help them discuss their concerns in the future.

Patients made suggestions for *restructuring the physical environment*, via interpersonal communication, to help them express their instrumental concerns and emotions. Many patients mentioned that a doctor could focus on providing medical information (e.g., test results) and answering instrumental concerns about the same medical topics, in combination with another consultation with a nurse about emotions of psychosocial and practical topics. The reason for this suggestion is that patients indicated to perceive nurses as more empathic, and they think that nurses have more time. However, some patients also stressed that, especially for emotions, they would rather have a “trust person” in the hospital. According to these patients, this trust person could be a social worker, someone with a psychology background, or a former patient. The trust person should also be part of the patient's care from the beginning and should be there for the emotional part of the patient's disease trajectory. The trust person should be available to discuss emotions face-to-face and via phone or email.

Tailoring was discussed in the context of interpersonal and mediated communication to help patients express instrumental concerns and emotions on all of the different topics, and it was added to the taxonomy. This technique may be perceived as an overarching technique that may be applied to the previously mentioned techniques. *Tailoring* was described by the patients as the possibility of tailoring intervention content and information to their personal situation and characteristics. For example, *tailoring* was discussed by patients in the context of the concern lists. Patients mentioned that they preferred a list with categories of information and concerns that they could unfold to facilitate their concern expression and retrieve tailored information for the specific concerns that they are experiencing.

4 | DISCUSSION

In this study, we provided an overview of patients' needs for support to express their instrumental concerns and emotions about medical, psychosocial and practical topics. Patients indicated a desire for interventions that contained the following techniques: practical social support, emotional social support, help with preparation, prompts/cues, instruction on how to perform the behaviour, feedback on behaviour and restructuring of the physical environment. Tailoring was mentioned as an overarching technique for all of the previous techniques. Patients most frequently mentioned the need for interpersonal communication interventions to aid concern expression. Our results show that only some needs for support were exclusively related to instrumental concerns or emotions.

When asked for their needs for support, patients suggested a coach to help them learn to elicit their concerns during a consultation

or complementary consultation with a nurse or a trust person to discuss more psychosocial and practical concerns. According to the attentional narrowing hypothesis, emotionally arousing situations (e.g., being diagnosed with cancer or discussing prognosis) require attentional resources, which leave fewer resources available for the process of, for example, treatment-related information (Christianson & Loftus, 1991; Jansen et al., 2008). Clinical guidelines were proposed to assist nurses with the difficult task of communicating emotional news (Clayton, Butow, & Tattersall, 2005). Communicating stressful information requires careful tailoring to an individual patient's preferences and a consultation with a trained coach, nurse or trust person before the consultation with the physician and a discussion of patients' concerns could be beneficial (Jansen et al., 2008).

Coaches and trust persons are important for supporting patients in preparation for their consultation, accompanying patients to the consultation and discussing their emotions. Previous studies evaluated the effectiveness of a coach on patient participation in oncology consultations (e.g., Rodenbach et al., 2017; Street et al., 2010). These studies showed that a preparation session with a coach prior to a consultation increased the discussion of emotional topics such as prognosis (Rodenbach et al., 2017) and affected question-asking behaviour, assertiveness and the expression of pain-related concerns (Street et al., 2010). However, patients are not always aware that these initiatives exist. Therefore, providers should actively assess whether patients have a need for these initiatives and refer them accordingly.

Patients indicated that they were reluctant to discuss emotions with a doctor or nurse. This reluctance is consistent with previous studies that showed that patients more often select medical topics from preparation tools than psychosocial and practical topics (Ghazali et al., 2015; Rogers, Audisio, & Lowe, 2015). This result may also explain the lack of effects of (the use of) concern lists on the discussion of concerns during consultations (Farrell et al., 2005; Hill et al., 2003) or why concerns in general are discussed to a lesser extent in consultations than information needs (Jansen et al., 2010). Patients preferred to discuss emotions with peers because they understand exactly what the patient is going through. Some patients also explained that they preferred online peer support because this gives them a sense of anonymity to discuss sensitive emotions. An example of a successful online peer support environment is PatientLikeMe, which is the world's largest website that connects cancer patients (Wicks et al., 2012). Previous studies demonstrated that participation in online environments (e.g., online discussion groups) empowered patients to communicate in a consultation. For example, patients who participated in online discussions felt more confident to clarify their needs (van Uden-Kraan et al., 2008). Therefore, incorporating emotional online social support from peers may be a promising avenue for concern expression interventions.

We used BCTs, as outlined in Michie et al.'s (2013) BCT taxonomy, to structure patients' needs for support. We found two BCTs that were not listed in the taxonomy: help with preparation and tailoring. This new identification suits the intention of the developers

of the taxonomy to encourage researchers to further refine and expand the taxonomy. Other techniques across behavioural domains could be defined, for example, use of fear appeals, and some BCTs may be especially important to one behavioural domain but not to other domains (Michie et al., 2018). This flexibility is nicely consistent with the current focus group study because qualitative research is especially useful for adjusting and renewing concepts and taking specific contexts into account (Braun & Clarke, 2013).

We also examined whether the intervention content was best delivered via interpersonal or mediated communication. Many interventions to facilitate concern expression are delivered via mediated communication, such as booklets (e.g., Hill et al., 2003), websites (e.g., Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008) and apps (e.g., Ghazali et al., 2015). However, the patients in our study most frequently mentioned the need for direct or mediated interpersonal communication (i.e., the possibility of interacting with another person online). Although patients had a high need for (mediated) interpersonal communication interventions, previous research showed that online and offline preparation tools were very beneficial for patients (Dimoska, Tattersall, Butow, Shepherd, & Kinnersley, 2008). Future research is needed to test the effectiveness of online and offline intervention components and how these components may reinforce each other.

Our results show that only some needs for support were exclusively related to instrumental concerns or emotions. This finding is very understandable in the light of our analysis of the concerns that cancer patients experience, which we described in a previous publication. Results of this previous study revealed that patients frequently explain their concerns as an interplay of instrumental concerns and emotions. We concluded that instrumental concerns must be taken into account in the operationalisation of concerns in research because instrumental concerns are often accompanied by emotions (e.g., receiving insufficient information and frustration) and emotions are often accompanied by instrumental concerns (e.g., fear and difficulties with searching, finding and judging of information; Brandes et al., 2017).

There are some limitations to this study that must be addressed. First, surprisingly, participants did not suggest that the behaviour of providers should change; the patients seemed to hold themselves responsible for concern expression. However, previous research concluded that patients believed that the responsibility of a successful consultation was held by the provider and the patient (Atherton, Youg, Kalakonda, & Salmon, 2018; Bensing et al., 2011). One explanation is the manner in which the initial questions were used to elicit responses in our focus groups. Contrary to Bensing et al. (2011), who explicitly asked their participants to formulate advice for patients and providers, and Atherton et al. (2018), who prompted patients to talk about what information they received in the consultation, we asked our participants what they needed to be able to express their concerns. Therefore, we focused our study on support for concern expression and not on information provision.

Second, the aim of this study was to examine what participants believed would help them or other patients to express their concerns.

We did not ask them to consider practical issues. Therefore, whether the suggestions for support are feasible, workable and attractive for all stakeholders involved in daily practice remain unclear. It would be worthwhile to conduct focus groups with healthcare providers to examine the feasibility of patients' support needs. Clearly, providers have their own opinions on what may work for patients, in which setting and when these interventions should be offered.

Third, participants were recruited via a panel of former patients with cancer who have prior experience with participating in research. These participants may not be fully representative of the patient population. As our aim was to provide an overview of needs for support in expressing instrumental concerns and emotions, this factor is less problematic. We purposefully applied maximum variation sampling within this panel to provide an overview of needs that arise at any moment in the disease trajectory. This variation is important because previous research demonstrated that people in different age groups, different stages in the disease trajectory, and with different types of cancer differed in coping styles and psychological distress (Calderón, Jiménez-Fonseca, Carmona-Bayonas, & Jara, 2017; Muñoz-Sánchez et al., 2018). Future quantitative research is required to systematically assess whether these differences affect the needs for support that were identified in the present focus group study. This quantitative research should also examine whether groups who were not included in the current study, particularly people with lower educational levels and more diverse ethnic backgrounds, agree on these needs for support or have other needs.

5 | CONCLUSION

In this study, we have provided practical guidelines for developing interventions to support concern expression. Patients mentioned the following needs: practical social support, emotional social support, help with preparation, prompts/cues, instructions, feedback and restructuring the physical environment. Tailoring was noted as an overarching need, and most patients preferred interpersonal communication to aid concern expression.

ACKNOWLEDGEMENTS

We would like to thank all the participants for their contribution and Prof. Susan Michie and Dr. Caroline Wood for facilitating a research visit at the Centre for Behaviour Change.

CONFLICT OF INTEREST

None of the authors declare a conflict of interest.

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How to cite this article: Linn AJ, van der Goot MJ, Brandes K, van Weert JCM, Smit EG. Cancer patients' needs for support in expressing instrumental concerns and emotions. *Eur J Cancer Care*. 2019;28:e13138. <https://doi.org/10.1111/ecc.13138>