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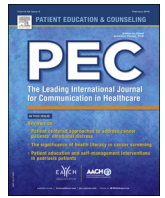
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Research paper

Understanding the interplay of cancer patients' instrumental concerns and emotions



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ABSTRACT

Objective: 1) to assess patients' descriptions of concerns, and 2) to inform a conceptual framework in which the impact of the nature of concerns on doctor-patient communication is specified.

Methods: Six focus groups were conducted with 39 cancer patients and survivors. In these focus groups participants were asked to describe their concerns during and after their illness.

Results: Concerns were described as instrumental concerns (e.g., receiving insufficient information) and emotions (e.g., sadness). Patients frequently explained their concerns as an interplay of instrumental concerns and emotions. Examples of the interplay were "receiving incorrect information" and "frustration", and "difficulties with searching, finding and judging of information" and "fear".

Conclusion: Instrumental concerns need to be taken into account in the operationalization of concerns in research. Based on the interplay, the conceptual framework suggests that patients can express instrumental concerns as emotions and emotions as instrumental concerns. Consequently, providers can respond with instrumental and emotional communication when patients express an interplay of concerns.

Practice implications: The results of this study can be used to support providers in recognizing concerns that are expressed by patients in consultations.

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1. Introduction

Half of the cancer patients experience clinical levels of psychological distress within one month after their diagnosis, and almost a third of the patients still experience such high levels of distress twelve months later [1]. High levels of distress are detrimental because they impair patients' overall well-being [2]. Adequate discussion of these concerns by healthcare providers (e.g., adequately exploring and responding to concerns) offers patients support in coping with their concerns and, consequently, reduces levels of distress [2,3]. However, concerns are not always adequately discussed in consultations, neither by patients nor providers [4,5]. Providers find it, for example, difficult to recognize cues and as a result the underlying concern might remain unaddressed [6]. It is important to get a clear understanding of what comprises patients' concerns. Such information could assist providers in recognizing concerns. The current literature, however,

shows two gaps; 1) we lack knowledge about how patients describe their concerns and 2) there is, to the best of our knowledge, no theoretical framework that helps to understand how the complex nature of concerns might affect doctor-patient communication. These gaps may be addressed by qualitatively examining patients' descriptions of concerns. Such an examination can generate new ideas about the nature of patients' concerns and inform a theoretical framework [7].

1.1. Concerns in the current literature

Table 1 provides an overview of how concerns are defined and measured via concern lists and coding manuals. This overview shows differences in the ways that concerns are defined and measured. For example, in some concern list studies, concerns represent "patient generated issues of importance" [8–12], whereas other concern list studies define concerns as "the amount of burden a patient experiences about a topic" [13–15]. In coding manuals concerns are mostly defined as explicit expressions of immediate negative emotions such as fear [e.g.,16–22]. In other studies, however, emotions are not taken into account in the definition of concerns [e.g.,23]. As a result of concern list and

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Table 1

A description of the different ways concerns are defined and measured in concern lists and coding manuals.

Instrument	Definition	Description of the content of the instrument
Concern lists		
Concern checklist [e.g. 4,8,9]	"A patient generated issue of current importance".	A list with topics that patients can be concerned about. Examples of these topics are: future, pain and emotional reaction.
Distress thermometer and problem list [e.g.13–15]	No explicit definition of concerns.	List consists of several problem topics that are classified into the categories: practical, family/social, emotional, spiritual and physical.
Patient Concern Inventory [PCI,e.g.,11,26,27]	"Issues a patient wants to discuss during the consultation in the clinic that day".	List of issues that are classified into the categories; physical and functional well-being, treatment related, social care and social well-being, psychological, emotional and spiritual well-being.
Coding manuals		
Roter Interaction Analysis System [RIAS e.g.,16,37]	"A condition or an event that is serious, worrisome, distressing, or deserving of special attention and of particular concern right now during a medical interview. These statements have a strong and immediate emotional or psychosocial component".	The RIAS distinguishes affective and instrumental communication behavior categories. Concerns are mentioned in relation to both categories. In the affective communication behavior, "shows concern" is a sub-category (definition is described in the left column). In the instrumental communication behavior category, concerns are described in the sub-categories "gives information psychosocial/feelings" and "ask questions psychosocial/feelings". The category "gives information psychosocial/feelings" refers to statements that are related to psychosocial concerns and problems. The statements have an affective dimension but they are less immediate, intimate and/or intense than concerns. "Ask questions psychosocial/feelings" refers to questions about concerns.
VR-CoDES [e.g.,17,19]	"A clear and unambiguous expression of an unpleasant current or recent emotion where the emotion is explicitly verbalized (I worry about) with a stated issue of importance for the patient ("I am so worried about my husband's illness") or without ("I am so anxious")".	The VR-CoDES distinguishes between concerns and cues. Concerns refer to explicit descriptions of emotions (definition is described in the left column). Cues refer to verbal or non-verbal hints of unpleasant emotions and they would need a clarification from the provider.
Empathic and Potential Empathic Opportunity Method [E-PE-O; 20,21]	"A direct and explicit description of an emotion"	The E-PE-O distinguishes empathic opportunities (also referred to as emotional concerns) and potential empathic opportunities. Whereas an empathic opportunity refers to the explicit description of an emotion, a potential empathic opportunity refers to a statement of a patient where a provider might deduce an emotion but it is not explicitly verbalized.
Booth and Maguire Rating System [38]	No explicit definition of concerns.	The emotional level of patients' utterances is coded (0=facts only, 1 = hints and feelings, 2 = mentioning of feelings and 3 = full expression of feelings). Information giving was rated as significant if patients expressed concerns about prognosis, diagnosis and/or adverse sequelae.
Communicative acts of patient participation [22]	"Utterances in which the patients expresses worry, anxiety, fear, anger, frustration and other forms of negative affect or emotions".	Three types of verbal patient communication behaviors are distinguished. Aside from expressing concerns (defined in the left column), asking questions and being assertive are described. Asking questions refers to utterances intended to seek information and clarification, and being assertive refers to utterances in which patients express their rights, beliefs, interests and desires.
Model for describing psychosocial issues [23]	"Talking about what is most pressing".	The occurrence and content of concerns are coded.
Medical Interaction Processing System (MIPS; [39])	No explicit definition of concerns. Examples of concerns are given: "I am worried about this pain" and "I think I am having a heart attack".	In the MIPS an utterance of a patient is accompanied by a code that specifies the content of the utterance. Examples of content codes are medical details and side effects of main treatment.
Medical Interview Aural Rating Scale [MIARS; 40–42]	No explicit definition of concerns.	The MIARS is focused on coding cues. The manual distinguishes three level of cues in which concerns are embedded. The three levels are: level 1 cue (a hint for worry or a concern), level 2 cue (an expression that explicitly mentions worry or concern) and level 3 (a clear expression of an emotion such as anger or crying). The MIARS refers to emotional cues, other studies have expanded on the MIARS by adding informational cues [e.g.42].

coding manual studies, concerns are mostly described in the literature on the basis of surveys, the concerns that patients select on a concern list and the concerns that are expressed by patients during a consultation. In the current study, we ask patients to voice their concerns freely in focus groups to gain insight into patients' descriptions of concerns in a different context.

1.2. Theoretical framework of concerns

To the best of our knowledge, there is not a clear theoretical framework in which the nature of patients' concerns and its possible influence on doctor-patient communication, is specified. Such a theoretical framework is important to inform interventions,

for example, to assist providers in recognizing concerns during consultations. The stress-coping framework [3] shows how doctor-patient communication can lead to adequate stress-coping. In this framework, it is argued that patients have two types of needs; an emotional and an instrumental need. Emotional needs refer to concerns and the need to feel known whereas instrumental needs refer to information and the need to know. To address an emotional need, providers should use emotional communication behaviors (e.g., showing empathy). This can then lead to emotional coping. Instrumental needs should be addressed with instrumental communication behaviors (e.g., information provision), which can lead to instrumental coping [3,22]. In the present study we embed the nature of concerns, as described by the patients in the

focus groups, into the stress-coping framework to present a conceptual framework that clarifies how the nature of concerns affects doctor-patient communication.

2. Methods

2.1. Participants and procedure

Inclusion criteria were that participants had to be 18 years or older and currently diagnosed with cancer or have had cancer in the past. To find patients and survivors who were willing to share their stories with us, we used a patient panel (i.e., PanelCom, www.panelcom.nl) to recruit participants via email. In total 221 panel members received an invitation, and 39 panel members responded to the email and agreed to participate. Table 2 shows the demographic and disease characteristics of the participants. We conducted four face-to-face focus groups (FFGs, $n=30$) and two online focus groups (OFGs, $n=9$). A combination of these two types of focus groups was chosen to be able to include participants who were not able to travel to the FFGs locations (e.g., because they felt too ill). Participants were assigned to a FFG based on their availability. After the FFG's, two OFGs were conducted simultaneously during two days. The focus groups comprised of two topics. The first topic had the aim to explore patients' descriptions of concerns. The second topic had the aim to examine patients' needs for support to discuss concerns and is described in a different paper [24].

We started the data collection with the four FFGs and these were moderated by two researchers (KB together with MG or AL) who also took notes. The FFGs were conducted in an open way, video-taped and transcribed verbatim. First, the researchers introduced themselves and explained the aim of the study. Participants were then asked to introduce themselves by stating their name, where they were from and why they wanted to participate in this study. After that, participants were asked to remember that they were diagnosed and to indicate what kind of concerns they had experienced from that moment until now. Concerns were not defined by the researchers. Instead the researchers asked the patients to explain what they thought a concern was. After the first FFG, the first author watched the videotape, read the notes of both moderators and made a list of the concerns that were mentioned. This list was used in the second FFG as a starting point for discussion. Participants could then explain if they experienced similar concerns and were asked to come up with new concerns. This process was repeated in the remaining focus groups to make sure that the list was as complete as possible at the end of the data collection.

The OFGs started with a list of concerns derived from the FFGs. The OFGs were moderated by the first author. Participants logged in on a protected website with a username and password. The moderator posted statements and questions at the beginning of the day for all participants (e.g., what were your concerns during your disease trajectory?). During the day, based on the reactions of participants, the moderator posted follow-up statements and questions. Participants received an email when a new statement was posted by the moderator. The moderator facilitated discussion between participants by repeating statements of participants and asking whether other participants could respond. The OFGs were held a-synchronously so that participants could respond on times that were convenient to them. All participants had to sign an informed consent form before the FFG or OFG started. Every participant received an incentive (fifteen euros) for their contribution and FFG participants also received travel reimbursement. At the end of all focus groups participants filled out a questionnaire eliciting demographic and disease characteristics. The study was

Table 2
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	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)	
Range	6–168	
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.

approved by the ethical committee of the authors' university (2015-CW-31).

2.2. Analysis

The transcripts were coded and analyzed in Atlas.TI. The first step in the analytical process was open coding [25]. Each transcript

was divided into fragments that represented a concern and only these fragments were coded. The transcript of the first FFG was coded by two authors (KB and MG) to discuss the codes. The remaining five transcripts were coded by the first author. Doubts about interpretations during this process were discussed and resolved with the authors who were present at the FFGs (MG and AL). The codes emerged inductively, there were no a priori codes. After iterative coding of the concerns, the codes were discussed in the team and different structures were employed to present the data in a clear way. Eventually we have decided that the best way to structure the data was to divide the concerns in instrumental concerns (i.e., concerns related to information) and emotions. The second step was focused coding [26]. Concerns were coded as instrumental concerns if they were about information (e.g., receiving insufficient information) and concerns were coded as emotions if they contained a clear description of an emotion (e.g., feeling sad) and/or when patients used non-verbal communication to indicate the emotion (e.g., hand gestures and/or facial expressions). After coding concerns as instrumental concerns and emotions, sub-categories were established. Instrumental concerns comprised four sub-categories of concerns: information overload, receiving insufficient information, receiving incorrect information, and difficulties with searching, finding and judging information. Emotions comprised seven sub-categories: fear, loneliness, shame, frustration, denial, insecurity, and sadness (see Table 3). After coding all the sub-categories, we found that patients often discussed instrumental concerns and emotions in the same fragments. This made it complex to code them separately because in most utterances and fragments patients described an interplay of instrumental concerns and emotions. Thus, the focus of our analysis changed during the coding process to a deeper interest in the interplay of instrumental concerns and emotions. The last step was therefore to look for patterns in interplays of instrumental concerns and emotions. We examined which codes of

instrumental concerns and emotions were coded together in a fragment. When a combination of instrumental concerns and emotions was identified, we explored how the interplay was described (i.e., was the instrumental concern accompanied by an emotion or was the emotion accompanied by an instrumental concern).

3. Results

3.1. Instrumental concerns and emotions

Patients described both instrumental concerns and emotions. Instrumental concerns referred to information overload (e.g., receiving too much information at the same time), receiving insufficient information (e.g., patients did not receive any information about a certain topic in the consultation), receiving incorrect information (e.g., information that was given during the consultation turned out to be different), and difficulties with searching, finding and judging of information (e.g., concerns about whether medical information on the internet was approved by medical experts). Seven emotions were described by patients; fear, loneliness, shame, frustration, denial, insecurity and sadness. Table 3 shows a complete overview of instrumental concerns and emotions and in what context they were described by patients. Both types of concerns were mentioned repeatedly in the same fragments of patients suggesting an interplay. Different interplays were identified namely instrumental concerns that led to emotions or emotions that led to instrumental concerns.

3.2. Instrumental concerns accompanied by emotions

To describe the interplay of instrumental concerns that were accompanied by emotions, we discuss two examples that are illustrative for this combination (i.e., receiving incorrect

Table 3
Patients' instrumental concerns and emotions with examples of the sub-categories.

Concerns	Examples
Instrumental concerns	
Information overload	Receiving too much information at once in a consultation which made it difficult for patients to remember what was being said. Specifically described in the context of bad-news consultations.
Receiving insufficient information	This concern was described in several contexts: 1) information that patients gathered themselves on the internet was not mentioned in the consultation, 2) little information was available because the patient, for example, had a rare form of cancer, 3) patients received no information at all about a certain topic and 4) lack of information on the internet about a certain topic.
Receiving incorrect information	Information turned out to be incorrect after a period of time (e.g., side-effects were downplayed). This was described for information that was received during a consultation (e.g., incorrect diagnosis) and information that was gathered on the internet (e.g., prognostic information).
Difficulties with searching, finding and judging of information	Difficulties in navigating the internet for information. Concerns about whether information on websites was approved by medical experts, find stories of patients with the same disease who were terminal and whether they were able to judge whether the information was applicable to their specific disease situation.
Emotions	
Fear	Fear was described as an emotion that changes over time. In the beginning of the disease there was fear about survival but at the same time patients adopted a survival mode. After treatments, fear became more prevalent and complex.
Loneliness	Loneliness was referred to by patients as feeling alone even though they had support from their partner and family. They had the feeling that their social environment did not fully understand what it means to have this disease.
Shame	Shame was mostly mentioned in relation to self-care. Some patients had to live with a stoma or had to apply self-catheterization which imposed feelings of shame, especially if patients needed help with applying self-care.
Frustration	Frustration was caused by situations (e.g., patients had to follow a fixed after-care program and they could not decide which activities they wanted to participate in), others (e.g., patients did not want to be seen and treated as patients by their social environment the entire time) and themselves (e.g., patients were in a constant battle with themselves because they wanted to keep the control over their lives but sometimes they were too ill to do that).
Denial	Patients in denial did not believe their diagnosis when they received it. Reasons for denial were that patients did not feel ill at all or believed that cancer was something that would never happen to them.
Insecurity	Insecurity refers to patients' feelings of vulnerability. For example, patients talked about insecurity in relation to bodily changes. They felt insecure because of hair loss and the way people looked at them when they wore a wig.
Sadness	Sadness was discussed in two contexts. Sadness in the context of the patient and the patient's loved ones. Patients, for example, mentioned to feel sad when they noticed that they were losing their independency or had to learn to live with the limitations of their treatments (e.g., with a stoma). In relation to loved ones, sadness was experienced when patients saw the impact their disease had on the lives of their loved ones.

information and frustration, and receiving insufficient information and insecurity). First, the interplay of concerns about receiving incorrect information and frustration refers, for example, to experiencing unsuspected side-effects. Sometimes side-effects were downplayed in a consultation. For instance, in the case of the stories of two breast cancer survivors, providers told them that the chances of them experiencing capsular tissue were smaller than the factual statistics. This led to feelings of frustration when capsular tissue was nevertheless experienced. This is illustrated by one of the survivors who experienced capsular tissue after a breast reconstruction. This survivor raised her voice when she shared this example. She used hand gestures and widely opened her eyes, indicating her frustration:

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

Second, the interplay of receiving insufficient information and insecurity refers, for instance, to patients' body after cancer. Some patients indicated that they experienced insufficient information about how they would feel after cancer, when all the treatments were over. Patients explained that there was little information about what kind of complaints (e.g., fatigue) were normal to experience after treatment and how long these complaints would last. Intertwined with patients' descriptions of receiving little information, they expressed feelings of insecurity. A patient explained how she received little information about the period after cancer and how she felt insecure about her body after cancer:

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

3.3. Emotions accompanied by instrumental concerns

To describe the interplay of emotions that were accompanied by instrumental concerns, we discuss two examples that are illustrative for this combination (i.e., fear and difficulties with searching, finding and judging of information, and sadness and receiving insufficient information). The interplay of fear and difficulties with searching, finding and judging of information describes problems with finding reliable information online. For instance, patients experienced fear because they had side-effects after a treatment. To ease their mind whether this was a side-effect that was frequently experienced, they would search for information on the internet. In some cases, however, patient found it difficult to decide on which websites they could find reliable information. A patient referred to this by explaining that she had concerns about using the internet to reduce her fear caused by side-effects that she experienced after her lung cancer treatment:

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

The interplay of sadness and receiving insufficient information was described in the context of patients' loved ones. Patients felt sad because their children had difficulties to continue their “carefree” lives (e.g., going out, having fun with friends) or they felt they were a burden for their partner (e.g., because the partner had less time for him/herself). Some patients indicated that they

wanted information that could support their loved ones in coping with their disease. However, they perceived that there was insufficient information out there, for example on the internet, which made them feel even more concerned. A patient explained this by indicating that he experienced a lot of sadness when he saw how his disease had an impact on his wife and was concerned that there was little information available about after care for her:

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

4. Discussion and conclusion

4.1. Discussion

This study aimed to 1) examine patients' descriptions of concerns and 2) embed the nature of concerns into the stress-coping framework to understand how it can affect doctor-patient communication. These aims were addressed by qualitatively exploring how patients voiced the concerns they experienced during and after their disease. The results show that concerns can be categorized as instrumental concerns (e.g., receiving insufficient information) and emotions (e.g., sadness). More importantly, patients often discussed instrumental concerns and emotions in the same fragments, indicating that there is an interplay. This interplay can refer to instrumental concerns that are accompanied by emotions (e.g., receiving insufficient information and frustration) and to emotions that are accompanied by instrumental concerns (e.g., fear and difficulties with searching, finding and judging of information).

4.1.1. The interplay of concerns

The interplay of instrumental concerns and emotions is important to take into account when defining and measuring concerns (Table 1 displays the overview of how concerns are currently defined and measured in the literature). Some concern list studies already implicitly mention the interplay. Both the Patient Concern Inventory [PCI; 11,27,28] and the distress thermometer combined with a problem list [13,14,29] specify emotions such as anger and fear, and a variety of other topics that patients might want information about (e.g., side-effects). Similar to concern list studies, the interplay is also suggested in coding manual studies. While most coding manuals emphasize the emotional nature of concerns (see Table 1), the RIAS [16] indicates that concerns can be both instrumental and emotional. The RIAS distinguishes instrumental and emotional communication categories. Showing concern (i.e., the expression of a condition or event that has an immediate and strong emotional component) is specified as affective communication. Asking psychosocial questions (i.e., questions about concerns) and giving psychosocial information (i.e., statements that refer to psychosocial concerns but that are less immediate and intense than concerns that are coded under “showing concern”) both refer to concerns and are specified as instrumental communication. Thus, the RIAS shows that concerns can be coded on the instrumental and emotional level and might therefore be an appropriate manual to code the interplay in consultations. To analyze the interplay with the RIAS we suggest using sequence analysis. For example, research that combines the RIAS with sequence analysis shows that when

patients talk for several utterances, they are more likely to express an emotion [30]. It could be interesting to examine whether patients expressed an instrumental concern before the emotion or the other way around. The coding program Observer [31] offers the possibility to code these nuances and might therefore be a promising program for coding the interplay.

Additionally, the VR-CoDES [17,19] can be used as a base to code the interplay. The VR-Codes differentiates between cues and concerns. Cues refer to verbal or non-verbal hints that suggest an underlying unpleasant emotion. These cues have different subcategories in the VR-CoDES manual (i.e., cue a-g). Concerns refer to clear and unambiguous expressions of unpleasant emotions. Whereas concerns emphasize the expression of explicit emotions, most cues (i.e., subcategories cue b-e) can also be instrumental utterances. For example, cue subcategories cue-d and cue-e can be coded without an indication of an emotion. These subcategories can be coded when the expression of the patient is neutral but it emphasizes a stressful event or condition. Such a stressful event or condition could, for instance, be incorrect information. Thus, the VR-CoDES manual offers the possibility to code instrumental cues, emotional cues and explicit expressions of emotions. Similar to the RIAS, we also suggest combining the VR-CoDES with sequence analysis. Studies using the VR-CoDES and sequence analysis indicate that the expression of cues can result in a clear expression of an emotion later in the consultation [e.g.,32]. It could be insightful to understand which specific subcategories of cues lead up to clear expressions of emotions.

4.1.2. Towards a conceptual framework

The second aim of the study was to propose a conceptual framework in which the complex nature of concerns is embedded in the stress-coping framework to assess its impact on doctor-patient communication. Bensing and Verhaak's stress-coping framework [3] and other stress coping models such as the common sense model of illness [33,34] specify two separate paths for instrumental and emotional needs. Contrary to this framework, the results of our study show that concerns are described by patients as an interplay of instrumental concerns and emotions, indicating that the nature of concerns cannot be understood as either instrumental or emotional. Therefore, we added the interplay to the stress-coping framework (see Fig. 1). The interplay suggests that patients may also express their emotions as requests for information or their instrumental concerns as emotions. Furthermore, the conceptual framework suggests that providers could use both responses (affective and instrumental) for both types of concerns. For example, when patients express an emotion,

providers may also be able to adequately reduce this emotion with an instrumental reaction rather than an emotional reaction. These responses could then lead to both types of coping behaviors (problem oriented and emotional coping). In addition, a feedback loop is added in the framework. This feedback loop indicates that, depending on the way that patients cope with a particular concern, their concern can change accordingly (e.g., when patients adequately cope with a concern, it can decrease).

This framework serves as a starting point to examine concerns and doctor-patient communication more dynamically rather than as a linear process in which a certain expression requires a certain response to have an impact on a certain coping behavior. More empirical research investigating the dynamic relations is needed to support this conceptual framework. We have some suggestions about how our conceptual framework can be empirically tested. Before a consultation patients can be asked to fill out a concern list. Next, researchers can audio- or videotape consultations and code the interplay of instrumental concerns and emotions with sequence analysis. Alternatively, researchers could use surveys to ask patients whether they expressed the concerns that they selected before the consultation on the concern list. Further, they can answer questions about how their provider responded when they expressed a concern (e.g., did the provider show empathy or give information). Coping scales [e.g.,35] can be used to measure the extent to which the patient coped with a concern. The feedback loop can be measured by asking patients whether the concern they initially indicated before the consultation changed.

4.1.3. Limitations

The time since diagnosis in this study was quite high (on average 51 months). Certain concerns such as fear remain stable over time and are not dependent on the time of diagnosis [36]. However, other concerns can develop over time and can be more prevalent right after diagnosis than further along in the disease trajectory [4]. Therefore, it is possible that we found patterns of interplays in our sample that are only prevalent further in the disease trajectory. For example, concerns about incorrect information were mentioned to be experienced after a while when patients realized that they were experiencing long-term side-effects that were not mentioned in prior consultations. A replication of this study with patients who were more recently diagnosed could provide insights into the interplay of instrumental concerns and emotions at the beginning of the disease. Furthermore, regarding the conceptual model, we did not include appraisal although it is a concept that has been included in other stress-coping models such as the common sense model of illness [33,34]. We chose not to include appraisal because we wanted

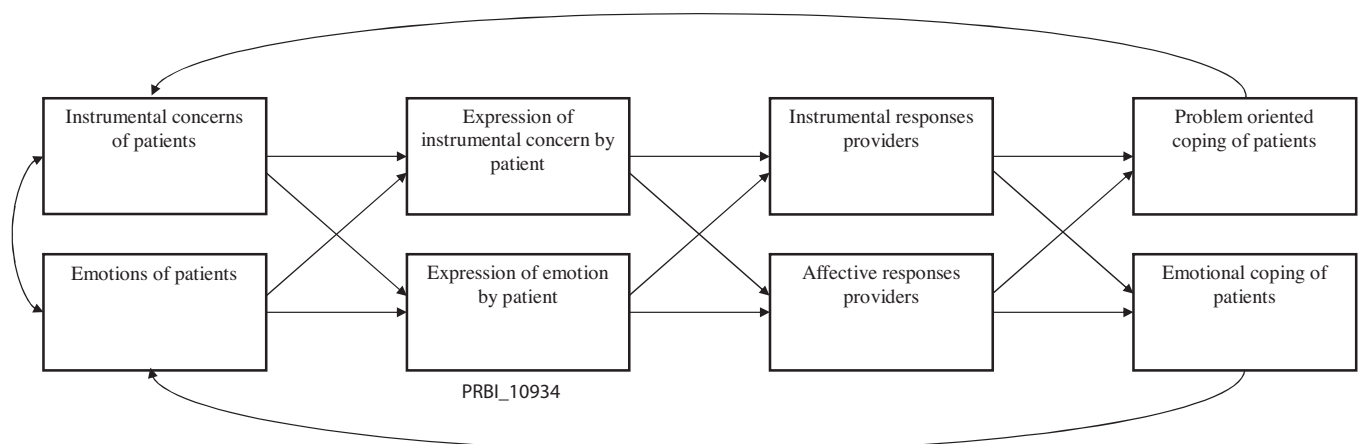


Fig. 1. Conceptual framework (based on the stress-coping framework) addressing the interplay of instrumental concerns and emotions of patients and how this can affect communication in the consultation and coping.

to propose a model in which all the constructs were measurable so that the model could be tested. Appraisal can, in some cases, be an automatic and unconscious process which may be difficult for patients to reflect on, and including this construct could make the model too complex to test.

4.2. Conclusion

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

4.3. Practice implications

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

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Conflict of interest

None declared.

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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