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

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

Abstract

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

Introduction

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

Operationalization of concerns

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

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

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

Theoretical frameworks of concerns

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

Methods

Participants and procedure

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

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

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

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

Table 5.1

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

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

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

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

Analysis

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

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

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

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

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

Table continues on next page

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

Results

Interplay of instrumental concerns and emotions

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

Instrumental concerns accompanied by emotional concerns

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

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

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

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

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

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

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

Emotional concerns accompanied by instrumental concerns

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

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

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

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

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

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

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

Discussion and conclusion

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

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

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

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

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

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

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

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

Practice implications

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

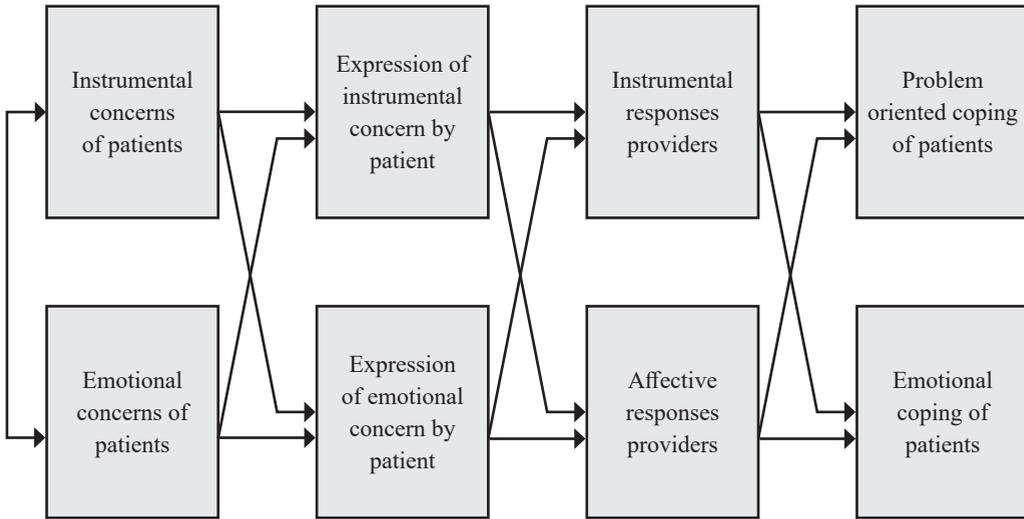


Figure 5.1. Conceptual model (based on the stress-coping model) addressing the interplay of instrumental and emotional concerns of patients and how this can affect communication in the consultation and coping.

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