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**Communicating about concerns in oncology**

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*Citation for published version (APA):*  
Brandes, K. (2017). Communicating about concerns in oncology.

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# CHAPTER 1: INTRODUCTION

*“You are always afraid. You don’t have trust in your own body any more. Cancer, the total package, the uncertainty, it is horrible”*

*(female cancer patient who participated in a focus group; chapter 5 and 6).*

The majority of cancer patients and survivors (64%) experience serious concerns such as fear (Dutch Cancer Society, 2016). When such concerns accumulate, they can lead to high levels of psychological distress which can be detrimental for patients and survivors. For instance, psychological distress can worsen pain or lead to depression (Chochinov, 2001; Heaven & Maguire, 1998). To prevent such an accumulation of concerns, it is important that healthcare providers and patients communicate about concerns in an optimal way (Ryan et al., 2005).

Optimal communication about concerns can be enhanced if patients participate actively by expressing their concerns in a consultation (Street, Makoul, Arora, & Epstein, 2009; Street, 2001). Providers can contribute to optimal communication about concerns by listening actively, exploring concerns and responding with empathy (Back & Arnold, 2014; Ryan et al., 2005). This optimal communication is associated with positive outcomes for patients such as reduced levels of psychological distress and better well-being (de Haes & Bensing, 2009; Street et al., 2009). However, optimal communication is hard to achieve. For example, many patients feel that their concerns have not been discussed optimally (Farrell, Heaven, Beaver, & Maguire, 2005; Hill, Amir, Muers, Connolly, & Round, 2003). One of the reasons for suboptimal communication about concerns is that patients often do not express their concerns explicitly but rather express them implicitly as indirect cues or hints (Grimsbø, Ruland, & Finset, 2012; Zimmermann, Del Piccolo, & Finset, 2007). These indirect cues and hints are difficult to recognize and providers are therefore sometimes unable to address concerns, or lack the skills that are essential for effective cue responding (Butow, Brown, Cogar, Tattersall, & Dunn, 2002). Another reason is that, instead of actively stimulating patients to express their concerns clearly, providers often wait until a patient expresses one. Patients, however, often do not initiate concern expression themselves (Hack, Degner, & Parker, 2005). It is still unclear why patients often do not initiate concern expression in a consultation despite the possible benefits.

To date, most research about optimizing the communication of concerns has been focused on the behavior of the provider and not on the behavior of the patient (Zimmermann et al., 2007). Similarly, there is a lack of knowledge about how patients can be optimally supported to express their concerns. This dissertation therefore aims to gain insight into how communication about concerns during a consultation can be improved by exploring the factors that explain and support patients’ concern expression. What explains and what supports concern expression is examined from two different

theoretical perspectives; a behavior change perspective and a stress-coping perspective. Hereafter, the focus of this dissertation, the current state of the literature on concern expression and both theoretical perspectives are discussed.

### **Focus on the patient**

The focus of this dissertation is on the patient. In healthcare research, patient-centered care is nowadays seen as a “golden standard”. A central part of patient-centered care is that care is provided according to the preferences, values and needs of the patient (Epstein et al., 2005). In line with patient-centered care, research about patient-provider communication has shifted in the past decades from a paternalistic bio-medical model, in which providers guide the communication in consultations, to a bio-psychosocial model, in which the patient is central and the needs and preferences of the patient should guide the communication (Bensing & Verhaak, 2004). Due to these changes in healthcare and patient-provider communication, both patients and providers have the responsibility to contribute to the consultation. It is therefore important that a patient clearly indicates his or her needs and preferences and concern expression is one of the possibilities to do that (Street, 2001). Expressing concerns in a consultation can be difficult for patients and they might therefore benefit from interventions that aim to improve their concern expression. Most research on concern expression, however, has focused on interventions to improve the communication of the provider (e.g., elicitation of concerns and responding to expressed concerns; Zimmermann et al., 2007). While this research is of great importance, additional research on the patient is needed to explain and support patients’ concern expression. Therefore, patients are the focus of this dissertation.

### **Concerns and concern expression**

Concerns can comprise a variety of topics like concerns about medical topics such as side-effects of treatment, psychosocial topics such as the emotional burden a partner and/or children might experience, and practical topics such as work (Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premlatha, 1996; Mellblom et al., 2014). Until now, concern expression in consultations is mainly examined by investigating which concerns patients have and asking whether patients felt that their concerns were discussed (e.g., Farrell et al., 2005; Hill et al., 2003). Furthermore, studies have used coding manuals such as the VR-CODES (Del Piccolo et al., 2011; Zimmermann et al., 2011) and the Roter Interaction Analysis System (RIAS; Roter & Larson, 2002) to assess the number of actual expressed concerns in a consultation and the responses of providers. Concerns and concern expression are operationalized differently across studies. To illustrate, in some studies that use concern lists (i.e., lists with topics of concerns that patients can fill out prior to their consultation) to gain insight into what kind of topics patients are concerned about, concerns are operationalized as “issues

of importance” (e.g., Heaven & Maguire, 1998). In studies using a coding manual to assess the number of concerns that are expressed in consultations, concerns are operationalized as “emotions” and concern expression as “an explicit expression of an emotion” (VR-CoDES; Del Piccolo et al., 2011; Zimmermann et al., 2011). In part 1 of this dissertation the latter operationalization of concern expression is used. We chose this operationalization because it is widely used in the concern expression literature.

### **Interventions to support concern expression**

Various interventions have been developed to stimulate concern expression in oncology consultations. These interventions are mostly focused on providers’ communication and consisted of communication skills trainings with the aim to improve providers’ elicitation of concerns (e.g., Butow et al., 2008; Heaven & Maguire, 1996) and providers’ responses to patients’ expressed concerns (e.g., Butow et al., 2008). The provider interventions, however, have shown only small or no effects on providers’ elicitation of concerns (Butow et al., 2008; Heaven & Maguire, 1996). Patient interventions have mainly focused on the use of concern lists prior to consultations (e.g., Ghazali, Roe, Lowe, & Rogers, 2013; Ghazali, Roe, Lowe, & Rogers, 2015; Heaven & Maguire, 1998). Some concern lists are also used as aids for both the patient and the provider (Heyn, Ruland, & Finset, 2012; Tuinman, Gazendam-Donofrio, & Hoekstra-Weebers, 2008). These patient interventions have shown that they are helpful for providers to identify distress in patients (Tuinman et al., 2008). One study also showed that a concern list can lead to significantly more expressed cues and concerns in an oncology consultation (Heyn et al., 2012). However, the number of clear expressed concerns in this study only comprised 18.7% of the total expressed cues and concerns. Thus, concern expression might not have been supported in the most optimal matter in this study. In order to know how to support patients’ concern expression, it is crucial to first understand what factors explain why some patients do and other patients do not express their concerns. When these factors are known, concern expression can be targeted in an intervention accordingly.

### **Two theoretical perspectives**

To examine what explains and supports patients’ concern expression, two theoretical perspectives are used in this dissertation; a behavior change perspective (part 1 of the dissertation) and a stress-coping perspective (part 2 of the dissertation). These two different theoretical perspectives were adopted to explore concern expression as thoroughly as possible. The behavior change perspective was chosen because it offers guidance in how to identify determinants that explain a behavior (in this case concern expression) and intervention targets that can support a behavior (specific elements of determinants that can be targeted in an intervention to affect a change). Using a behavior change

theory has the advantage that determinants are proposed that are expected to have a causal relation with intention and behavior (Michie & Abraham, 2004; Michie & Prestwich, 2010). Thus, when little is known about what explains a behavior (as it was the case of concern expression), a behavior change theory can offer a good starting point to unravel underlying determinants. Where the behavior change perspective has behavior (i.e., concern expression in the consultation) as an endpoint, the stress-coping perspective sheds light on what can possibly happen when concerns are expressed in a consultation (i.e., providers' responses to concern expression and consequences for coping). Furthermore, in addition to the behavioral determinants that are proposed by the behavior change perspective, the stress-coping perspective offers insights into other factors that can explain concern expression, namely the needs that patients have prior to the consultation (Bensing & Verhaak, 2004). Thus, the stress-coping perspective was chosen for its potential to offer another perspective into what explains and supports concern expression.

### **A behavior change perspective (part 1 of the dissertation)**

Interventions that are developed via a behavior change approach (i.e., first identifying determinants that might serve as intervention targets and then developing an intervention accordingly) have been shown to be more effective in changing intentions and behaviors than interventions that do not follow this approach (Avery, Donovan, Horwood, & Lane, 2013). The integrative model of behavioral prediction (IMBP; Fishbein, 2000) was chosen in this dissertation as a starting point to identify determinants that explain patients' intention to express concerns in consultations. The IMBP was selected because it incorporates determinants such as attitudes and self-efficacy. Some of these determinants have been proposed in qualitative studies as possible determinants of concern expression (e.g., van Bruinessen et al., 2013; Henselmans et al., 2012). The IMBP posits that behavior is determined by the intention to perform the behavior. An intention is formed on the basis of someone's attitude (i.e., positive and negative feelings and attributes towards the behavior), perceived social norm (i.e., the extent to which individuals believe that others want them to perform the behavior) and self-efficacy (i.e., the extent to which an individual thinks that he or she is capable of performing the behavior). Further, the IMBP proposes that an individual should not encounter any barriers and must possess the adequate skills to perform the behavior in order to translate an intention into actual behavior (Fishbein, 2000; Fishbein & Yzer, 2003; Fishbein & Cappella, 2006).

After the determinants have been tested to establish which ones have a causal relation with patients' intention to express concerns, an intervention can be developed in which these determinants are targeted (Fishbein & Cappella, 2006). Ideally, the determinants will be targeted separately and together to clearly investigate the change generating process (i.e., exploring whether targeting a

determinant resulted in a change in intention or not; Michie & Abraham, 2004). Although the IMBP approach has been used in many studies to change intentions and behaviors (e.g., Boudewyns & Paquin, 2011; Robbins & Niederdeppe, 2015; Zhao et al., 2006), it has never been applied to concern expression. The behavior change perspective is adopted in this dissertation to examine whether it is an appropriate model for explaining and supporting concern expression.

### **The stress-coping perspective (part 2 of the dissertation)**

Next to understanding the underlying determinants of concern expression, it is important to understand how the nature of concerns can impact patients' concern expression. While there are no specific behavior change theories in which the nature of concerns are embedded, stress-coping theories (e.g., the stress-coping model) can offer guidance because in these theories concern expression is incorporated. The stress-coping model (Bensing & Verhaak, 2004) is a framework that incorporates patients' needs to express concerns and might therefore complement the IMBP in unravelling what explains and supports concern expression. The stress-coping model explains that stress in patients can lead to two different needs; an instrumental need and an emotional need. An instrumental need refers to the need to know and understand (e.g., information about symptoms and side-effects). An emotional need refers to the need to feel known and understood (e.g., the need for emotional support and to express concerns). This framework proposes that a provider should respond with instrumental behavior when an instrumental need is expressed (e.g., providing information). This could lead to problem-focused coping. When an emotional need is expressed, a provider should respond with an emotional behavior (e.g., showing empathy), which can result in emotional coping. The needs that patients have are possibly related to the nature of patients' concerns. For example, patients experience concerns about topics that are instrumental (e.g., medical topics) and topics that are emotional (e.g., psychosocial topics). We adopted the stress-coping perspective to qualitatively investigate how the nature of patients' concerns can be understood and how these insights can be used to explain and support concern expression.

### **Aim of the dissertation**

The aim of this dissertation is to gain insight into how communication about cancer patients' concerns during a consultation can be improved. In order to address this aim, two research questions are proposed:

1. What explains cancer patients' concern expression during consultations?
2. What supports cancer patients' concern expression during consultations?

### Dissertation outline

This dissertation consists of five papers that are based on four different datasets. **Chapters 2 and 3** are based on one survey dataset. **Chapters 5 and 6** are based on one focus group dataset.

**Chapter 4** consists of two studies based on two datasets. In **part 1 (chapters 2, 3 and 4)** concern expression is examined from a behavior change perspective and in **part 2 (chapters 5 and 6)** from a stress-coping perspective (see Figure 1 for the outline of the dissertation). The studies and outline of this dissertation are based on progressive insights, which means that the aim and research questions of a subsequent study were inspired by the results of the previous studies.

**Chapter 2** examines which types of barriers, i.e., barriers related to the behavior of the provider, barriers related to the logistics of a consultation and/or barriers related to the legitimacy of expressing concerns, are most influential in preventing patients' concern expression during a consultation.

**Chapter 3** investigates which determinants, derived from the IMBP, are related to patients' intention to express concerns in a consultation. Further, it is examined which content of the determinants needs to be targeted in an intervention to accomplish a change in intention. **Chapter 4** then tests the effects of messages in which the determinants are targeted separately and together on patients' attitudes, perceived social norm and intention to express concerns. Additional analyses are performed to explore the differences between patients who had a potential to change and those who had no potential to change. In **chapter 5**, patients' concerns are explored qualitatively and classified according to the stress-coping model into instrumental and emotional concerns. A new framework is proposed in which the nature of patients' concerns is embedded. In **chapter 6** patients' needs for interpersonal and mediated communication support in expressing concerns are assessed. A framework for the different needs for support for instrumental and emotional concerns about medical, psychosocial and practical topics is presented. Last, **chapter 7** provides the summary, general discussion and conclusion of this dissertation. Furthermore, implications for future research and practice are discussed.

	Behavior change perspective	Stress-coping perspective
Explaining concern expression	Chapters 2 and 3	Chapter 5
Supporting concern expression	Chapter 4	Chapter 6

*Figure 1. Outline of the dissertation*



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