Communicating about concerns in oncology

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CHAPTER 3:
UNRAVELING THE DETERMINANTS
OF CANCER PATIENTS’ INTENTION
TO EXPRESS CONCERNS

Abstract

Little is known about the behavioral determinants that underlie cancer patients’ intention to express concerns during a consultation. This information can be relevant to developing effective interventions for cancer patients. In this study, the integrative model of behavioral prediction (IMBP) is used as a framework to unravel the determinants of patients’ intention to express concerns. The objectives of this study are to examine which of the IMBP determinants (attitude, perceived social norm and/or self-efficacy) are significantly related to intention and what content of these determinants can be targeted to effect a change in patients’ intention. An online survey based on the IMBP determinants was distributed. A total of 236 cancer patients and cancer survivors participated. The results of the survey showed that patients’ attitudes and perceived social norm were the most important determinants of their intention to express concerns. The largest change in patients’ intention might be achieved by targeting the affective attitude, referring to the extent to which patients believe that expressing concerns is (un)pleasant, and the social norm, referring to the extent to which patients feel (un)supported by significant others in expressing concerns.
Introduction

A life-threatening disease such as cancer can evoke many concerns in patients (Farrell, Heaven, Beaver, & Maguire, 2005). A concern is defined as: “an unpleasant current or recent emotion” (Zimmermann et al., 2011, p.144). Concerns that are experienced by patients include medical concerns (e.g., patients are worried about the possible side-effects of their treatment), psychosocial concerns (e.g., patients are anxious that they might not survive cancer) and practical concerns (e.g., patients are concerned about whether they can keep their jobs; Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premlatha, 1996; Hill, Amir, Muers, Connolly, & Round, 2003).

Studies have indicated that many cancer patients do not express these concerns sufficiently. For example, patients often express their concerns indirectly with cues (i.e., unclear verbal or non-verbal hints of experienced concerns) rather than directly and explicitly (Grimsbø, Ruland, & Finset, 2012; Heyn, Ruland, & Finset, 2012). Healthcare providers often do not notice those cues and indicate that they better detect concerns when these concerns are expressed explicitly (Butow et al., 2008). When concerns are explicitly verbalized by patients, it is easier for healthcare providers to respond adequately. Receiving adequate information to address concerns has been associated with positive outcomes for patients, such as better psychological well-being (De Haes & Bensing, 2009; Street, Makoul, Arora, & Epstein, 2009). In contrast, when patients do not explicitly express concerns, and these concerns remain undetected, they can worsen and possibly lead to depression (Chochinov, 2001; Ryan et al., 2005). Thus, it is important to support patients in expressing their concerns. Interventions focusing on patients’ concern expression could provide support; however, these interventions are scarce.

Previous interventions to facilitate concern expression have mainly targeted the communication behavior of healthcare providers during the consultation (e.g., eliciting concerns; Butow et al., 2008). These interventions have not always been effective in improving concern expression. For example, Butow and colleagues (2008) did not find any significant effects of their communication skills training on healthcare providers’ elicitation of concerns. A possible reason for the lack of effects could be that only the behavior of the provider is targeted. Interventions that target the behavior of both the provider and the patient are often more effective in improving patient participation during oncology consultations (Brandes, Linn, Butow, & Van Weert, 2015). Thus, existing interventions that focus on providers’ behavior might be more effective if they are combined with interventions that focus on patients’ concern expression. As previously noted, interventions targeting patients’ concern expression are scarce. To develop an effective intervention for patients, it is important to identify the determinants that explain their intention to express concerns (Fishbein, 2000).
From behavioral theories such as the integrative model of behavioral prediction (IMBP; Fishbein, 2000), we know that individuals’ attitudes, perceived social norm and self-efficacy can predict their intention to perform any given behavior. Moreover, studies that use behavioral theories such as the IMBP to inform their intervention development are more effective in changing intentions and health behavior than interventions that do not follow this approach (Avery, Donovan, Horwood, & Lane, 2013). A few studies on concern expression have examined the determinants of intention from the IMBP individually (e.g., Manne, Alfieri, Taylor, & Dougherty, 1999; Okuyama et al., 2008; Zakowski et al., 2003). However, to our knowledge, there are no studies that have assessed attitude, perceived social norm and self-efficacy together to examine which of these are most strongly related to patients’ intention to express concerns and are therefore potential candidates for intervention targets. Thus, this study aims to address this gap in the literature by using the IMBP as a framework.

**Theoretical Background**

**Integrative Model of Behavioral Prediction**

The IMBP is based on several health behavior models: the health belief model (Janz & Becker, 1984; Rosenstock, 1974), the social cognitive theory (Bandura, 1986), the theory of reasoned action (Fishbein & Ajzen, 1975) and the theory of planned behavior (Ajzen, 1991). Behavioral theories such as the IMBP guide researchers in intervention development. By identifying the determinants that predict individuals’ intention to perform a health behavior, researchers can determine possible intervention targets. Researchers can then properly evaluate which elements of their intervention worked and led to a change in intention (Fishbein & Capella, 2006; Michie & Prestwich, 2010).

The IMBP has frequently functioned as a framework for understanding why individuals do or do not intend to perform a behavior and for identifying potential intervention targets in different health communication domains; for example, this model has been used to explore the determinants of intention in the contexts of getting tested for sexual transmitted diseases (Boudewyns & Paquin, 2011), getting vaccinated against the human papillomavirus (Dillard, 2011) and maintaining healthy sleep behaviors (Robbins & Niederdeppe, 2015). The IMBP has also been applied in cancer research to explore determinants that are related to cancer prevention behaviors, cancer detection behaviors and cancer-related information seeking (Smith-McLallen & Fishbein, 2009; Smith-McLallen et al., 2011). These studies were all successful in explaining variance in intention and in identifying potential intervention targets. In addition, Fishbein (2000) argued that the IMBP can be applied to any given behavior. Thus, this study uses the IMBP as a starting point to understand why cancer patients do or do not intend to express their concerns and to identify intervention targets.
The IMBP proposes that background characteristics, such as demographic (e.g., age), disease (e.g., time since diagnosis), and psychological (differing by behavior) characteristics, should be taken into account as control variables (Fishbein, 2000). This study includes psychological characteristics as control variables that have been suggested in the literature as possibly influencing patients’ concerns and concern expression, namely, patients’ monitoring coping style (Miller, 1995), cancer-related stress reactions (Stanton et al., 2002) and illness perceptions (Hagger & Orbell, 2003). Furthermore, the IMBP postulates that individuals’ intention to perform a behavior will determine their behavior. Individuals’ intention is formed by their attitudes toward the behavior, the perceived social norm and their self-efficacy regarding performance of the behavior. Attitude refers to individuals’ positive and/or negative feelings toward performing a behavior. Perceived social norm refers to the extent to which individuals believe that people who are important to them (e.g., spouse and family) want them to perform the behavior. Self-efficacy refers to the extent to which individuals believe that they are able to perform the behavior (Fishbein, 2000; Fishbein & Capella, 2006; Fishbein & Yzer, 2003). In addition to models like the theory of planned behavior that propose the same determinants of intention, the IMBP has the advantage of including measures (i.e., barriers and skills) that possibly moderate the intention-behavior gap. This gap can occur when individuals who have a perfect intention to perform a behavior fail to act on it (Fishbein, 2000; Fishbein & Capella, 2006; Fishbein & Yzer, 2003). The intention-behavior gap can be targeted best when individuals already have a perfect intention. However, research shows that patients’ intention to express concerns might not be optimal (Street, 2001). Therefore, the focus of this study is on explaining intention.

Past studies have indicated that, in line with the IMBP, attitudes (e.g., Okuyama et al., 2008), perceived social norm (e.g., Zakowski et al., 2003) and self-efficacy (e.g., Street, 2001) play a role in patients’ concern expression; thus, it can be expected that these determinants are also related to patients’ intention to express concerns. Therefore the objective of this study is to examine whether cancer patients’ attitudes, perceived social norm and self-efficacy to express concerns are positively related to their intention to express concerns during a consultation.

Although studies have examined the relations among the different determinants of intention (i.e., patients’ attitudes, perceived social norm and self-efficacy with concern expression; e.g., Manne et al., 1999; Okuyama et al., 2008; Street, 2001), none of these studies has compared these determinants to examine which are most strongly related to patients’ intention to express concerns. To examine the latter, we propose the following research question:

Research question 1: Which of the determinants (attitudes, perceived social norm and/or self-efficacy) has/have the strongest relation to patients’ intention to express concerns during a consultation?
Accomplishing Changes in Intention

After the identification of the determinants (i.e., attitudes, perceived social norm and self-efficacy) that are significantly related to intention, it is still unknown what content of those determinants (i.e., the specific content of patients’ attitudes, perceived social norm and self-efficacy) must be addressed to effect a change in intention. Information about the specific content that can contribute to a change in intention can be used as a starting point to determine intervention targets. One of the techniques that can be used to identify that specific content is a percentage to gain analysis (Brennan, Gibson, Liu, & Hornik, 2013). With this analysis, it is possible to calculate what content of the determinants can yield the largest change in intention when they are successfully targeted in an intervention for concern expression (Brennan et al., 2013; Hornik & Woolf, 1999). For example, when an intervention is designed to target patients’ intention, and attitude would be a strong determinant of intention, the content of patients’ attitudes (e.g., whether it is pleasant or unpleasant to express concerns during a consultation) can provide insight into what must be targeted to effect a change in intention. It is unknown what content of the IMBP determinants must be targeted to accomplish a change in cancer patients’ intention to express concerns (the content will also depend on the determinants that are significantly related to intention). Therefore, the second research question is as follows:

Research question 2: What specific content of the determinants of intention (the content of patients’ attitudes, perceived social norm and/or self-efficacy) should be best targeted in an intervention to accomplish the largest change in cancer patients’ intention to express concerns during a consultation?

Methods

Participants and Procedure

The participants were recruited via patient association websites, kanker.nl (a national panel of cancer patients in the Netherlands), and a panel of cancer patients from the authors’ university. Participants were eligible if they were at least 18 years old and if they were currently receiving or had in the past received treatment for cancer. This study was approved by the ethical committee of the authors’ university (2013-CW-74).
Study Design
The items in the survey were based on IMBP questionnaires (Francis et al., 2004; Montano & Kasprzyk, 2008). In accordance with the IMBP, the survey first elicited background characteristics of the participants, including whether participants were undergoing treatment for cancer at the time of the survey. Participants who indicated that they were currently undergoing treatment were asked the questions about the IMBP determinants (attitude, perceived social norm, self-efficacy and intention) in the present tense (i.e., the questions concerned consultations in their current cancer treatment). If participants indicated that they were not currently undergoing treatment, they were asked the questions about the IMBP determinants in the past tense (i.e., the questions asked them to reflect back on consultations in their past cancer treatment). During the survey, the definition of concern expression was given several times (i.e., clearly and explicitly verbalizing emotions experienced during the disease). The survey was pre-tested by one cancer patient and one cancer survivor, neither of whom was included in the study.

Measures
First, background characteristics (i.e., demographic, disease and psychological characteristics) were elicited. The disease and psychological characteristics that were measured in this study have been commonly used in previous studies on cancer communication. Second, questions were asked about the participants’ intention to express concerns during a consultation. Finally, in accordance with the IMBP, questions about the determinants of intention were asked, namely participants’ attitudes, perceived social norm and self-efficacy to express concerns during a consultation. Attitude, perceived social norm and self-efficacy were operationalized with validated IMBP measures (Francis et al., 2004; Montano & Kasprzyk, 2008).

Background Characteristics Measures
Demographic and disease characteristics. The participants were asked to specify their gender, age and level of education. Level of education was recoded as high (higher vocational education and university), middle (senior secondary vocational education and university preparatory vocational education) or low (primary education, lower vocational education, preparatory secondary vocational education and intermediate secondary vocational education). The participants also indicated the date that they were diagnosed (which was recoded as time since diagnosis in months), whether they were still receiving treatment, their treatment goal (curative or palliative), their type of cancer and what types of treatments they had had.
**Psychological characteristics.** Monitoring coping style was measured with a three item 5-point scale derived from the Threatening Medical Situation Inventory (TMSI; Miller, 1987; Van Weert, Jansen, De Bruijn, Noordman, Van Dulmen, & Bensing, 2009). Statements on, for example, reading as much as possible about cancer could be rated from 1 (*not at all applicable to me*) to 5 (*strongly applicable to me*). The total scores on monitoring coping styles were derived by the sum of scores on the three items ($\alpha = .84$, range 3-15, $M = 11.70$, $SD = 3.25$). A higher score indicated a higher monitoring coping style.

Cancer-related stress reactions were measured with the Dutch version of the Impact of Events Scale (Van der Ploeg, Mooren, Kleber, Van der Velden, Peter, & Brom, 2004), which divides cancer-related stress reactions into intrusive thinking (seven items, $\alpha = .89$, range 0-35, $M = 18.88$, $SD = 8.96$) and avoidant thinking (eight items, $\alpha = .79$, range 0-40, $M = 14.08$, $SD = 8.59$). The participants indicated on a 4-point scale (0 = *not at all*, 1 = *rarely*, 3 = *sometimes* and 5 = *often*) whether they had experienced certain stressful situations, such as having bad dreams about cancer. The total scores of the subscales were calculated as the total scores of their items.

Illness perceptions were measured with the Dutch version of the Brief Illness Perceptions Questionnaire (De Raaij, Schröder, Maissan, Pool, & Wittink, 2012). The participants had to indicate on a 10-point scale per illness perception whether a given statement, such as that cancer influenced their daily lives, applied to them. A higher score indicated a more threatening perception of cancer (eight items, $\alpha = .63$, range 0-10, $M = 6.79$, $SD = 1.36$).

**IMBP Measures**

**Intention.** Intention to express concerns was measured with three items (Francis et al., 2004; Montano & Kasprzyk, 2008) in which participants had to indicate whether they intended to express their concerns during their next consultation with their healthcare provider on a 7-point scale (1 = *strongly disagree* to 7 = *strongly agree*, $\alpha = .95$, $M = 4.66$, $SD = 1.87$).

**Attitude.** Attitude was measured with six items on 7-point semantic differential scales (Francis et al., 2004; Montano & Kasprzyk, 2008). The participants had to indicate whether expressing concerns toward their healthcare provider was unpleasant-pleasant, bad-good, not useful-useful, not helpful-helpful, a disadvantage-an advantage, and not stressful-stressful ($\alpha = .86$, $M = 5.91$, $SD = .98$).
**Perceived social norm.** Perceived social norm was measured with eight items (Francis et al., 2004; Montano & Kasprzyk, 2008). The participants had to indicate on a 7-point scale (1 = strongly disagree to 7 = strongly agree) whether their significant others (i.e., people who were important to them) expected or wanted them to express their concerns toward a healthcare provider and whether they complied with those expectations or wishes. Thereafter, the participants had to indicate whether their significant others (i.e., their spouse, children, siblings and friends) wanted them to express concerns toward their healthcare provider. Furthermore, the participants were asked whether they believed that other cancer patients expressed their concerns to their healthcare providers (α = .82, M = 5.90, SD = 1.01).

**Self-efficacy.** Self-efficacy was measured with five items (Francis et al., 2004; Montano & Kasprzyk, 2008). The items measured, for example, whether the participants found it easy to express concerns, whether the participants felt able to express concerns toward their healthcare provider and whether they decided themselves to express concerns toward their healthcare provider on 7-point scales (1 = strongly disagree to 7 = strongly agree, α = .81, M = 5.32, SD = 1.26).

**Analysis**
First, bivariate correlations were calculated to assess whether attitude, perceived social norm and self-efficacy were positively related to patients’ intention to express concerns. Second, a hierarchical regression analysis was conducted with standardized variables to examine whether attitude, perceived social norm or self-efficacy had the strongest relation with intention. Variables were added in the hierarchical regression analysis in two steps: (1) demographic, disease and psychological characteristics and (2) attitude, perceived social norm and self-efficacy. Finally, percentages to gain in intention were calculated as proposed by Brennan and colleagues (2013). Intention and the content of the determinants that were related to intention were recoded as 1 = desired (everyone who had the maximum score and did not need an intervention) and 2 = all others (everyone who did not have the maximum score and could benefit from an intervention). Thus, by recoding intention in two categories, the participants who may or may not benefit from an intervention were separated. Thereafter, a cross-tabulation was used with intention and the content of the determinants of intention. The percentage to gain represented the proportion of patients who would have a positive change in their intention when an intervention was 100% successful in targeting the specific content of a determinant (i.e., the percentage of patients who had a maximum score on, for example, both the intention scale and the unpleasant/pleasant content of the attitude scale minus the percentage of patients who only had a maximum score on the intention scale). For example, if 15% of all the participants would have the maximum score on the intention scale, and 30% of the participants
would have the maximum score on both the intention scale and the unpleasant/pleasant content of the
attitude scale, then the percentage to gain would be 30%-15% = 15%. Thus, in this example, under
the ideal circumstances of an intervention that was 100% effective, 15% of the patients would change
their intention to express concerns after they were exposed to an intervention targeting the unpleasant/
pleasant content of their attitudes. This analysis was conducted for the content of each determinant.

Results

Response
In total, 268 participants started the online survey, and 236 participants (88.1%) completed it. A non-
response analysis showed that the participants who did not complete the survey differed in gender
from those who did complete it ($\chi^2 (1) = 9.70, p < .001$). Of the 32 participants who did not complete
the survey, the majority were female ($n = 27; 84.4$%). The survey was also completed by more
females ($n = 131; 55.5$%). However, the percentage of females in the non-response group was higher.
The participants who did not complete the survey were also younger ($M = 48.55, SD = 12.99$) than
the participants who did complete it ($M = 56.32, SD = 11.82; p = .004$). The participants who did and
did not complete the survey did not differ in their level of education.

Participants
The majority of the participants were female (55.5%), lived together with a partner (52.1%) and had
children (80.1%). The mean age of the sample was 57.23 ($SD = 12.25$), and approximately half of the
participants were highly educated (51.9%). All the demographic characteristics of the participants are
displayed in Table 3.1.

Almost a quarter of the participants had been diagnosed with breast cancer (24.0%), and a
fifth had digestive-gastrointestinal cancer (20.9%). More than half of the participants were not
undergoing treatment at the time they completed the survey (52.5%). Furthermore, surgery (31.8%),
chemotherapy (22.7%) and radiotherapy (20.7%) were the most received treatments. All the disease
characteristics are shown in Table 3.2.
Table 3.1
*Demographic Characteristics of the Participants (N=236)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>105</td>
<td>44.5</td>
</tr>
<tr>
<td>Female</td>
<td>131</td>
<td>55.5</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M (SD)</td>
<td>57.23 (12.25)</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>20-83</td>
<td></td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
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<td></td>
</tr>
<tr>
<td>Low</td>
<td>54</td>
<td>23.4</td>
</tr>
<tr>
<td>Middle</td>
<td>57</td>
<td>24.7</td>
</tr>
<tr>
<td>High</td>
<td>120</td>
<td>51.9</td>
</tr>
<tr>
<td><strong>Living arrangements</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>41</td>
<td>17.4</td>
</tr>
<tr>
<td>Partner</td>
<td>123</td>
<td>52.1</td>
</tr>
<tr>
<td>Partner and child(ren)</td>
<td>56</td>
<td>23.7</td>
</tr>
<tr>
<td>Child(ren)</td>
<td>10</td>
<td>4.2</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>2.6</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>189</td>
<td>80.1</td>
</tr>
<tr>
<td>No</td>
<td>47</td>
<td>19.9</td>
</tr>
<tr>
<td><strong>Employed</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>91</td>
<td>38.6</td>
</tr>
<tr>
<td>No</td>
<td>145</td>
<td>61.4</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dutch</td>
<td>228</td>
<td>96.6</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>3.4</td>
</tr>
</tbody>
</table>

*Note. n varies due to missing data*
Table 3.2
Disease Characteristics of the Participants (N=236)

<table>
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<tr>
<th>Characteristic</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of cancer</strong></td>
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<td></td>
</tr>
<tr>
<td>Breast</td>
<td>63</td>
<td>24.0</td>
</tr>
<tr>
<td>Digestive-gastrointestinal</td>
<td>55</td>
<td>20.9</td>
</tr>
<tr>
<td>Heamatologic</td>
<td>41</td>
<td>15.6</td>
</tr>
<tr>
<td>Lung</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td>Gynaecological</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td>Urologic</td>
<td>51</td>
<td>19.4</td>
</tr>
<tr>
<td>Head and neck</td>
<td>2</td>
<td>0.8</td>
</tr>
<tr>
<td>Skin</td>
<td>14</td>
<td>5.3</td>
</tr>
<tr>
<td>Other</td>
<td>29</td>
<td>11.0</td>
</tr>
<tr>
<td><strong>Time since diagnosis (months)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M (SD)</td>
<td>55.5 (59.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Patients still undergoing treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>112</td>
<td>47.5</td>
</tr>
<tr>
<td>No</td>
<td>124</td>
<td>52.5</td>
</tr>
<tr>
<td><strong>Treatment intent</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Curative</td>
<td>144</td>
<td>61.0</td>
</tr>
<tr>
<td>Palliative</td>
<td>84</td>
<td>35.6</td>
</tr>
<tr>
<td>Unknown</td>
<td>8</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No treatment</td>
<td>11</td>
<td>2.1</td>
</tr>
<tr>
<td>Surgery</td>
<td>163</td>
<td>31.8</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>116</td>
<td>22.7</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>106</td>
<td>20.7</td>
</tr>
<tr>
<td>Immunotherapy</td>
<td>13</td>
<td>2.5</td>
</tr>
<tr>
<td>Hormone replacement therapy</td>
<td>48</td>
<td>9.4</td>
</tr>
<tr>
<td>Chemoradiation</td>
<td>3</td>
<td>0.6</td>
</tr>
<tr>
<td>Goal directed therapy</td>
<td>12</td>
<td>2.3</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td>Other</td>
<td>39</td>
<td>7.6</td>
</tr>
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</table>

Note: n varies due to missing data or multiple answers
Explaining intention

The overall objective of this study is to examine whether cancer patients’ attitudes, perceived social norm, and self-efficacy to express concerns are positively related to their intention to express concerns. Bivariate correlations (Table 3.3) showed that patients’ attitudes ($r = .21$, $p = .001$), perceived social norm ($r = .32$, $p < .001$) and self-efficacy ($r = .14$, $p = .031$) were all positively related to their intention to express concerns during their next consultation.

Table 3.3

<table>
<thead>
<tr>
<th>Measure</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intention</td>
<td></td>
<td>.21**</td>
<td>.32***</td>
<td>.14*</td>
</tr>
<tr>
<td>2. Attitude</td>
<td></td>
<td></td>
<td></td>
<td>.27***</td>
</tr>
<tr>
<td>3. Perceived social norm</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Self-efficacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. $N = 236$.

*p < .05. ** $p < .01$ *** $p < .001$

The first research question was as follows: “Which of the determinants (attitude, perceived social norm and/or self-efficacy) has/have the strongest relation with patients’ intention to express concerns during their next consultation?” A hierarchical regression analysis was conducted to answer this research question. As a first step, in accordance with the IMBP, demographic, disease and psychological characteristics of the patients were entered. These background characteristics explained 7% of the variance in patients’ intention to express concerns ($F (10, 213) = 1.60$, $p = .108$). As a second step, attitude, perceived social norm and self-efficacy were added. This second step yielded a significant $R^2$ change of 12% ($p < .001$). The final model explained 19% of the variance in patients’ intention to express concerns ($F (13, 210) = 3.66$, $p < .001$). Perceived social norm had the strongest relation with intention ($b^* = .26$, $p < .001$), followed by attitude ($b^* = .17$, $p = .022$). Self-efficacy did not have a significant relation with intention in the final model ($b^* = .03$, $p = .671$). Table 3.4 shows the entire hierarchical regression analysis.
Table 3.4
Hierarchical Regression Analysis Predicting Intention to Express Concerns

<table>
<thead>
<tr>
<th>Predictor</th>
<th>Δ R²</th>
<th>b*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td>.07</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>.10</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-.01</td>
<td></td>
</tr>
<tr>
<td>Level of education</td>
<td>-.02</td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>-.02</td>
<td></td>
</tr>
<tr>
<td>Undergoing treatment</td>
<td>.11</td>
<td></td>
</tr>
<tr>
<td>Treatment goal</td>
<td>.02</td>
<td></td>
</tr>
<tr>
<td>Monitoring coping style</td>
<td>.20***</td>
<td></td>
</tr>
<tr>
<td>Intrusive thinking</td>
<td>-.06</td>
<td></td>
</tr>
<tr>
<td>Avoidant thinking</td>
<td>.02</td>
<td></td>
</tr>
<tr>
<td>Illness perceptions</td>
<td>.09</td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td>.12***</td>
<td></td>
</tr>
<tr>
<td>Attitude</td>
<td>.17*</td>
<td></td>
</tr>
<tr>
<td>Perceived social norm</td>
<td>.26***</td>
<td></td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>.03</td>
<td></td>
</tr>
<tr>
<td><strong>Total R²</strong></td>
<td>.19***</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>236</td>
<td></td>
</tr>
</tbody>
</table>

*p < .05. ***p < .001.

Percentage to Gain Analysis

The second research question was as follows: “What specific content of the determinants of intention (the content of patients’ attitudes, perceived social norm and/or self-efficacy) should be best targeted in an intervention to accomplish the largest change in cancer patients’ intention to express concerns during their next consultation?”

The hierarchical regression analysis showed that perceived social norm had the strongest relation with intention. Attitude also had a significant relation with intention. Therefore, percentage to gain analyses were conducted for the content of both attitude and perceived social norm because they are both potential candidates for intervention targets (see Appendix 3.1 for the cross-tabulations per content measure). For attitude, the highest percentages to gain in intention could be yielded for
the affective component of patients’ attitudes, namely the extent to which patients felt unpleasant when they expressed concerns during a consultation (20.0%). The second highest percentage to gain could be achieved with the extent to which patients believed that expressing concerns could be disadvantageous (17.4%). For perceived social norm, the highest percentage to gain in intention could be yielded for an injunctive norm component, namely the extent to which patients believed that significant others did not want them to express concerns during a consultation (14.4%) and for the extent to which patients complied with the wishes or expectations of significant others (12.9%).

Discussion

This study aimed to use the IMBP to identify the determinants that are related to cancer patients’ intention to express concerns. The results show that patients’ attitudes and perceived social norm underlie their intention to express concerns during their next consultation. We also examined what content of patients’ attitudes and perceived social norm could yield the largest improvement in intention and are potential candidates for intervention targets. Potential candidates for intervention targets are: (1) the extent to which patients think that expressing concerns during a consultation will make them feel (un)pleasant, (2) the extent to which patients believe that expressing concerns can be (dis)advantageous, (3) the extent to which patients believe that significant others do (not) want them to express concerns in a consultation and (4) the extent to which patients comply with the wishes or expectations of significant others.

The results show that particularly patients’ affective attitudes (i.e., the extent to which concern expression during a consultation can be (un)pleasant) in particular are related to their intention to express concerns. An attitude consists of both a cognitive (i.e., positive/negative attributes of the behavior) and an affective (i.e., positive/negative feelings about the behavior) component (e.g., Fabrigar & Petty, 1999; Trafimow & Sheeran, 1998). Some studies have shown that the affective component of an attitude is a stronger predictor of intention than the cognitive component (e.g., French et al., 2005; Lowe, Eves, & Carroll, 2002). This may also be the case for patients’ intention to express concerns. Concern expression is classified in the literature as an affective behavior (Bensing & Verhaak, 2004; Street & Millay, 2001), and therefore, the affective component of patients’ attitude could be most decisive in their overall attitude formation and their intention to express concerns.

The extent to which patients believed that their significant others wanted them to express concerns during a consultation was also related to patients’ intention to express concerns. It is possible that
patients hold this belief because they think that their significant others might not be able to cope with their concerns (Zhang & Siminoff, 2003), for example, because in some cases spouses or family members have had avoidant reactions when cancer patients have tried to express their concerns about their disease at home (Manne et al., 1999; Zakowski et al., 2003; Zhang & Siminoff, 2003). Other studies (e.g., Clayton, Butow, & Tattersall, 2005) suggest that spouses and family members do prefer openness about patients’ concerns during medical consultations so that the patient can receive adequate information to address his or her concerns. Thus, it seems that the support of spouses and family members can differ among patients and situations. Interventions are needed for those patients who feel that they do not receive adequate support from their significant others. More research in this area is needed to explore why certain patients feel that they do not receive adequate support from their significant others.

Because of the cross-sectional data collection, the results of this study must be interpreted with care. Nonetheless, little was previously known about what should be targeted in concern expression interventions, and the results of this study can function as a starting point for determining intervention targets in this area. Studies that actually target patients’ attitudes and perceived social norm are needed to establish whether patients’ intention to express concerns, and consequently their behavior, can improve. For example, we found that the largest change in intention could be yielded by addressing patients’ affective attitudes (i.e., the unpleasant feeling that patients could experience when they expressed concerns). Future studies could try to target patients’ affective attitudes by developing interventions that focus on affective persuasion. Matching an intervention to the component of an attitude that must be targeted will increase its effectiveness (e.g., Fabrigar & Petty, 1999). In the case of an affective attitude, this could be done by providing the patients with positive emotional consequences of concern expression (Abraham & Michie, 2008; Michie et al., 2013). Future studies could try to target patients’ perceived social norm similarly. Such an intervention can inform patients about the approval of people who are important to them regarding concern expression during consultations (Abraham & Michie, 2008).

Another direction for future research is to expand on the current study by identifying other determinants of cancer patients’ intention to express concerns. The IMBP is a model that combines determinants from many behavioral theories, and it is proposed that the model can be applied to any given behavior (Fishbein, 2000). However, the IMBP only explained 19% of the variance in cancer patients’ intention to express concerns. Although this is a promising starting point because little was previously known about what predicts cancer patients’ intention to express concerns, it would be useful to know which other determinants could contribute to the explained variance. For example,
expressing concerns is an affective behavior; therefore, affective determinants such as anticipated emotions (e.g., regret; French et al., 2005) or personality characteristics of communication (e.g., being introvert or extrovert; Street, 2001) might also explain variance in why patients do or do not intend to express their emotions.

This study had some limitations that must be addressed. First, we only used direct measures for the determinants, and we did not measure the underlying beliefs of patients’ attitudes and perceived social norm. Measuring the underlying beliefs of these determinants would give more detailed information to guide the development of an intervention. However, we did look at the content of these determinants to give the most comprehensive implications that were possible on the basis of the available data. Second, the cross-sectional nature of the study made it impossible to properly investigate the relation between intention and behavior. This relation can be examined best by measuring intention and behavior at different time points. Thus, to further examine the intention-behavior relation for concern expression, future studies could distribute an IMBP survey and then, at a later point in time, audio- or videotape a consultation to code the number of concerns that patients express. Finally, we recruited patients via patient association websites and panels, which could have yielded a sample that was not completely representative of the cancer patient population. Recruiting patients in a less biased environment, such as a hospital waiting room, could perhaps result in a more representative sample, and replication of this study in such a setting is therefore recommended.

To conclude, this study examined cancer patients’ intention to express concerns in a new manner, namely by using the IMBP to unravel its underlying determinants. We found that patients’ affective attitudes and perceived social norm are related to their intention to express concerns. Future studies could examine how these determinants of intention can be targeted most effectively by, for example, exploring interventions that focus on affective persuasion and on the approval by family members of concern expression.
Chapter 3

References


Appendix 3.1

Cross-Tabulations with Percentage to Gain Analyses for All the Underlying Measures for Attitude, Perceived Social Norm and Communicative Skills

Cross-Tabulation of Attitude Measure Unpleasant - Pleasant and Intention

<table>
<thead>
<tr>
<th>(n = 236)</th>
<th>Attitude Unpleasant - Pleasant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All others</td>
</tr>
<tr>
<td>All others</td>
<td>93.4%</td>
</tr>
<tr>
<td>Desired</td>
<td>6.6%</td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Percentage to gain: 34.8% - 14.8% = 20.0%

Cross-Tabulation of Attitude Measure a Disadvantage – an Advantage and Intention

<table>
<thead>
<tr>
<th>(n = 236)</th>
<th>Attitude a Disadvantage - an Advantage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All others</td>
</tr>
<tr>
<td>All others</td>
<td>95.9%</td>
</tr>
<tr>
<td>Desired</td>
<td>4.1%</td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Percentage to gain: 32.2% - 14.8% = 17.4%

Cross-Tabulation of Attitude Measure Not Stressful - Stressful and Intention

<table>
<thead>
<tr>
<th>(n = 236)</th>
<th>Attitude Not Stressful - Stressful</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All others</td>
</tr>
<tr>
<td>All others</td>
<td>91.9%</td>
</tr>
<tr>
<td>Desired</td>
<td>8.1%</td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Percentage to gain: 26.4% - 14.8% = 11.6%
Cross-Tabulation of Attitude Measure Bad - Good and Intention

<table>
<thead>
<tr>
<th>(n = 236)</th>
<th>Attitude Bad – Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intention to express concerns</td>
<td>All others</td>
</tr>
<tr>
<td>All others</td>
<td>95.0%</td>
</tr>
<tr>
<td>Desired</td>
<td>5.0%</td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Percentage to gain: 24.8% - 14.8% = 10.0%

Cross-Tabulation of Attitude Measure Not Useful - Useful and Intention

<table>
<thead>
<tr>
<th>(n = 236)</th>
<th>Attitude Not Useful - Useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intention to express concerns</td>
<td>All others</td>
</tr>
<tr>
<td>All others</td>
<td>95.4%</td>
</tr>
<tr>
<td>Desired</td>
<td>4.6%</td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Percentage to gain: 23.4% - 14.8% = 8.6%

Cross-Tabulation of Attitude Measure Not Helpful – Helpful and Intention

<table>
<thead>
<tr>
<th>(n = 236)</th>
<th>Attitude Not Helpful - Helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intention to express concerns</td>
<td>All others</td>
</tr>
<tr>
<td>All others</td>
<td>93.5%</td>
</tr>
<tr>
<td>Desired</td>
<td>6.5%</td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Percentage to gain: 21.7% - 14.8% = 6.9%
Cross-Tabulation of Perceived Social Norm Measure Significant Others Want the Patient to Express Concerns and Intention

(n = 236)  PSN People Who are Important Want the Patient to Express Concerns Intention to express concerns | All others | Desired | Total
---|---|---|---
All others | 91.5% | 70.8% | 85.2%
Desired | 8.5% | 29.2% | 14.8%
% in the column | 100.0% | 100.0% | 100.0%

Percentage to gain: 29.2% - 14.8% = 14.4%

Cross-Tabulation of Perceived Social Norm Measure Compliance with the Expectations and Wishes regarding Concern Expression of Significant Others

(n = 236)  PSN Compliance Intention to express concerns | All others | Desired | Total
---|---|---|---
All others | 88.4% | 72.3% | 85.2%
Desired | 11.6% | 27.7% | 14.8%
% in the column | 100.0% | 100.0% | 100.0%

Percentage to gain: 27.7% - 14.8% = 12.9%

Cross-Tabulation of Perceived Social Norm Measure Significant Others Expect the Patient to Express Concerns and Intention

(n = 236)  PSN People Who are Important Expect the Patient to Express Concerns Intention to express concerns | All others | Desired | Total
---|---|---|---
All others | 90.6% | 73.7% | 85.2%
Desired | 9.4% | 26.3% | 14.8%
% in the column | 100.0% | 100.0% | 100.0%

Percentage to gain: 26.3% - 14.8% = 11.5%
### Cross-Tabulation of Perceived Social Norm Measure Patients’ Belief That Their Partner Thinks that He or She Should Express Concerns and Intention

(n = 204)*

<table>
<thead>
<tr>
<th>PSN People Partner</th>
<th>Intention to express concerns</th>
<th>All others</th>
<th>Desired</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All others</td>
<td>94.6%</td>
<td>80.4%</td>
<td>86.8%</td>
<td></td>
</tr>
<tr>
<td>Desired</td>
<td>5.4%</td>
<td>19.6%</td>
<td>13.2%</td>
<td></td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td></td>
</tr>
</tbody>
</table>

Percentage to gain: 19.6% - 13.2% = 6.4%

*N varies because there was also a “not applicable to me” answer category

### Cross-Tabulation of Perceived Social Norm Measure Patients’ Belief That Their Child(ren) Think(s) that He or She Should Express Concerns and Intention

(n = 177)*

<table>
<thead>
<tr>
<th>PSN People Child(ren)</th>
<th>Intention to express concerns</th>
<th>All others</th>
<th>Desired</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All others</td>
<td>91.3%</td>
<td>81.2%</td>
<td>86.4%</td>
<td></td>
</tr>
<tr>
<td>Desired</td>
<td>8.7%</td>
<td>18.8%</td>
<td>13.6%</td>
<td></td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td></td>
</tr>
</tbody>
</table>

Percentage to gain: 18.8% - 13.6% = 5.2%

*N varies because there was also a “not applicable to me” answer category

### Cross-Tabulation of Perceived Social Norm Measure Patients’ Belief That Their Sibling(s) Think(s) that He or She Should Express Concerns and Intention

(n = 185)*

<table>
<thead>
<tr>
<th>PSN Siblings</th>
<th>Intention to express concerns</th>
<th>All others</th>
<th>Desired</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All others</td>
<td>92.3%</td>
<td>75.0%</td>
<td>85.9%</td>
<td></td>
</tr>
<tr>
<td>Desired</td>
<td>7.7%</td>
<td>25.0%</td>
<td>14.1%</td>
<td></td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td></td>
</tr>
</tbody>
</table>

Percentage to gain: 25.0% - 14.1% = 10.9%

*N varies because there was also a “not applicable to me” answer category
Cross-Tabulation of Perceived Social Norm Measure Patients' Belief That Their Friends Think that He or She Should Express Concerns and Intention

(n = 212)*

<table>
<thead>
<tr>
<th>Intention to express concerns</th>
<th>All others</th>
<th>Desired</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All others</td>
<td>91.5%</td>
<td>74.7%</td>
<td>84.9%</td>
</tr>
<tr>
<td>Desired</td>
<td>8.5%</td>
<td>25.3%</td>
<td>15.1%</td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Percentage to gain: 25.3% - 15.1% = 10.2%

*N varies because there was also a “not applicable to me” answer category

Cross-Tabulation of Perceived Social Norm Measure Patients' Belief That Other Cancer Patients Express Concerns and Intention

(n = 204)*

<table>
<thead>
<tr>
<th>Intention to express concerns</th>
<th>All others</th>
<th>Desired</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All others</td>
<td>89.3%</td>
<td>75.4%</td>
<td>85.7%</td>
</tr>
<tr>
<td>Desired</td>
<td>10.7%</td>
<td>24.6%</td>
<td>14.3%</td>
</tr>
<tr>
<td>% in the column</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Percentage to gain: 24.6% - 14.3% = 6.4%

*N varies because there was also a “not applicable to me” answer category