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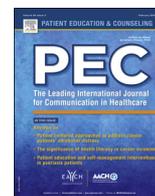
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## Communication study

## Patients' reports of barriers to expressing concerns during cancer consultations

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## ABSTRACT

**Objective:** To identify cancer patients' most influential barriers to expressing concerns during cancer consultations in a new manner by examining patients' reports of perceived barriers and perceived occurrence of barriers in consultations.

**Methods:** Two online focus groups ( $N = 16$ ) and an online survey ( $N = 236$ ) were conducted among cancer patients and cancer survivors. The online focus groups and survey were used to examine two elements of patients' barriers, i.e., patients' reports of perceived barriers and perceived occurrence of barriers in consultations. Composite scores of these two elements were calculated to determine influential barriers.

**Results:** Results showed that the most influential barriers were related to providers' behavior (e.g., providers do not explicitly invite patients to express concerns) and the environment where the consultation takes place (e.g., perceived lack of time).

**Conclusion:** The results of this study indicate that influential barriers to expressing concerns are barriers that patients cannot overcome themselves (i.e., they are related to providers' behavior or the environment of the consultation). A collaborative approach between researchers, providers and policy makers is needed to overcome these barriers.

**Practice implications:** The results of this study can be used to develop strategies to overcome barriers to patients expressing concerns.

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## 1. Introduction

Almost 38% of the cancer patients experience clinical psychological distress of such high levels that it requires treatment [1]. Unfortunately, psychological distress is not often detected by healthcare providers, which can affect patients' suffering and impair their overall well-being [2,3]. If patients clearly express their concerns in a consultation, providers' recognition of psychological distress can improve [2,4–6]. However, patients often do not clearly express their concerns but rather express concerns as indirect cues [7–9]. Patients' tendency to express their concerns as cues can be problematic since providers often find it difficult to detect cues [10]. Patients clearly expressing their concerns can therefore be beneficial for both the provider (e.g., the provider gets more insight into what is

going on with the patient) and the patient (e.g., the patient could receive relevant information to deal with concerns). However, many cancer patients experience communication barriers that may prevent them from clearly expressing their concerns during a consultation [4,11–13].

Studies on communication barriers have mainly explored barriers to patient participation in general [4,11,12]. Although expressing concerns is a component of patient participation [4,14], studies hardly differentiate between expressing concerns and other components of patient participation such as question asking. Barriers to expressing concerns can differ from barriers to question asking. Patients will express concerns to satisfy an affective need (i.e., the need to feel known and understood) and to facilitate emotional coping with their disease while they will ask a question to satisfy an instrumental need (i.e., the need to know and understand) to facilitate problem-oriented coping [15]. Hence, studies that focused on barriers of patient participation in general might not have captured the differences between barriers to expressing concerns and question asking and knowledge on the barriers to expressing concerns is lacking.

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To our knowledge, there is only one study that did specifically examine cancer patients' perceived barriers to expressing concerns [13]. This study provided valuable insight into patients' barriers, but it did not assess patient reports explaining whether patients perceive the occurrence of these barriers in cancer consultations or not. More insights into patients' reports of their experiences with the occurrence of barriers in consultations can be relevant to determine the magnitude of the barriers. Especially since patients' experiences with communication in consultations is one of the core elements of patient-centered communication [16]. Thus, in order to develop good strategies to overcome patients' barriers, the actual experiences of patients need to be taken into account. Therefore, this study aims to examine patients' barriers to expressing concerns in a new manner, namely by creating a composite score of patients' reports of perceived barriers and perceived occurrence of the barriers in cancer consultations to determine the most influential barriers to expressing concerns.

### 1.1. Types of barriers

In this study three types of barriers to expressing concerns are distinguished: (1) barriers related to the providers' behavior (2) barriers related to the environment where the consultation takes place and (3) legitimacy barriers. Communication barriers regarding providers' behavior have been described extensively in the patient participation literature [4,11,12]. For example, when providers do not explicitly invite patients to discuss concerns, patients can perceive this as a barrier that prevents them from expressing a concern [13]. Environmental barriers are described in the health behavior change literature [17–19] and often include time and location which are also barriers that seem to play a role in expressing concerns. For example, patients can believe that their provider has limited time to discuss concerns [11,13]. Furthermore, in the patient participation literature it is also stressed that patients can perceive barriers about the legitimacy of expressing concerns [4,12,13]. For example, patients can have the belief that expressing concerns will deteriorate the relationship with their provider [13]. The present study examines to what extent patients report perceiving these barriers and their occurrence in consultations.

## 2. Methods

### 2.1. Procedure of the study

This study consisted of several steps: (1) literature was reviewed to gain insight into the possible barriers to expressing concerns, (2) a pre-study consisting of online focus groups was conducted to explore any new barriers that were not described in the literature and (3) a survey based on the literature and the pre-study was administered to examine the most influential barriers. The current study was approved by the ethical committee of the authors' university (2013-CW-74).

### 2.2. Pre-Study

#### 2.2.1. Participants and procedure

Participants of the online focus groups (OFGs) were recruited via patient association websites. Inclusion criteria were: (1) being 18 years or older and (2) being treated for cancer (currently or in the past). Sixteen participants agreed to participate and signed an informed consent form. A-synchronous OFGs were chosen for the following reasons: (1) it is a feasible way to include participants who are ill, (2) it allows participants to react for a longer period of time and to take their time to construct a more in-depth reaction and (3) it can remove possible barriers to discuss sensitive topics such as emotional concerns regarding cancer [20]. Participants were randomly assigned to one of the two a-synchronous OFGs. During the five days that the study was active, the OFGs were conducted on a secure website that could be entered with a code name and a password. A semi-structured interview guide was developed on the basis of the barriers that were derived from the literature. Every day a new open-ended question or statement was posted. After a topic was posted participants were asked to give their reactions and to engage in a discussion with each other. A moderator (KB) facilitated the discussion by repeating statements or reactions of participants and asking if other participants could react. Participants always received an email after a new theme was posted on the website to remind them that they could give reactions. All themes remained posted on the website for the entire

**Table 1**  
Barriers to expressing concerns.

Construct	Online focus groups (N = 16)	Literature
Barriers related to providers' behavior		
My provider does not react with empathy when I express a concern	x	x <sup>a</sup>
My provider does not provide me with the right information to reduce my concerns	x	x <sup>b</sup>
My provider does not explicitly invite me to discuss my concerns	x	x <sup>c</sup>
My provider already gives me a lot of information during a consultation	x	x <sup>d</sup>
My provider gives me the feeling that I am stupid when I express my concerns	x	x <sup>d</sup>
My provider responds defensively when I express my concerns	x	x <sup>d</sup>
Barriers related to the environment of the consultation		
My provider does not have time to listen to my concerns	x	x <sup>d,e</sup>
The consultation before my consultation overran its time	x	
My provider constantly looks at his or her computer screen	x	
There are interns present during the consultation with my provider	x	
My provider is replaced by another provider	x	x <sup>d</sup>
I bring my spouse or family members to a consultation	x	
I could not choose my own provider	x	x <sup>d</sup>
Legitimacy barriers		
I am afraid that I waste my provider's time when I express my concerns	x	x <sup>e</sup>
I feel ashamed when I express my concerns	x	
I am afraid that expressing my concerns will deteriorate the relationship with my provider	x	x <sup>c</sup>

Note: The letters next to the x's refer to the literature about the barriers.

<sup>a</sup> Zimmerman et al. [7].

<sup>b</sup> Henselmans et al. [12].

<sup>c</sup> Okuyama et al. [13].

<sup>d</sup> Sepucha et al. [11].

<sup>e</sup> Street [4].

week so that participants could always go back to a topic and post another reaction or read the reactions of other participants.

### 2.3. Analysis and results

The majority of participants of the OFGs ( $n = 9$ ) were female and the mean age was 56.69 years ( $SD = 9.29$ ). Most of the participants had been diagnosed with urologic cancer ( $n = 7$ ) or breast cancer ( $n = 6$ ). The data of the OFGs were categorized and analyzed using MAXQDA10. As a first step in analyzing the OFG data, we meticulously reviewed and read the reactions of the participants and we then categorized the reactions into the three main categories that were derived from the literature: (1) barriers related to providers' behavior (2) barriers related to the environment where the consultation takes place and (3) legitimacy barriers. Furthermore, we explored whether the examples that participants mentioned within those categories, were in line with examples that were derived from the literature. Table 1 shows an overview of the categories of barriers and the examples that were derived from the literature and the OFGs. In total sixteen barriers were mentioned during the OFGs. Eleven of those sixteen barriers were also mentioned in other literature on patient participation and expressing concerns. Participants endorsed five barriers that were not described in the literature but were elicited by the moderator. Four of the five barriers could be categorized as environmental barriers, namely (1) the consultation before the patient's consultation overran its time, (2) the provider constantly looks at his or her computer screen, (3) there are interns present in the consultation room and (4) there are family members or a spouse present in the consultation room. Furthermore, one new legitimacy barrier was mentioned, namely feeling ashamed to express concerns (see Table 1).

### 2.4. Survey

#### 2.4.1. Participants and procedure

Participants of the online survey were recruited via patient association websites, kanker.nl (a large panel of cancer patients in The Netherlands) and a cancer patient panel of the authors' university. The inclusion criteria were the same as those of the OFGs. In total 236 participants completed the survey.

### 2.5. Measures

First, the survey elicited background characteristics. Sixteen barriers were included in the survey (Table 1). In order to calculate composite scores for the barriers, participants had to report the extent to which they had perceived the barriers during consultations on a 7-point scale (1 = *strongly disagree* to 7 = *strongly agree*) and how often these barriers occurred on a 4-point scale (1 = *never* to 4 = *always*). Last, three subscales were created: providers' behavior barriers (six items,  $\alpha = 0.76$ ), environmental barriers (seven items,  $\alpha = 0.61$ ) and legitimacy barriers (three items,  $\alpha = 0.85$ ).

### 2.6. Analysis

Based on the QUOTE methodology [21] composite scores, i.e., Quality Impact Indices (QIIs), were calculated by multiplying the scores on the perceived barriers with the fraction (100%) of participants that indicated that the barrier occurred often (i.e., perceived barrier score  $\times$  proportion of perceived occurrence of the barrier). In order to calculate the fraction of occurrence, this scale was recoded (0 = *the barrier sometimes occurred* and 1 = *the barrier often occurred*). Thus, when participants had a mean score of 4.80 (on the 7-point perceived barrier scale) on the item "my

provider does not respond with empathy" and this barrier occurred often according to 49.6% of the participants, the QII score would be  $4.80 \times 0.496 = 2.38$ . A QII score of .60 or more indicated a potential barrier and a QII score of 1.75 or more an influential barrier [21,22].

## 3. Results

### 3.1. Participants

Most participants (55.5%) were female. The mean age was 57.23 years ( $SD = 12.25$ ) and the majority were diagnosed with breast cancer (24.0%) or digestive-gastrointestinal cancer (20.9%). Table 2 shows the background characteristics of the participants.

### 3.2. QII scores barriers

Barriers related to providers' behavior had on average the highest mean QII score ( $M = 1.44$ ,  $SD = 0.56$ ) followed by environmental barriers ( $M = 1.33$ ,  $SD = 0.47$ ). According to the mean QII score, legitimacy barriers ( $M = 0.26$ ,  $SD = 0.12$ ) formed hardly any barriers to expressing concerns. Within the subscales several specific influential barriers could be identified. For the barriers that were related to providers' behavior the most influential barriers

**Table 2**  
Background characteristics of 236 participants of the survey.

Characteristic	N	%
Gender		
Male	105	44.5
Female	131	55.5
Age		
M (SD)	57.23 (12.25)	
Range	20–83	
Educational level		
Low	56	23.7
Middle	58	24.6
High	122	51.7
Living arrangements		
Alone	41	17.4
Partner	123	52.1
Partner and child(ren)	56	23.7
Child(ren)	10	4.2
Other	6	2.6
Type of cancer		
Breast	63	24.0
Digestive-intestinal	55	20.9
Haematologic	41	15.6
Gynaecological	4	1.5
Urologic	51	19.4
Lung	4	1.5
Skin	14	5.3
Head and neck	2	0.8
Other	29	11.0
Patients still undergoing treatment		
Yes	112	47.5
No	124	52.5
Treatment		
No treatment	11	2.1
Surgery	163	31.8
Chemotherapy	116	22.7
Radiotherapy	106	20.7
Immunotherapy	13	2.5
Hormone replacement therapy	48	9.4
Chemoradiation	3	0.6
Goal directed therapy	12	2.3
Unknown	1	0.2
Other	39	7.6

were: providers not responding with empathy after a concern was expressed ( $M = 2.38$ ,  $SD = 0.99$ ), providers not inviting the patient explicitly to discuss concerns ( $M = 2.18$ ,  $SD = 1.20$ ) and providers not providing the patient with the right information to reduce concerns ( $M = 2.14$ ,  $SD = 0.97$ ). For barriers related to the environment where the consultation takes place, the most influential barriers were: patients could not choose their own provider ( $M = 2.49$ ,  $SD = 1.35$ ) and the idea that providers do not have time to listen to concerns ( $M = 2.26$ ,  $SD = 0.90$ ). Table 3 shows participants' mean QII scores on the subscales of the barriers and the separate items.

#### 4. Discussion and conclusion

##### 4.1. Discussion

This study aimed to examine patients' barriers to expressing concerns in a new manner by combining patients' reports of perceived barriers with patients' reports of perceived occurrence of the barriers in consultations. The most influential barriers in cancer consultations were related to providers' behavior and the environment where the consultation takes place. These results confirm similar findings from previous studies on perceived barriers to patient participation [4,11–13] and contributes to these studies by showing that patients also report that these barriers occur during cancer consultations. Influential barriers related to providers' behavior were about providers not responding with empathy, providers not explicitly inviting patients to discuss their concerns and providers not providing patients with the right information to reduce concerns. These aspects of providers' behavior have been described in many studies [2,7,10,12,23–27]. The results of this study emphasize that these aspects need to be targeted in interventions aiming to reduce barriers to expressing concerns. For example, such an intervention could consist of communication skills training for providers. The effectiveness of communication skills training on providers' empathetic responses and elicitation of concerns has been shown in an oncology setting [28]. However, the results of the current study show that, according to patients' experiences, these skills are not always used in oncology consultations. Perhaps this is this case because the skills are not always thoroughly trained

with role-plays in which providers actually have to use the skills. It has been argued that role-play with simulated patients might have a greater effect on the attainment of skills than didactic methods [29]. Future research could further explore the longitudinal outcomes of training that include role-play and whether patients perceive less barriers in consultations with providers who have received role-play training.

Influential barriers related to the environment where the consultation takes place were about patients' lack of opportunity to choose their own provider and providers' lack of time to listen to concerns. When patients choose their own provider, there might be more concordance between the provider and the patient. This can influence patients' trust in their provider and possibly their concern expression [30]. However, little research has been conducted in this area. Future studies could further explore whether there are differences in patients who could or could not choose their own provider on different communication outcomes such as expressing concerns. Furthermore, when patients can determine their own consultation length beforehand this can possibly influence their expression of concerns. In a recent study among GPs [31] patients were given the opportunity to determine their own consultation length. This resulted in a more balanced consultation with patients being better able to manage consultation time and feeling more confident to be assertive. Being assertive during a consultation is a form of patient participation just like expressing concerns [4]. Therefore, it is possible that giving patients the opportunity to determine their own consultation length also influences expression of concerns. Future research could further examine this in an oncology setting.

By taking into account patients' reports on the perceived occurrence of barriers during cancer consultations, this study also yields different results than previous studies. For example, Street [4] argued that legitimacy barriers, such as patients' belief that they might waste their providers' time when they express concerns, play a role in expressing concerns. Although patients strongly agreed that they perceive legitimacy barriers, they also indicated that they do not perceive the occurrence of these barriers in consultations. It could be that patients can overcome these barriers themselves during consultations. For example, patients hold the belief that they will waste their provider's time when they

**Table 3**  
Means and standard deviations of perceived barriers and QII means and the percentage of patient reports on barriers that occurred in consultations.

Item description	Perceived barriers <sup>a</sup>	Occurrence in consultations	QII score
	M (SD)	%	M (SD)
<b>Barriers related to providers' behavior</b>			
My provider does not react with empathy when I express a concern	4.80 (2.00)	49.6	1.44 (0.56)
My provider does not provide me with the right information to reduce my concerns	4.54 (2.06)	47.0	2.38 (0.99)
My provider does not explicitly invite me to discuss my concerns	3.62 (1.99)	60.2	2.14 (0.97)
My provider already gives me a lot of information during a consultation	2.94 (1.72)	50.0	2.18 (1.20)
My provider gives me the feeling that I am stupid when I express my concerns	2.94 (1.72)	50.0	1.47 (0.86)
My provider responds defensively when I express my concerns	4.42 (2.31)	4.2	0.19 (0.10)
My provider responds defensively when I express my concerns	4.76 (2.08)	5.9	0.28 (0.12)
<b>Barriers related to the environment of the consultation</b>			
My provider does not have time to listen to my concerns	5.18 (2.06)	43.6	1.33 (0.47)
The consultation before my consultation overran its time	2.88 (1.91)	41.5	2.26 (0.90)
My provider constantly looks at his or her computer screen	2.88 (1.91)	41.5	1.20 (0.79)
There are interns present during the consultation with my provider	4.35 (2.13)	19.1	0.83 (0.41)
My provider is replaced by another provider	2.63 (1.84)	6.8	0.18 (0.13)
I bring my spouse or family members to a consultation	4.17 (1.99)	13.6	0.29 (0.12)
I could not choose my own provider	2.53 (1.86)	29.2	1.79 (1.31)
Legitimacy barriers	3.50 (1.89)	71.2	2.49 (1.35)
I am afraid that I waste my provider's time when I express my concerns			0.26 (0.12)
I feel ashamed when I express my concerns	4.08 (2.24)	7.6	0.31 (0.17)
I am afraid that expressing my concerns will deteriorate the relationship with my provider	4.35 (2.18)	6.8	0.30 (0.15)
	4.00 (2.18)	4.2	0.17 (0.09)

Note:  $N = 236$ .

<sup>a</sup> Perceived barriers were measured on a 7-point scale (1 = strongly disagree to 7 = strongly agree).

express a concern but during a consultation they will express a concern regardless of their belief.

It has to be noted that patients in our sample were highly educated and middle aged. Research indicates that this particular group of patients is most communicative during consultations [32]. There is a possibility that patients who are less educated do experience more legitimacy barriers to expressing concerns compared to patients who are highly educated. Furthermore, barriers related to providers' behavior and the environment where the consultation takes place were identified as influential barriers by a highly-educated sample and could even be more influential in a lower-educated sample. Particularly patients who are less educated might therefore benefit from interventions that empower patients to express concerns such as concern prompt lists [33]. A replication of this study among a different sample (e.g., less educated patients) is warranted to determine whether the same barriers are experienced.

This study relies solely on patients' reports of barriers. It would be interesting to further explore patients' barriers by including observational data. For example, by comparing patients' experiences of barriers that are related to providers' behavior (e.g., not responding with empathy) with a recorded consultation that has been coded with the Verona coding manual or RIAS, which both include the coding of providers' reactions to patients expressing concerns [34,35]. Schinkel et al. [36] have compared patients' perceptions of information provision with observational data and reported low correlations between the two measures, showing that it is difficult to use patients' reports as a proxy for observational data for this particular communication outcome. A comparison study of patients' perceptions and observational data regarding barriers to expressing concerns can provide insight into whether patients' perceptions of barriers are a reliable proxy for observational data.

#### 4.2. Conclusion

The most influential barriers for patients to express concerns during cancer consultations are barriers related to providers' behavior (e.g., providers do not explicitly invite patients to discuss concerns) and the environment where the consultation takes place (e.g., perceived lack of time in a consultation for expressing concerns). In other words, barriers which patients cannot overcome themselves. To reduce these barriers, a collaborative approach from researchers, providers and policy makers is needed.

#### 4.3. Practice implications

The results of this study can be used to develop strategies to overcome barriers to patients expressing concerns during cancer consultations. These strategies should particularly be focused on providers' behavior (e.g., communication skills training) and the environment where the consultation takes place (e.g., policy makers could consider making it possible for patients to choose their own provider).

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#### Conflict of interest statement

None declared.

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