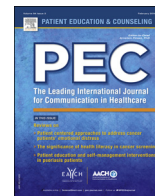




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Research paper

Understanding the interplay of cancer patients' instrumental concerns and emotions

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ABSTRACT

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

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

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

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

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

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1. Introduction

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

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

1.1. Concerns in the current literature

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

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Table 1

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

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

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

1.2. Theoretical framework of concerns

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

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

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