



Communication Study

Advanced cancer patients' and caregivers' use of a Question Prompt List



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ABSTRACT

Objective: The objective of this study was to provide insight into how advanced cancer patients and their caregivers use a Question Prompt List (QPL) during a consultation and for preparation for future consultations.

Methods: Audiotaped consultations and follow-up phone calls of 28 advanced cancer patients were coded and content analyzed. Questions asked and concerns expressed in consultations were coded for initiator, content, inclusion in the QPL and exact wording. Patients' reported and future use of the QPL were coded from the phone calls.

Results: The majority of patients reported that they used the QPL. Questions asked by patients and caregivers predominately coincided with questions from the prognosis section of the QPL. Questions were rarely asked literally from the QPL, instead questions were tailored to patients' own circumstances.

Conclusion: QPLs are useful to stimulate discussion on prognosis among advanced cancer patients and caregivers. Patients tailored questions from the QPL to their own circumstances which may suggest high involvement and engagement. The development of more specific tailored communication interventions for advanced cancer patients is warranted.

Practice implications: Implementation of QPLs in the advanced cancer setting may be beneficial for patients, caregivers and healthcare providers to facilitate discussion of topics such as prognosis.

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1. Introduction

Advanced cancer patients have identified optimal communication with their healthcare provider as one of the most important elements of their end-of-life care [1]. One aspect of optimal communication is the provision of information tailored to patients' and caregivers' needs. Receiving more tailored, and thus more personally relevant information, has been associated with reduced unmet information needs [2], and improved psychological outcomes such as reduced levels of anxiety [3,4]. The provision of

tailored information does not always occur, in part because healthcare providers may not know exactly what information an individual patient requires [5,6]. Patients and caregivers can indicate their information needs through active participation in their medical consultations [7–10]. However, many patients indicate that they do not achieve their preferred level of active participation during their consultations [11].

Participation during consultations can be improved through the provision of a Question Prompt List (QPL) [12–15]. A QPL is an evidence-based list of questions that patients and/or caregivers receive before a consultation. QPL recipients can select the questions that are relevant to them to ask during their consultation [12]. QPLs tested in an advanced cancer care setting have shown promising results regarding patient participation. For example, cancer patients who received a QPL asked twice as many questions than controls, particularly regarding prognosis [7]. Although the

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effectiveness of a QPL on patient participation has been established in a variety of systematic reviews [13–16], little is known about how patients use a QPL.

A few studies shed light on how QPLs are used, including exploration of which particular questions from a QPL were asked during a consultation [17]. However, to our knowledge, no studies have examined how patients word questions from a QPL or of their own devising. Furthermore, the extent to which asked questions coincide with the questions from a QPL has not been explored for advanced cancer patients and their caregivers.

1.1. Question Prompt List

The QPL used in this study was developed for patients with advanced cancer who were still seeing their medical oncologist. It was developed as a component of a more comprehensive intervention delivered by a trained nurse to encourage and facilitate greater discussion of prognosis and end-of-life care.

1.2. Question asking

When patients participate during a consultation they can either ask questions or express concerns [18]. Previous studies have suggested that patients more frequently ask questions than they express concerns [e.g., 18]. Normative or prescriptive theories, such as Argyris and Schön's Model II versus Model I [19], suggest that direct questions are more effective and empowering than expressing indirect concerns. However, in QPL studies these differences have not been explored. Furthermore, there may be gender differences in communication during a consultation. Female patients are often more communicative during a consultation than male patients [20,21]. However, gender differences in QPL studies with advanced cancer patients have not yet been examined and might occur because males and females could be influenced differently by the QPL.

1.3. Topics of question asking

Previous studies concluded that patients who received a QPL discussed more topics that were prompted on the QPL than patients who did not receive a QPL, especially regarding prognosis [e.g., 7]. Furthermore, it could also be useful to explore which topics are addressed during the consultations that do not coincide with topics from the QPL. That information could contribute to the refinement and improvement of QPLs in future research. In addition, caregivers can have many questions that differ from those of patients [22,23]. For example, questions on what kind of support is available to them [7]. Questions regarding these issues were incorporated in the QPL of this study.

1.4. Objectives of the study

On the basis of the above mentioned information, we examine how advanced patients and caregivers use a QPL by exploring (1) usefulness and usage of the QPL, (2) question asking and (3) topics of question asking. Usefulness and usage covers patients' report on whether the QPL was useful, whether they read it, used it and planned to use it again, and whether patients' wording of questions coincided with the wording of questions in the QPL. Question asking covers the frequency of question asking and concern expression in all patients and caregivers and for male and female patients and care givers. Last, topics of question asking covers the topics of the questions asked and concerns expressed by patients and caregivers that coincided with questions from the QPL, the topics of the questions asked and concerns expressed that did not coincide with the QPL and those of the questions patients plan to ask in their next consultation.

2. Methods

2.1. Participants and procedure

This study is a secondary analysis of the intervention arm of a larger RCT [24]. The aim of the overall RCT study was to examine the effectiveness of a nurse delivered intervention that included the QPL [24]. Oncologists from four hospitals in Sydney, Australia identified eligible patients with advanced cancer (of any primary site) for the larger study. Participants were eligible if their oncologist believed they had a life expectancy of between two to twelve months. Participants were excluded if they did not speak English and/or had psychiatric morbidity or cognitive impairment.

Participants completed a baseline questionnaire eliciting demographic and disease information, and were randomized to receive the QPL (Appendix A) in a face-to-face meeting at the hospital with a trained nurse (with their caregiver present if possible), or to receive standard care. The nurses were trained in the delivery of a communication support program facilitating communication about end-of-life issues. During the session, the nurse encouraged participants to consider which QPL questions they would like to ask, discussed barriers and facilitators to asking questions and provided information regarding advance care planning and enduring guardianship. Patients' next oncology consultation was audiotaped. Patients attended a regular follow-up oncology consultation within 2–3 weeks of the face-to-face coaching session. Approximately 2 weeks after the oncology consultation, they received a follow-up phone call (also audiotaped) from the nurse to discuss how the consultation went, whether they asked questions, if they used the QPL and if they planned to use the QPL again. Nurses used a semi-structured intervention guide for these phone calls. All intervention patients, for whom an audiotape of both their oncology consultation and the follow-up nurse phone call was available, were included in this analysis.

2.2. Measures

Demographic and disease details were elicited by a study-developed questionnaire [24,25]. Data on question asking and concern expression were derived from the audio-taped and transcribed oncology consultations. Data on patient reported actual and planned use of the QPL were derived from the nurse follow-up phone calls.

A coding manual was developed to ensure relevant data were captured. Participant statements seeking a response from the oncologist during the consultation were coded as questions or concerns. Questions were defined as a clear need for information or clarification in the form of a question (e.g., What is currently happening with my cancer?). Concerns were defined as statements where a patient indicated a clear need for emotional support in addition to information using phrases such as: "I am worried" (e.g., I am worried about what is currently happening to my cancer). Participants' questions and concerns were examined to establish whether they coincided with the content of questions from the QPL. For example, any question seeking information about the current disease status was coded as coinciding with the QPL question "What is currently happening to my cancer?". Questions coinciding with a QPL question were further coded as having identical or non-identical wording to the QPL question. They were coded as identical only if the exact same wording was used. Two researchers (KB and PB) initially cross-coded two consultations and phone-calls. Disagreements in coding were resolved through discussion and the remaining consultations and phone calls were coded by KB. KB and PB double coded a sample of six consultations and phone-calls to examine inter- and intra-rater reliability.

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