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Communication study

How long do I have? Observational study on communication about life expectancy with advanced cancer patients

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ABSTRACT

Objective: To examine how communication about life expectancy is initiated in consultations about palliative chemotherapy, and what prognostic information is presented.

Methods: Patients with advanced cancer (n = 41) with a median life expectancy <1 year and oncologists (n = 6) and oncologists-in-training (n = 7) meeting with them in consultations (n = 62) to discuss palliative chemotherapy were included. Verbatim transcripts of audio-recorded consultations were analyzed using MAXqda10.

Results: Life expectancy was addressed in 19 of 62 of the consultations. In all cases, patients took the initiative, most often through direct questions. Estimates were provided in 12 consultations in various formats: the likelihood of experiencing a significant event, point estimates or general time scales of “months to years”, often with an emphasis on the “years”. The indeterminacy of estimates was consistently stressed. Also their potential inadequacy was regularly addressed, often by describing beneficial prognostic predictors for the specific patient. Oncologists did not address the reliability or precision of estimates.

Conclusion: Oncologists did not initiate talk about life expectancy, they used different formats, emphasized the positive and stressed unpredictability, yet not ambiguity of estimates.

Practice implications: Prognostic communication should be part of the medical curriculum. Further research should address the effect of different formats of information provision.

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1. Introduction

Patients' awareness of prognosis is considered to be of vital importance for informed decision-making and care planning at the end of life [1–5]. Indeed, studies, mainly from the USA, demonstrate that a realistic sense of prognosis is related to a preference for comfort care and a higher rate of advance care planning [1–3]. However, physicians do not routinely provide life expectancy estimates to their patients with life-limiting disease. For example, of almost 10,000 international physicians, a majority reported that they always inform patients about incurability but only a third

reported that they always inform patients about life expectancy [6]. Similarly, observational studies demonstrate that, although the majority of patients with advanced cancer are informed about incurability, far fewer are informed about life expectancy [7,8].

These findings may reflect the challenges of, and possibly ambivalent attitudes towards, communicating prognostic information. Disclosing life expectancy information often entails delivering “bad news”. Oncologists may fear that explicit information about life expectancy destroys patients' hope [9,10]. Oncologists may also dread the emotions that prognostic information can raise during the consultation and may themselves feel uncomfortable when talking about death [11]. This multifaceted discomfort may not only explain the absence of prognostic communication, but also oncologists' well-documented tendency to provide overly optimistic estimates [12] and their hesitance to use the words “death” or “die” [13,14].

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The lack of disclosure of life expectancy information may also reflect oncologists' difficulties with communicating risk information, including medians, ranges of probabilities, and its inherent uncertainty. This information is challenging to both communicate and to understand. Healthcare providers are generally reluctant to be too definitive in their estimates and stress the importance of incorporating uncertainty in their message [11]. Two sources of uncertainty are particularly pertinent to prognostic estimates in cancer care [15]. The first is the fundamental inability to predict single-event outcomes of individuals (captured by the concept of probability) and the second is the imprecision of prognostic estimates that arises from limitations in risk evidence (captured by the concept of ambiguity). Arguably, physicians should communicate uncertainty arising from both sources when informing patients about prognosis [16]. A recent study in the curative setting showed that uncertainty was disclosed in about half of the consultations about adjuvant treatment for breast cancer, and most often this concerned probability as a source of uncertainty [17]. Few studies examined if and how oncologists do so when discussing life expectancy with their patients with advanced cancer.

Finally, and importantly, oncologists are faced with the challenge of assessing whether the individual patient in front of them wishes to receive prognostic information. Internationally, most people (73%) state they would want to be informed about life expectancy in the scenario of having ≤ 1 year to live [18]. Patients with advanced cancer similarly prefer honest prognostic information [19–21], yet certainly not all wish to receive exact or definitive time-frames [21–28]. Oncologists often have a hard time predicting their patients' information preferences [25,29] and prefer to wait for patients to pose questions [6,11]. Indeed, a recent study on consultations with advanced cancer patients about scan results showed that prognostic talk was usually initiated by the patient [30]. However, some patients prefer their physicians to initiate discussions about prognosis [28] and may believe their doctor to be unable or unwilling to provide prognostic estimates [22]. To our knowledge, few studies have actually observed how oncologists assess and respond to individual patients' needs for life expectancy information in the palliative setting.

The current study examines how medical oncologists who care for patients with incurable cancer communicate about life expectancy in consultations that require decision-making about palliative systemic treatment. We observed by whom and how talk about life expectancy is initiated, and the content and manner in which information is presented, including prognostic uncertainty. We sought to generate insights to increase awareness among oncologists and help identify key problems and potential solutions to improve communication about life expectancy, and to support oncologists in this difficult task.

2. Methods

2.1. Design

Data for this secondary qualitative analysis were derived from a prospective observational study on communication about patients' values and preferences concerning the start or continuation of palliative systemic treatment [31].

2.2. Sample and setting

All medical oncologists, both staff members and oncologists-in-training, from the Department of Medical Oncology of the Academic Medical Center Amsterdam (expert center for upper gastro-intestinal cancer treatment) were eligible. In the

Netherlands, oncologists-in-training work under supervision yet communicate with patients largely independently.

Patients were eligible if they 1) met with the oncologist to discuss either the start of (a new line of) chemotherapy or the continuation of current chemotherapy following a CT/PET-CT scan, 2) had a median life expectancy of <1 year without chemotherapy, and 3) were offered chemotherapy with a median survival benefit of ≤ 6 months. Patients meeting these criteria include patients with metastasized or inoperable tumors of the pancreas, esophagus, stomach, liver, gall bladder, bladder or sarcoma; or patients with any type of cancer who were treated with an additional line of palliative chemotherapy ($>$ first line). We use the term palliative systemic treatment to define systemic treatment with no curative intent.

2.3. Procedure

Eligible patients scheduled for a consultation were consecutively identified by a researcher. Treating oncologists were asked to confirm eligibility (October 2012 to August 2013). A researcher invited patients to participate by telephone. Patients subsequently received written information. A researcher met with the patient in the waiting room to answer questions and obtain written informed consent. The researcher placed an audio-recorder on the table to record the consultation but did not attend the discussion. As we aimed to describe communication about life expectancy when it occurs, and not to draw conclusions about the frequency of occurrence, we aimed to record a second decision making consultation for all participants. This way, we increased the chance of detecting such talk. The second recording was made using the same procedure. The local Medical Ethics Committee provided an exemption for the study to seek formal approval.

2.4. Analysis

Verbatim transcripts of the consultations were read independently by two researchers with a background in psychology (IH) and communication science (JV). All fragments in which either oncologists, patients or companions – implicitly or explicitly – referred to life expectancy were identified and marked using MAXqda10 software [32]. Fragments could encompass multiple turns and could reflect oncologists providing estimates but also, for example, patients requesting estimates, expressing a wish *not* to know estimates, or repeating estimates received from other physicians. Fragments that occurred without the physician in the room were excluded, as were fragments referring to the survival benefit of treatment only. In case of disagreement, consensus was reached through discussion.

The identified fragments were re-read by the psychologist (IH) and a medical oncologist (HvL); IH coded all fragments in MAXqda10. Coding was done mostly inductively (data-driven). HvL supervised the development of the coding tree in the early stages of coding, and checked the final coding of a random one-third of the fragments ($n=7$). Again, consensus was reached through discussion and adjustments were incorporated in the coding of the full set.

We examined *by whom* and *how* life expectancy was raised. First, we registered whether mention of life expectancy was initiated by the patient, the companion or oncologist. In addition, we categorized how this was done. Then, we identified and categorized potential triggers of the fragments by observing where the fragment occurred within the full conversation.

To describe *what* and *how* information was provided, we first looked for oncologists' efforts to tailor information, i.e., oncologists asking questions about the patient's specific information needs (yes/no). Second, we categorized *what* information about life

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