

# Does a prompt list help patients and caregivers to ask questions about cancer prognosis and care?

→ Maria Friedrichsen

Results of a randomised controlled trial show that question prompt lists may benefit communication. However, there are still areas to investigate before prompt lists can be described as evidence-based medicine.

Communication in oncology and palliative care (PC) is a complex area to investigate because of its sensitive nature. An ambitious study from Australia (see opposite) provides useful information on how to enhance patient and caregiver participation during consultations with the physician. The results showed that patients and family members who were randomised to the question prompt list (QPL) group asked twice as many questions as controls, without increasing their level of anxiety. These results are also confirmed by other studies. Glynne-Jones et al.<sup>1</sup> found that 65% of patients with cancer thought the prompt sheet was very helpful. Bruera et al.<sup>2</sup> confirmed that patients with breast cancer scored the prompt sheet as very helpful (8.47 of 10). These studies indi-

cate that a prompt list should be used in clinical practice because a majority of patients, family members and physicians find it user-friendly. Patients become more active and may appreciate assistance in formulating questions about sensitive issues such as prognosis. A pivotal question is whether an increased number of questions during a consultation is a sign of quality or merely quantity.

A lot of different factors influence the patient-physician communication process in cancer care, such as patients' status, gender, education, words chosen, emotional state, and communication style and skill.<sup>3,4,5</sup> Most cancer communication studies have focused on an early-stage cancer setting, but it should be recognised that a lot of changes also occur later during a patient's cancer trajectory, even in the palliative

phase. In the transition to the late palliative phase, several events can arise, such as bad news about prognosis, the development of infections or new symptoms and the onset of existential and social concerns. Patients' needs may fluctuate as a result of these events. Clayton et al. have focused on patients with advanced cancer who had specific problems but were still well enough to visit their physician. The majority of the patients studied by Clayton et al. had an estimated survival of more than 12 weeks. Is it possible to transfer the prompt list concept to palliative home or hospice care where patients are in the terminal phase of their disease course? If the list is modified and significantly shortened, I believe it would be useful in this context.

There is a complex interplay during palliative care between the patient, family

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caregiver, physician and other individuals and factors. A physician who is not interested in talking about existential matters will probably find the prompt list distressing, as he or she will not, or cannot, answer specific questions. Clayton et al. showed that physician endorsement increased the total number of questions asked by patients. Physicians also claimed that patients might not be prepared to discuss certain topics. The result that 62% of the patients disagreed that the questions in the brochure made them anxious might mean that more than one-third of patients did become anxious. This possibility should be questioned.

On the other hand, a prompt list might be a way to legitimise these sensitive questions, help to build relationships and empower both patients and family members. We still do not fully know how patients interpret and recall information, or whether a prompt list will help patients from different cultures.

#### References

1. R Glynn-Jones et al. (2006) Can I look at my list? An evaluation of a 'prompt sheet' within an oncology outpatient clinic. *Clin Oncol (R Coll Radiol)* 18:395–400
2. E Bruera et al. (2003) Breast cancer patient

perception of the helpfulness of a prompt sheet versus a general information sheet during outpatient consultation: a randomized, controlled trial. *J Pain Symptom Manage* 25:412–419

3. MJ Friedrichsen et al. (2002) Cancer patients' interpretations of verbal expressions when given information about ending cancer treatment. *Palliat Med* 16:323–330

4. RL Street Jr et al. (2005) Patient participation in medical consultations: why some patients are more involved than others. *Med Care* 43:960–969

5. RL Street Jr et al. (2007) Physicians' communication and perceptions of patients: is it how they look, how they talk, or is it just the doctor? *Soc Sci Med* 65:586–598

## Synopsis

Josephine M Clayton, Phyllis N Butow, Martin HN Tattersall et al. (2007) **Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care.** *J Clin Oncol* 25:715–723

**Background.** Although communication is a critical aspect of medical care at the end of life, formulating questions about prognosis and end-of-life issues is difficult for some patients unless prompting is given.

**Objective.** To evaluate whether providing a question prompt list (QPL) for patients with advanced cancer and their caregivers improves the usefulness of consultations with a palliative care (PC) physician.

**Design and intervention.** Fifteen PC physicians at nine specialist services in two Australian states were involved in this randomised controlled trial. Between October 2002 and August 2004 consecutive patients with advanced cancer were identified and asked to participate. Most of the participants were recruited from outpatient PC clinics, and enrollment was generally within three consultations following initial contact with the PC physician. The QPL comprised a 16-page A5 booklet containing 12 questions grouped into nine topics for discussion. Following random assignment to receive either a routine consultation, or the QPL 20–30 minutes before the consultation, discussions with the PC physician took place. The discussions were audiotaped and transcribed, and coded to describe physician endorsement, and questions and concerns raised by the patient or caregiver, as well as other topics of discussion. Patients completed questionnaires before, and at 24 hours and three weeks after the consultation.

**Outcome measure.** The primary outcome measure was total number of patient questions during the consultation.

**Results.** There were 174 participants, 92 of whom were randomised to the QPL group. Patients in the QPL group asked 2.3 times more questions than controls (95% CI 1.68–3.18;  $P < 0.0001$ ) and raised more issues (expressed either as a direct request for information or a statement inviting a response) than patients in the control group (17.6 vs 12.7 items; ratio 1.39; 95% CI 1.17–1.64;  $P = 0.0002$ ). Caregivers in the QPL group asked 2.11 times more questions (95% CI 1.4–3.18;  $P = 0.0005$ ) and raised more issues (9.9 vs 6.6; ratio 1.49; 95% CI 1.11–2.00;  $P = 0.008$ ) than caregivers in the control group. Mean duration of the consultation was longer in the QPL group than in the control group (37.8 vs 30.5 min;  $P = 0.002$ ). In comparison with the control group, both caregivers and patients in the QPL group asked more questions about prognosis. Patients in the QPL group had less unmet need for 8 of 11 individual information items, although this outcome was significant only for "what to expect in the future" ( $P = 0.04$ ). There were no overall differences between the groups in anxiety or patient or physician satisfaction following the consultation. The number of questions asked by patients increased with the degree of physician endorsement of the QPL. According to a final questionnaire, 12 of 13 physicians felt the QPL was a useful tool (one physician did not answer those questions).

**Conclusion.** An abbreviated version of the QPL could be useful for facilitating end-of-life discussions with patients who have advanced cancer, and their caregivers.

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