

## Original Article

**Cite this article:** Sato A *et al.* (2022). Assessing the need for a question prompt list that encourages end-of-life discussions between patients with advanced cancer and their physicians: A focus group interview study. *Palliative and Supportive Care* **20**, 564–569. <https://doi.org/10.1017/S1478951521001796>

Received: 10 December 2020

Revised: 1 October 2021

Accepted: 17 October 2021


**Key words:**

Advanced cancer; Communication; Decision-making; End-of-life discussion; Question prompt list

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# Assessing the need for a question prompt list that encourages end-of-life discussions between patients with advanced cancer and their physicians: A focus group interview study

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**Abstract**

**Objective.** Early integration of palliative and cancer care improves the quality of life and is facilitated by discussions about the end of life after cessation of active cancer treatment between patients with advanced cancer and their physicians. However, both patients and physicians find end-of-life discussions challenging. The aim of this study was to assess the need for a question prompt list (QPL) that encourages end-of-life discussions between patients with advanced cancer and their physicians.

**Methods.** Focus group interviews (FGIs) were conducted with 18 participants comprising 5 pancreatic cancer patients, 3 family caregivers, 4 bereaved family members, and 6 physicians. Three themes were discussed: question items that should be included in the QPL that encourages end-of-life discussions with patients, family caregivers, and physicians after cessation of active cancer treatment; when the QPL should be provided; and who should provide the QPL. Each interview was audio-recorded, and content analysis was performed.

**Results.** The following 9 categories, with 57 question items, emerged from the FGIs: (1) preparing for the end of life, (2) treatment decision-making, (3) current and future quality of life, (4) current and future symptom management, (5) information on the transition to palliative care services, (6) coping with cancer, (7) caregivers' role, (8) psychological care, and (9) continuity of cancer care. Participants felt that the physician in charge of the patient's care and other medical staff should provide the QPL early during active cancer treatment.

**Significance of results.** Data were collected to develop a QPL that encourages end-of-life discussions between patients with advanced cancer and their physicians.

**Introduction**

In cancer care, physicians often have to give bad news to patients and caregivers, such as when cancer treatment has failed and cessation of active cancer treatment is advisable. Optimal communication between patients, caregivers, and physicians has been addressed as a core component of cancer care (Steinhauser *et al.*, 2000). Even for patients with newly diagnosed advanced cancer, early integration of palliative care has been shown to improve the quality of life (Temel *et al.*, 2017). The American Society of Clinical Oncology clinical practice guidelines recommend that inpatients and outpatients with advanced cancer should receive dedicated palliative care services early in the disease course, concurrent with active treatment (Ferrell *et al.*, 2017). However, both patients and physicians find discussions about prognosis and end-of-life issues to be challenging (Kaplan *et al.*, 1996). Our previous interview study at an outpatient clinic found that, when receiving bad news, patients preferred physicians to give them opportunities to ask questions and wanted to be told about frequently asked questions from other patients in advance (Fujimori *et al.*, 2005).

Butow *et al.* developed a question prompt list (QPL) containing frequently asked questions from cancer patients (Butow *et al.*, 1994). Patients refer to the QPL beforehand and then ask the physician questions at the consultation. In subsequent work, various types of QPLs have been developed and reported to be useful and effective in increasing patients' question-asking behaviors (Bruera *et al.*, 2003; Clayton *et al.*, 2003). We also conducted a randomized controlled trial and reported the usefulness of a QPL for patients with advanced cancer when

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making an initial treatment decision (Shirai et al., 2012). In systematic reviews, QPLs have been shown to have a significant effect on facilitating discussions on specific topics, such as prognosis (Brandes et al., 2015; Sansoni et al., 2015). Brandes et al. (2014) suggested that consultations in the setting of advanced cancer could be tailored to the specific information needs of patients and caregivers. Rodenbach et al. (2017) suggested that a combined QPL and coaching intervention was effective in helping patients and caregivers discuss topics of concern, including prognosis.

Cessation of cancer treatment and end-of-life issues mark a major turning point and necessitate communication that is difficult for both patients and physicians because of the complex decision-making required (Buckman, 1984). Previous studies showed that patients with advanced cancer, who need to discuss anticancer treatment cessation and transition to palliative care, preferred to have end-of-life discussions (Clayton et al., 2003; Walczak et al., 2013; Umezawa et al., 2015). Their preferences included discussing both their current condition and the future disease course. Furthermore, patients with rapidly progressing cancer, such as pancreatic cancer, were more likely to prefer that their physician carefully tell them to prepare mentally and to maintain hope in addition to providing the prognosis. It is likely that pancreatic cancer patients, family caregivers, bereaved family members, and physicians have extensive experience with end-of-life discussions after the cessation of active cancer treatment. Therefore, the aim of this study was to assess the need for a QPL that encourages end-of-life discussions between patients with advanced cancer and their physicians.

## Methods

### Participants and procedure

We recruited pancreatic cancer patients, family caregivers, and bereaved family members who participate in a pancreatic cancer patient support group (NPO PanCAN Japan) and physicians working in the Department of Hepatobiliary and Pancreatic Oncology at the National Cancer Center (NCC) Hospital. Written informed consent was obtained from all participants. Eligibility criteria were as follows: patients with rapidly progressing pancreatic cancer who received active cancer treatment; family caregivers who provided care to a family member with rapidly progressing cancer; bereaved family members who experienced the death of a family member with rapidly progressing cancer; and physicians who regularly treating patients with cancer. Participants were excluded if they were not able to understand Japanese or if they were too ill.

### Study design

Focus group interviews (FGIs) and content analysis were performed.

### Procedure

This study was approved by the National Cancer Center Institutional Review Board, Japan. We conducted four FGIs and one individual interview. Each interview took about 180 min. One FGI with patients who had pancreatic cancer and two FGIs with family caregivers and bereaved family members were conducted at the office of NPO PanCAN Japan. One FGI with physicians and one individual interview with a physician were conducted at the NCC Hospital. All FGIs were conducted by a clinical psychologist with experience conducting interviews

(M.F.). At the start of each interview, the interviewer (M.F.) introduced herself and explained the purpose, background, methods, and schedule of the FGI. Based on an interview guide (Supplementary material), participants were asked to discuss three themes: the question items that should be included in the QPL that encourages the end-of-life discussions with patients, family caregivers, and physicians after cessation of active cancer treatment; when the QPL should be provided; and who should provide the QPL booklet. The participants engaged in an open discussion guided by the interviewer. When necessary, the interviewer asked further questions to clarify replies. All interviews were recorded using digital voice recorders.

## Analysis

All recorded dialogue was transcribed, and the transcribed dialogue was independently divided into basic blocks, each of which was a single utterance that did not include multiple different meanings in the sentence. Utterances of similar content were organized and summarized into categories, and the number of utterances was counted for each. If a person mentioned the same thing multiple times, it was counted once. Not all participants commented on all the questions. Three cancer specialists (Y.S., S.U., and M.M.) independently coded the basic blocks so that the same meaning was assigned to one attribute. When opinions about the coding differed, discussions were held until consensus was reached. The attributes of coding integrity were checked throughout the coding process (Pope and Mays, 1999; Colorafi and Evans, 2016).

## Results

### Participant characteristics

We recruited 21 people who participated in NPO PanCAN Japan, 10 members of NPO PanCAN Japan living in the suburbs of Tokyo, and 6 physicians who treated patients with cancer. Eighteen of these 37 agreed to participate (response rate 48.6%). The 18 participants comprised 5 patients with pancreatic cancer (including 1 who had just stopped active cancer treatment; 3 in their 50s, 1 in their 60s, and 1 in their 70s), 3 family caregivers (1 spouse and 2 daughters) of patients (2 with biliary tract cancer and 1 with pancreatic cancer), 4 bereaved family members (2 spouses, 1 son, and 1 brother) of patients (1 with biliary tract cancer and 3 with pancreatic cancer), and 6 physicians. Five patients, 1 family caregiver, 2 bereaved family members, and 1 physician were over the age of 50 years. There were 13 men (3 patients, 1 family caregiver, 3 bereaved family members, and 6 physicians) and 5 women (2 patients, 2 family caregivers, and 1 bereaved family member). Two patients had recurrence/metastasis.

### Questions for the QPL

In total, 57 question items in 9 categories emerged from 150 utterances regarding question items required for the QPL. The nine categories were (1) preparing for the end of life, (2) treatment decision-making, (3) current and future quality of life, (4) current and future symptom management, (5) information on the transition to palliative care services, (6) coping with cancer, (7) caregivers' role, (8) psychological care, and (9) continuity of cancer care. The 57 question items in these 9 categories are shown in Table 1.

**Table 1.** Participants' preferences on question items for the QPL

Factors	Question items	<i>n</i>	Cancer patients	Family caregivers	Bereaved family members	Physicians
(1) Preparing for the end of life		48	1	3	6	38
	What can I expect in my last days of life?	11		1	1	9
	Are there any services or resources that would be useful for me or my caregivers (such as financial, social, and healthcare services)?	10			1	9
	What is likely to happen at the very end?	7			1	6
	Is it possible to know my life expectancy?	5			1	4
	Is it possible to give a time frame for when treatment will fail?	4			2	2
	What will happen when treatment fails?	3	1			2
	What should I do if I cannot go to the hospital?	3				3
	Can I get information about the place for care at the end of life?	1				1
	Can I be contacted if a new treatment is developed?	1				1
	What should I do if I am too unwell?	1		1		
	Can I get information about cardiopulmonary resuscitation?	1				1
	Can I ask how to use my medicine?	1		1		
(2) Treatment decision-making		29	5	2	7	15
	Can I talk about my concerns about treatment?	8	1			7
	What can I expect when treatment fails?	6	3			3
	What is the purpose of treatment?	4			2	2
	Can I take folk medicine or complementary and alternative medicine during treatment?	4		1	3	
	What treatment options are available for me when my current treatment fails?	2	1	1		
	What are the pros and cons of treatment?	2			1	1
	Can you tell me about the newly developed treatment?	1				1
	Can you tell me about cancer immunotherapy?	1			1	
	What will happen if I decide not to have treatment?	1				1
(3) Current and future quality of life		28	6	2	1	19
	Can I talk about my lifestyle?	4	1			3
	Is it OK for me to travel?	4				4
	What kind of food should I eat?	3		1	1	1
	Should I consider preparing my will?	3	2	1		
	How long can I work?	2				2
	Can I talk about my needs for living?	2				2
	Is it better to put my affairs in order?	2				2
	Can I talk about a farewell note?	2	2			
	Is it OK for me to smoke?	1				1
	Is it OK for me to drink?	1				1
	Can I talk about financial matters?	1				1
	Can I talk about my sense of values?	1				1
	Can you give me tips on how to take medicine?	1	1			
	Can I talk about nursing care insurance?	1				1
(4) Current and future symptom management		20	1	2	3	14
	What treatments can help manage my symptoms, such as pain, nausea, fatigue, depression, insomnia, and anxiety?	9	1		1	7

(Continued)

Table 1. (Continued.)

Factors	Question items	<i>n</i>	Cancer patients	Family caregivers	Bereaved family members	Physicians
	What is currently happening with my cancer?	4			2	2
	What will happen in the future with my cancer?	3		1		2
	What can I do if my symptoms worsen?	2				2
	Will my caregiver know what to do for worsening symptoms?	1		1		
	What are the common side effects of treatment?	1				1
(5) Information on the transition to palliative care services		7			4	3
	What information is available about palliative care?	4			2	2
	Can you tell me about the difference between hospice and palliative care in a hospital?	2			2	
	Can I talk about my concerns about the transition to the palliative care?	1				1
(6) Coping with cancer		6		1		5
	Was there a way to detect my cancer earlier?	2				2
	Do my family members have a higher risk of getting cancer?	2				2
	Why did I have a recurrence of cancer?	1		1		
	What caused my cancer?	1				1
(7) Caregivers' role		5			2	3
	What kind of support can my caregivers provide?	1				1
	Can my caregivers talk about their preferences for care?	1			1	
	Who can my caregivers talk to if they have worries or concerns?	1				1
	Can you tell me about end-of-life care?	1			1	
	Can you tell me about home medical care skills?	1				1
(8) Psychological care		5			3	2
	Who can take care of my mental health?	3			2	1
	Can I talk about my anxiety?	1			1	
	Can you tell me about mental care that I can receive?	1				1
(9) Continuity of cancer care		2	2			
	Which physician will treat me after cessation of active treatment?	2	2			
Total		150	15	10	26	99

### When the QPL should be provided?

Five opinions on when the QPL should be provided were compiled from 14 utterances: (1) during first-line treatment, (2) during second-line treatment, (3) between first-line and second-line treatments, (4) before first-line treatment, and (5) during the transition from second-line treatment to palliative care services (Table 2).

### Who should provide the QPL?

Seven opinions on who should provide the QPL were compiled from 17 utterances: (1) the physician in charge of the patient's care, (2) a nurse (certified nurse specialist), (3) medical staff who is not a physician, (4) medical staff who is not a nurse, (5) medical staff (not specified), (6) a nurse after a physician briefly explains the QPL, and (7) a psychologist (Table 3).

### Discussion

In this study, we conducted FGIs with patients, family caregivers, bereaved family members, and physicians and collected basic data in order to assess the need for a QPL that encourages end-of-life discussions between patients with advanced cancer and their physicians. From the results, 57 question items emerged in 9 categories related to physical and psychological symptoms, treatment and care for symptoms, preparations for the end of life, and continuity of cancer care. These results were generally consistent with those of previous studies (Walczak et al., 2013; Umezawa et al., 2015). Participants responded that a QPL would help patients remember the questions they wished to ask and would prompt them to consider issues of which they were previously unaware.

In this study, anxiety and concern about cancer progression and future treatment, knowledge for when treatment fails, symptom management, and life expectancy emerged as question items to be included in the QPL. Most of the utterances about

**Table 2.** When the QPL should be provided to patients with advanced cancer?

	<i>n</i>	Cancer patients	Family caregivers	Bereaved family members	Physicians
(1) During first-line treatment	5		2		3
(2) During second-line treatment	3				3
(3) Between first-line and second-line treatments	3			3	
(4) Before first-line treatment	2	1			1
(5) During the transition from second-line treatment to palliative care services	1	1			
Total	14	2	2	3	7

**Table 3.** Who should provide the QPL to patients with advanced cancer?

	<i>n</i>	Cancer patients	Family caregivers	Bereaved family members	Physicians
(1) Physician in charge of the patient's care	8	2		2	4
(2) Nurse (certified nurse specialist)	2		2		
(3) Medical staff who is not a physician	2	1			1
(4) Medical staff who is not a nurse	2				2
(5) Medical staff (not specified)	1			1	
(6) Nurse after a physician briefly explains the QPL	1				1
(7) Psychologist	1		1		
Total	17	3	3	3	8

end-of-life preparations were from physicians, followed by bereaved family members; only one utterance was from a patient. Patients experience high levels of anxiety and thus may be more reluctant to have end-of-life discussions than their physician and family members (El-Jawahri et al., 2014). Death-related topics can elicit psychologically strong emotions in patients and physicians, and may be unconsciously avoided (Stiefel et al., 2019). Since all of the patient study participants were pancreatic cancer patients with poor prognoses, they may have been more resistant to the topic of end-of life due to their imminent death. In contrast, previous studies have found that patients with advanced cancer prefer to have discussions with their physician about their physical and psychological status, their symptoms and symptom management, and the transition to palliative care (Clayton et al., 2003; Walczak et al., 2013; Yeh et al., 2014; Umezawa et al., 2015; Bouleuc et al., 2021). Furthermore, our previous study found that patient preferences regarding the communication of bad news by physicians vary according to demographic and psychological variables but not according to disease variables, whereas preferences for discussing life expectancy differed according to the individual (Fujimori and Uchitomi, 2009; Umezawa et al., 2015). The small number of patients with pancreatic cancer who participated in these studies did not allow us to conclude that there are no disease differences in patient preferences regarding the communication of bad news by physicians; however, it suggests that patients' individual preferences need to be taken into account when engaging in end-of life discussions. Therefore, it might be necessary to consider patients' individual preferences when engaging in end-of life discussions.

By using the QPL, healthcare providers could easily understand these individual differences.

Consistent with a previous study by Walczak et al. (2013), participants preferred end-of-life discussions that included advance care planning (ACP). The QPL for end-of-life discussions developed by Walczak et al. (2013) listed questions about ACP, preferences for future care, and helping patients and their caregivers to maintain autonomy and authority in treatment decisions once the patients have become incapacitated. In 2007, the Japanese Ministry of Health, Labour and Welfare (2007) developed guidelines for the decision-making process in end-of-life medical care to promote patient's self-determination at the end of life. And in 2018, the ministry issued revised guidelines that advocated ACP (Ministry of Health, Labour and Welfare, 2018). ACP is a process involving discussions between a patient, caregivers, and health providers about future medical and long-term care. In practice, ACP requires sufficient discussion among patients, caregivers, and health providers.

The participants preferred that the physician in charge of a patient's care and other healthcare professionals provide the QPL. In terms of when to provide the QPL, "during first-line treatment" and "during second-line treatment" were preferred. Chemotherapy treatment options for pancreatic cancer are currently limited, so it is necessary for patients, family caregivers, and physicians to hold discussions in the context of early integration of cancer treatment and palliative care. The American Society of Clinical Oncology recommends discussing prognosis and treatment options from the start of treatment and clarifying patients' wishes for the end of life (Peppercorn et al., 2011).

This study has three main limitations. First, the sample size was small, with only 18 participants comprising patients with pancreatic cancer, caregivers, bereaved family members, and hepatobiliary-pancreatic oncologists. However, various interviews



were carried out until saturation was reached and both the quality and quantity of the interviews were sufficient. Second, all of the patients in this study had pancreatic cancer and were relatively young, so caution should be exercised when generalizing the results. Third, the physicians provided more utterances compared with the patients. Individual differences in preferences for end-of-life discussions were observed between patients and physicians.

Using the group interview data, in future work we will develop a QPL and assess each item. In addition, we are planning a study to evaluate the efficacy of an integrated communication support program including QPL for patients with rapidly progressing advanced cancer and their caregivers. In conclusion, data were collected to develop a QPL that encourages end-of-life discussions between patients with advanced cancer and their physicians.

**Supplementary material.** The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951521001796>.

**Acknowledgments.** The authors would like to thank the patients and healthcare professionals who gave their time and shared their experiences during this study.

**Funding.** This study is supported by a Grant-in-Aid for Japan Agency for Medical Research and Development (no. JP 17ck0106237h0001), Project Mirai Cancer Research Grants, and the Grant-in-Aid from Japanese Ministry of Health Labor and Welfare (grant no. JPMH19EA1017).

**Conflict of interest.** The authors declare that there is no conflict of interest in this study.

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