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Original Article

A Question Prompt List for Advanced Cancer Patients Promoting Advance Care Planning: A French Randomized Trial



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Abstract

Context. Advance care planning is essential to enable informed medical decisions to be made and to reduce aggressiveness in end-of-life (EOL) care.

Objectives. This study aimed to explore whether a question prompt list (QPL) adapted to French language and culture could promote discussions, particularly on prognosis and EOL issues, among advanced cancer patients attending outpatient palliative care (PC) consultations.

Methods. In this multicenter randomized study, patients assigned to the intervention arm received a QPL to help them prepare for the next consultation one month later. The main inclusion criteria were advanced cancer patients referred to the PC team with an estimated life expectancy of less than one year. The primary endpoint was the number of questions raised, globally and by topic. The secondary objectives were the impact of the QPL on psychological symptoms, quality of life, satisfaction with care, and coping styles at two months.

Results. Patients ($n = 71$) in the QPL arm asked more questions (mean 21.8 vs. 18.2, $P = 0.03$) than patients in the control arm ($n = 71$), particularly on PC (5.6 vs. 3.7, $P = 0.012$) and EOL issues (2.2 vs. 1, $P = 0.018$) but not on prognosis (4.3 vs. 3.6, not specified). At two months, there was no change in anxiety, depression, or quality of life in either arm; patient satisfaction with doctors' technical skills was scored higher ($P = 0.024$), and avoidance coping responses were less frequent (self-distraction, $P = 0.015$; behavioral disengagement, $P = 0.025$) in the QPL arm.

Conclusion. Questions on PC and EOL issues in outpatient PC consultations were more frequent, and patient satisfaction was better when a QPL was made available before the consultation. *J Pain Symptom Manage* 2021;61:331–341. © 2020 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Early palliative care, advanced cancer patients, end-of-life discussions, question prompt list, communication

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Key Message

This multicenter randomized study assessed a question prompt list for advanced cancer patients attending French outpatient palliative care consultations. The results showed that it was an effective tool to foster patient questioning, primarily on supportive care and palliative care and end-of-life issues, without altering their quality of life or psychological status.

Introduction

The American Society of Clinical Oncology guidelines on patient-clinician communication and early palliative care (PC) include recommendations for discussing the illness and prognosis and for clarification of the aims of treatments early in the course of incurable illnesses.^{1,2} The most difficult interviews in PC focus on end-of-life (EOL) issues, also called advance care planning, including discussions about prognosis, treatment preferences, and priorities for the place of care provision and place of death.^{3,4} Inaccurate perceptions of the prognosis or the aims of care is frequently observed, and most patients with life-threatening illnesses report never having discussed EOL issues with clinicians.^{5–8} For physicians, EOL discussions require them to engage in emotional and upsetting discussions, manage uncertainty, and at the same time ensure that patients fully grasp the meaning of the medical information.^{9,10} On the patients' side, the amount of information needed varies, and some patients and/or families are reluctant to talk about their EOL period.^{11–13} Patients' emotions can inhibit discussions and their understanding, and anxiety and denial are two critical patient-related factors that regularly contribute to the challenges of discussing the aims of care in the setting of serious illness.¹⁴ Thus, broaching advance care planning at the right time is critical, and the patients' readiness to discuss such issues should be assessed by clinicians.¹⁵ The perception of symptom aggravation, the disclosure of treatment failure, or referral to PC can all open the way to EOL discussions.¹⁶

A higher level of information among patients is associated with health-related quality of life (QoL) as well as with lower psychological distress such as depression and anxiety.^{17–19} Interventions to improve immediate patient-physician communication have included question prompt lists (QPLs).²⁰ QPLs are thematically grouped and evidence-based lists of suggested questions patients can ask, showing them the range of possible topics to be discussed and assisting them with putting questions into words.^{21,22} This approach encourages active participation by patients in the search for medical information and highlights clinicians' willingness to address all topics. Results from

previous studies have evidenced the effectiveness of QPL interventions in enhancing patient participation, with an increase in the number of questions asked and in information recalled.^{23,24} A targeted QPL for clinical trials showed that participants mostly wanted information and asked questions about the personal benefits of a trial.^{25,26} In a recent study, patients using a QPL during consultation before beginning radiotherapy treatment reported significantly higher inter-activeness.²⁷ A QPL was also used in a more comprehensive communication program to enhance patient involvement in shared decision-making processes about palliative chemotherapy.²⁸ QPL is also one of the interventions previously described to encourage patients with cancer to envisage advance care planning.²⁹ In the PC setting, previous studies have shown that QPLs can increase the number of questions raised by patients on prognosis, EOL care, and spirituality, without any negative effects on QoL or on psychological distress.^{30–32} The specificity of our study is that it is the first to develop a QPL that is not in English. In the first part of our research, we translated and culturally adapted an American/Australian QPL to the French PC context.^{33,34} The hypothesis of the present study is that use of this QPL will highlight the needs of patients for information on PC, whereas until now, the information provided has been based on clinicians' representations of patient expectations, possibly at odds with the expectations of the patients themselves. The objective of the present study was to determine whether a French-adapted QPL could help patients ask questions about PC and promote EOL discussions among advanced cancer patients attending outpatient PC consultations.

Materials and Methods

Setting

Three French comprehensive cancer centers (Curie Institute in Paris, Léon Bérard Cancer center in Lyon, and Polyclinique de l'Ormeau in Tarbes) participated in the study. Each of them has a PC team integrated into overall cancer care. Referral to the PC team is triggered by oncologists for advanced cancer patients, according to usual criteria: physical symptoms and/or psychosocial distress. Seven PC physicians participated in the study. All patients received best PC following American Society of Clinical Oncology recommendations.

Design

This trial was a prospective, multicenter, randomized 1:1, and parallel group trial. The main inclusion criteria were the following: adult patients with locally

advanced or metastatic nonhaematological cancer (whether they were still receiving anticancer treatments), referred for the first time to the PC team, with a life expectancy estimated at less than one year, able to understand French, and to complete questionnaires. The exclusion criteria were current psychiatric disorders and patients with a life expectancy of less than two months. Randomization was centralized, with stratification on the center. The registered trial number is NCT02854293.

Intervention Arm

The QPL used in the study was adapted from an American and Australian booklet developed in the PC setting.³⁰ We first translated and refined it to French language and culture, on the basis of results from a focus group with specialized health professionals and individual semistructured interviews with advanced cancer patients in the setting of a previously published pilot testing study.³³ Addressing prognosis and EOL issues in the context of PC in France has been highlighted as particularly difficult. The clinicians involved in the adaptation found it disturbing to leave the term palliative care in the brochure title and chapter, and it was replaced by supportive and palliative care. We also had to remove some questions perceived by patients as disturbing, like *What are the worst days going to be like?*, *How can one know when one is going to die*, or *What can happen when the patient is in a coma* in the caregiver section. A question about the cost of care was not considered relevant in the context of French health system cover.

The French version of the QPL is a 16-page A5 booklet that contains 112 questions structured into 11 sections exploring the following 10 domains: the supportive care and PC team, symptoms, anticancer treatments, symptom management, lifestyle and QoL, expectations and prognosis, finding support, health care quality, carer support, EOL issues, and other questions.

Procedure

Patients were invited to enroll at the time of their first consultation (C1) with the PC team, and they completed questionnaires (baseline data) after providing written informed consent. Patients randomly allocated to the QPL arm received a booklet, with the instruction to read it at home whenever they wished, alone or with a relative, and to select items they would like to ask. The next consultation planned (C2) was audiorecorded. In the QPL arm, physicians had to endorse the use of the QPL with a standardized script, repeated once: Perhaps you remember I gave you a QPL at your last consultation. Have you prepared any questions? If so, I would like

you to ask them and I will now answer as best I can. Patients in the control arm were also systematically invited to ask any questions they wished. Patients were then seen at a third planned consultation (C3) and asked to complete questionnaires (data at two months). The three consultations were one month apart. PC physicians gave the questionnaires to the patients at the end of each consultation. Patients had the choice of completing them immediately or at home in the course of the next week. The same PC physician took on all the consultations for each patient throughout the study. An average of 20 patients was seen by each of the seven physicians who participated in the study.

Primary Endpoint and Coding of Audiotaped Consultations

The primary outcome measure was the total number of questions raised by patients during the second consultation (C2), comparing the two arms, globally and on the particular topics of prognosis and EOL issues. All transcripts were analyzed by two psychologists applying a list of codes relating to questions stemming from the QPL booklet themes. The coding lists were initially established independently by the two psychologists and then reconciled into one version after discussion with the research team. The first 25 transcripts were double-coded blind by the two psychologists. Coding discrepancies were discussed by the research team until agreement on the interpretation of the question or code was established. Individual coding was pursued after reaching consistent interpretations of the codes (overall kappa was 0.84, indicating excellent intercoder agreement).³⁵ Tearfulness on the part of patients during the PC consultation was also coded, and the consultation duration was measured.

Secondary Endpoints

QoL, psychological symptoms, and satisfaction were analyzed to check that the QPL was not deleterious for the patients and to determine coping styles to identify any potential influence of the QPL. QoL was assessed using McGill's scale, psychological distress using the Hospital Anxiety and Depression Scale (HADS), and satisfaction with care using the physicians' subscale of the European Organization for Research and Treatment of Cancer in-patient satisfaction questionnaire (European Organization for Research and Treatment of Cancer IN-PATSAT32), which addresses physicians' technical and interpersonal skills, information, and availability.^{36–38} Coping style was measured with the Brief-COPE, which contains 14 two-item subscales assessing active coping, planning, positive reframing, acceptance, humor, religion, use of emotional support, use of instrumental support, self-distraction,

denial, venting, substance use, behavioral disengagement, and self-blame.³⁹ The McGill, HADS, and PAT-SAT32 questionnaires were completed at C1 and C3. After the second consultation (C2), patients in the intervention arm completed a specific questionnaire about the QPL collecting the number of perusals, comprehensibility, helpfulness, and satisfaction, using a five-point Likert scale.

Sample Size Calculation

On the basis of the Australian study, the hypothesis was that an average of five questions would be asked about prognosis and EOL issues in the intervention arm against 2.5 in the control arm (SD 4.5).³⁰ According to this hypothesis, 138 patients (69 in each arm) were required in this study with a two-sided Type I error of 5% and a power of 90%, with no planned attrition rate.

Statistical Analyses

The comparison of the number of questions asked and the concerns expressed by the patients between the two arms was conducted in intent to treat using variance analysis, with a 5% limit of statistical significance. Missing values for the primary criterion were replaced by the mean for the primary criterion estimated on the available data from the control arm population (conservative strategy). For the sensitivity analysis, the missing values for the primary endpoint were replaced by the mean for the primary criterion estimated on the available data from the intervention arm population, using multiple imputations. Statistical data were presented in the form of percentages for categorical variables and means and SDs or medians and range for continuous variables. Categorical variables were compared using the Chi-squared or Fisher's test and continuous variables using Student's t-test or a nonparametric test (Wilcoxon test).

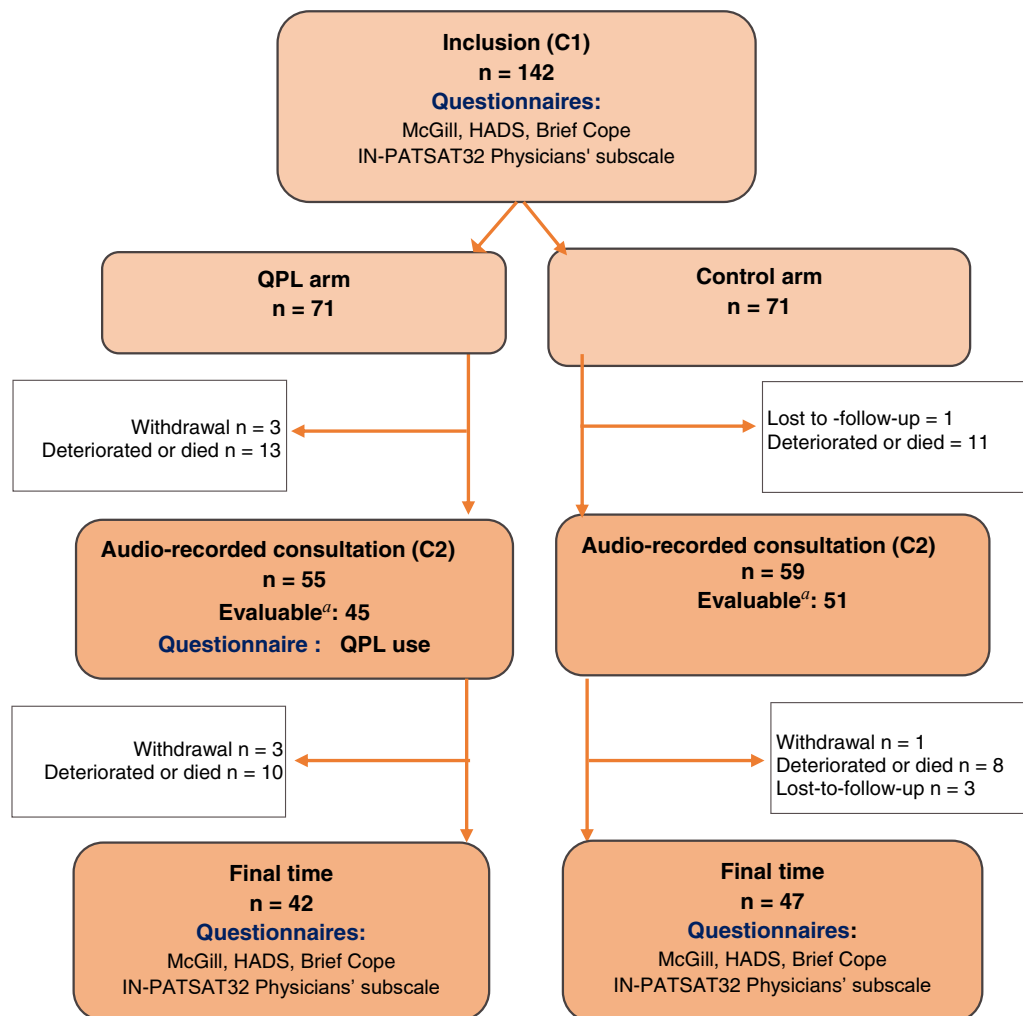


Fig. 1. Consort flow diagram. ^aTechnical problem that made the audiotapes inaudible. McGill = McGill Quality of Life questionnaire; HADS = Hospital Anxiety and Depression Scale; IN-PATSAT32 = in-patient satisfaction with cancer care questionnaire; QPL = question prompt list.

Univariate associations between sociodemographic factors (age, gender, educational level, and having children younger than 18 years) or clinical factors (performance status, painkiller treatment, disease status, and ongoing chemotherapy) and the questions asked were analyzed using variance analysis. Multivariate analyses using a stepwise linear regression model with random effect were conducted to study the impact of the QPL adjusted on the main clinical parameters, that is, the parameters with a P -value <0.10 in univariate analysis. The added value of each variable to the regression model was determined using a likelihood ratio test with a significance level of 5%.

Secondary endpoints were analyzed in the per-protocol population (patients with missing values for the secondary criteria of interest were excluded from the analysis). Scores for all questionnaires were calculated according to the instructions in related articles and the authors and were compared between the two arms using variance analysis at baseline and two months. To assess the potential time effect and time \times intervention interaction, a mixed robust analysis of variance was conducted to take into account the absence of normality of the data (the model is performed among the patients with data available at both time). Overall survival was estimated using Kaplan-Meier's method.

The data were managed according to good clinical practice guidelines, using data managers and software dedicated to data management (MACRO, Version 3; Elsevier, Amsterdam, Netherlands). All analyses were performed using R software, Version 3.4 (R Foundation for Statistical Computing, Vienna, Austria).⁴⁰

Results

Participant Flow and Patient Characteristics

From May 2016 to June 2017, 142 eligible patients were randomly selected, 71 in the QPL arm and 71 in the control arm. Fig. 1 shows the flow diagram. Because of early withdrawal, as certain patients deteriorated or died or were lost to follow-up, only 55 patients in the QPL arm and 59 patients in the control arm were able to attend the second audiorecorded consultation. In addition to this high attrition rate, we encountered a technical problem whereby some audiotapes were almost inaudible, and only 45 patients in the QPL arm and 51 in the control arm could be evaluated.

There was no difference in patient characteristics and baseline scores on the different questionnaires between the two arms (Table 1). In the QPL arm and control arm, respectively, the median age was

59.8 (range 32–88) years and 59.4 (range 28–93) years; female gender was 78.9% and 74.6%; the most frequent cancer localization was breast for 49.3% and 47.9%; the proportion of patients still undergoing anticancer treatment was 94.4% and 97.2%. The median survival time was five months.

Table 1
Patients' Baseline Clinical Characteristics

Patients' Baseline Clinical Characteristics	QPL; N = 71 (%)	Control; N = 71 (%)
Age (minimum–maximum)	59.8 (32–88)	59.4 (28–92)
Gender (female)	56 (78.9)	53 (74.6)
Living with a partner	33 (50.8)	43 (63.2)
Dependent children	10 (17.9)	6 (10.0)
Higher education	31 (47.0)	27 (39.7)
Religious practice	5 (7.8)	5 (7.4)
ECOG scale		
1	16 (22.5)	16 (22.9)
2	39 (55.0)	36 (51.4)
3	16 (22.5)	17 (24.3)
Painkillers		
Step 1	14 (25.9)	12 (21.4)
Step 2	17 (31.5)	17 (30.4)
Step 3	23 (42.6)	27 (48.2)
LDH rate (IU/L)	482 (545)	502 (376)
Albuminemia (g/L)	33.9 (5.5)	33.2 (6.8)
Primary site		
Breast cancer	35 (49.3)	34 (47.9)
Gastrointestinal cancer	13 (18.3)	9 (12.7)
Lung cancer	8 (11.3)	6 (8.5)
Others	15 (21.1)	22 (30.9)
Metastatic sites		
1 or 2	37 (52.8)	43 (60.6)
>2	33 (47.2)	28 (39.4)
Time between (yrs)		
Diagnosis and inclusion	5.9 (6.9)	6.4 (6.5)
Diagnosis and first metastasis	3.0 (4.8)	3.5 (4.5)
Palliative chemotherapy	67 (94.4)	69 (97.2)
Ongoing chemotherapy	48 (71.6)	49 (71.0)
Chemotherapy lines (numbers)		
Breast cancer	5.2 (3.2)	4.0 (2.6)
Others	2.2 (2.1)	2.4 (2.1)
Chemotherapy lines (numbers in the last year)		
Breast cancer	2.6 (1.1)	2.2 (1.0)
Others	1.9 (1.0)	1.8 (1.0)
HADS anxiety		
No disorder (score <8)	32 (47.7)	36 (52.2)
Suspected disorder (score 8–10)	17 (25.4)	19 (27.5)
Severe anxiety disorder (score >10)	18 (26.9)	14 (20.3)
HADS depression		
No disorder (score <8)	33 (49.3)	42 (61.8)
Suspected disorder (score 8–10)	22 (32.8)	11 (16.2)
Severe depression syndrome (score >10)	12 (17.9)	15 (22.0)
McGill QoL		
Physical symptoms	3.8 (1.6)	3.4 (1.6)
Psychological symptoms	5.6 (2.1)	4.8 (2.4)
Psychological symptoms	6.5 (2.2)	6.7 (2.2)
Spiritual well-being	6.1 (1.7)	6.0 (1.7)
Support	8.3 (1.9)	8.7 (1.6)

QPL = question prompt list; ECOG = Eastern Cooperative Oncology Group; LDH = lactate dehydrogenase; HADS = Hospital Anxiety and Depression Scale; McGill QoL = McGill Quality of Life questionnaire.

Patient Questions, Topics Discussed, Emotions Expressed, and Length of Consultation

In the intent-to-treat analyses, the number of questions voiced was significantly greater in the QPL arm than in the control arm: 21.8 (SD = 11) and 18.2 (SD = 8.4), respectively ($P = 0.027$) (Table 2). Sensitivity analyses showed that the results were similar. No demographic or clinical factor was associated with the increased number of questions raised by patients (Table 2). In the per-protocol analysis, the number of questions voiced was also significantly greater in the QPL arm ($n = 45$) than in the control arm ($n = 51$): 26.8 (SD = 11) and 20.8 (SD = 8.4), respectively ($P = 0.032$). In the group of patients who read the QPL entirely, the number of questions voiced was significantly greater in the QPL arm ($n = 31$) than in the control arm ($n = 71$): 25.4 (SD = 14.7) and 18.2 (SD = 8.4), respectively ($P = 0.01$).

In the per-protocol population, more than twice as many patients brought up EOL issues (64% vs. 29%, $P = 0.001$) and more than twice as many questions were raised on this topic (2.2 vs. 1.0, $P = 0.022$). The number of questions raised about supportive care and PC was significantly greater in the intervention arm (5.6 vs. 3.7, $P = 0.013$). Questions concerning support for caregivers were also more frequently brought up by patients from the QPL arm than by

those in the control arm (22.2% and 7.8%, respectively, $P = 0.046$). There was no difference for any other topics discussed (Table 3).

Patients expressing emotions such as crying were more frequent in intervention arm than in the control arm (10 of 35 vs. 4/47; $P = 0.046$). In the overall population, these patients asked statistically more questions compared with those with no observed emotional reactions (28 and 20, respectively; $P = 0.018$), with no statistical difference between the two arms.

The length of the consultation did not statistically differ in the QPL arm compared with the control arm: 33 minutes (SD = 16.3) vs. 27 minutes (SD = 12.4) ($P = 0.07$).

Patient-Related Outcomes at Two Months

At two months, QoL and psychological distress did not change compared with baseline in either arm. Patient satisfaction with physicians' technical skills increased, with higher scores in the QPL arm than in the control arm ($P = 0.024$).

Coping styles showed a positive trend, with two avoidance coping strategies that were less frequent at two months in the QPL arm compared with the control arm: self-distraction (5.7 and 4.8, respectively,

Table 2
Number of Questions Asked According to Clinical Parameters (Univariate Analysis)

Psychometric Questionnaires	QPL Arm ($n = 71$ Patients)	Control Arm ($n = 71$ Patients)	P^a
Number of questions, mean (SD)	21.8 (11)	18.2 (8.4)	0.027
Demographic and clinical parameters			
Gender			
Male	19.4 (7)	15.79 (7.72)	NS
Female	25.26 (14.59)	19.08 (10.54)	
Age			
65 yrs and younger	25.38 (10.66)	19.33 (11.7)	NS
65 yrs	22.71 (15.59)	17.37 (8.5)	
Minor children			
No	22.73 (14.41)	19.07 (10.37)	NS
Yes	29.43 (12.29)	20.75 (5.91)	
Higher education			
No	25.67 (13.9)	21.62 (9.54)	NS
Yes	12 (7.07)	12 (9.9)	
PS			
1	25.15 (15.21)	22.54 (12.46)	NS
2	24 (12.89)	15.96 (7.75)	
3	20.33 (7.43)	18.11 (10.65)	
Painkillers			
No	22.7 (10.14)	15.22 (6.44)	NS
Yes	24.31 (14.34)	18.81 (10.42)	
Disease status			
Partial response	39 (NA)	28 (26.87)	NS
Stabilization	22.71 (12.13)	19.12 (8.65)	
Progression	26.09 (17.85)	15.73 (9.46)	
Ongoing chemotherapy			
No	21.58 (15.73)	18.36 (9.91)	NS
Yes	24.84 (12.86)	18.11 (10)	

QPL = question prompt list; NS = not significant; PS = performance status; NA = not applicable.

^aIntent-to-treat analysis, P -values are calculated using analysis of variance.

Table 3
Effect of QPL According to Topics (Univariate Analyses)

Topics	Number of Patients (%)		<i>P</i> ^a
	QPL Arm; N = 45	Control Arm; N = 51	
Supportive care and PC team	43 (95.6)	43 (84.3)	NS ^b
	5.6 (4.3)	3.7 (2.8)	0.012
Physical symptoms	44 (97.8)	49 (96.1)	NS ^b
	10.7 (5.5)	11.5 (7.3)	NS
Anticancer treatment	40 (88.9)	43 (84.3)	NS
	4.1 (4.0)	3.8 (3.1)	NS
Symptom management	43 (95.6)	48 (94.1)	NS ^b
	8.8 (7.5)	10.5 (7.0)	NS
Lifestyle	41 (91.1)	48 (94.1)	NS
	6.6 (6.0)	7.2 (4.5)	NS
Expectations, prognosis	37 (82.2)	43 (84.3)	NS
	4.3 (3.6)	3.6 (2.6)	NS
Finding support	39 (86.7)	42 (82.4)	NS
	4.7 (4.5)	3.7 (3.4)	NS
Quality of care	25 (55.6)	23 (45.1)	NS
	1.7 (2.8)	0.9 (1.2)	NS
Caregivers	10 (22.2)	4 (7.8)	0.046
	0.4 (1.0)	0.2 (0.6)	NS
EOL issues	29 (64.4)	15 (29.4)	0.001
	2.2 (2.6)	1.0 (2.1)	0.018
Others	25 (55.6)	3 (62.7)	NS
	1.8 (2.9)	1.9 (2.6)	NS

QPL = question prompt list; PC = palliative care; NS = not significant; EOL = end of life.

^a*P* values were calculated using a two-sided Chi-squared test except for by using Fisher's exact tests.

^bUsing Fisher's exact tests.

$P = 0.015$) and behavioral disengagement (2.4 and 3, respectively, $P = 0.025$). No coping strategy predicted the number of questions asked.

Given the results of the univariate analysis, no multivariate analysis was conducted.

Concerning both subdimensions of HADS questionnaire, no difference was found between the two arms at baseline and two months. Nevertheless, the results showed a time effect without time \times intervention interaction: the anxiety increased significantly in the two arms between baseline and two months ($P < 0.001$), whereas the depression decreased ($P < 0.001$). Concerning the subdimensions of McGill questionnaire, difference between neither arms nor time effect was found for the physical status, spiritual, and support subdimensions. For the psychological symptoms subdimension, the overall intervention effect was slightly significant ($P = 0.05$) with no time effect: the psychological symptoms were more often observed in the QPL arm than in the control arm at baseline and two months. For the physical symptoms subdimension, the overall intervention effect was significant ($P < 0.001$) with no time effect; this difference trends to be more important at two months compared with baseline ($P = 0.06$). For the PATSAT32, no difference between the two groups was observed at two months

except for the technical subdimension where the satisfaction was more important in the QPL arm than in the control arm ($P = 0.024$) (Table 4).

Participants' Views on the QPL

Of the 46 patients in the intervention arm, 31 (67%) read all the sections in the booklet, 11 (24%) read it partially, and 4 (9%) did not read it. During an average of one month between inclusion and the next consultation, the patients read the booklet twice on average; 80% agreed that the QPL was helpful for communicating with their physician, and 90% thought it was easy to understand.

Discussion

The results of our study showed that patients in the QPL arm asked significantly more questions in outpatient PC consultations, particularly concerning supportive care and PC and EOL issues. The questions raised were mainly seeking information on the meaning of PC or advanced care planning. The QPL enabled patients to raise questions about EOL issues, in a way they might not have thought possible before reading it. These results are convergent with three randomized studies: in the first study, the QPL was used in an outpatient PC setting; in the second study, the QPL was a part of a nurse-led communication support program, in which patients attended a face-to-face meeting to identify questions they felt were relevant; in the third study, the QPL was part of personalized communication training for oncologists.^{30,41,42} Unlike these previous results, our results show no difference in the number of questions concerning prognosis issues. It has been shown in a qualitative study that many participants did not wish to know their life expectancy estimates, citing unreliable estimates, uncertain treatment outcomes, or a coping strategy consisting in not looking ahead.⁴³ With the recent improvements in physicians' communication skills, oncologists usually discuss incurability with their patients before referral to the PC. This could explain why patients mostly needed to discuss EOL issues when they first met the PC team. For other patients, sensitive topics of conversation such as short-term vital risks and risk of death might not be possible without a longer follow-up with a physician making it possible to build a trustful relationship.⁴⁴

In this study, most participants using the QPL felt that the tool was relevant and helpful (80%) in communicating with their doctor. This is consistent with previous publications.^{45,46} Surprisingly, our study shows that patient satisfaction increased with the physicians' technical skills, but this result needs to be confirmed. PC physicians could have been perceived

Table 4
McGill and HADS Scores Comparison at Baseline and Two Months, Intervention Effect, Time Effect, and Interaction Term; PATSAT32 Score Comparison at Two Months

Questionnaires	C1 (Baseline)			C3 (Two Months)			Intervention Effect	Time Effect	Interaction Term
	Median (Minimum–Maximum)	Mean (SD)	<i>P</i> ^a	Median (Minimum–Maximum)	Mean (SD)	<i>P</i> ^a			
HADS	67 Patients	69 Patients		37 Patients	44 Patients				
HADS anxiety	7.5 (3.6)	7.4 (3.8)	0.83	11.3 (3.2)	11.1 (3)	0.77	0.15	<0.001	0.8
HADS depression	8 (0–14)	7 (1–17)	0.74	12 (3–16)	11 (6–18)	0.47	0.24	<0.001	0.6
HADS depression	7.3 (3.8)	7 (3.9)		4.3 (2.8)	3.8 (3.1)				
HADS depression	8 (1–16)	6.5 (1–18)		4 (0–11)	4 (–1 to 15)				
McGill	66 Patients	68 Patients		37 Patients	44 Patients				
Physical status	3.8 (1.6)	3.4 (1.6)	0.13	3.9 (1.7)	3.3 (1.7)	0.22	0.14	0.1	0.96
Psychological symptoms	3.5 (0.7–7)	3.3 (0–9)	0.06	3.3 (1–7.5)	3.3 (1–8.3)	0.09	0.05	0.98	0.6
Psychological symptoms	5.6 (2.1)	4.8 (2.4)		5.8 (2)	4.9 (2.4)				
Psychological symptoms	6 (1–10)	5 (0–10)		6 (2–9)	5 (0–10)				
Spiritual	6.5 (2.2)	6.7 (2.2)	0.74	6.4 (2.2)	6.8 (2.4)	0.37	0.2	0.9	0.9
Spiritual	6.8 (2.5–10)	6.6 (2–10)		6.5 (2.3–10)	7.3 (2–10)				
Support	6.1 (1.7)	6 (1.7)	0.74	5.8 (1.7)	6.3 (1.6)	0.19	0.5	0.98	0.2
Support	6.2 (1.7–10)	6.1 (0–9.2)		5.7 (1.5–8.5)	6.3 (2.5–9.7)				
Physical symptoms	8.3 (1.9)	8.7 (1.6)	0.19	7.5 (2)	8.9 (1.4)	<0.001	<0.001	0.16	0.06
Physical symptoms	9 (2–10)	9 (3–10)		8 (1.5–10)	9.3 (3.5–10)				
PATSAT32				35 Patients	41 Patients				
Technical				13.1 (1.9)	11.9 (2.5)	0.024			
Technical				14 (8–15)	12 (5–15)				
Interpersonal				12.8 (2)	12.5 (2.9)	0.6			
Interpersonal				13 (7–15)	14 (3–15)				
Information				11.6 (2.3)	10.9 (2.8)	0.25			
Information				12 (6–15)	12 (3–15)				
Availability				11.4 (2.3)	11.3 (2.7)	0.9			
Availability				12 (7–15)	12 (5–15)				

McGill = McGill Quality of Life questionnaire; HADS = Hospital Anxiety and Depression Scale; PATSAT32 = patient satisfaction with cancer care questionnaire; QPL = question prompt list.

^aStudent's t-test.

^bPvalue of the mixed robust analysis of variance.

as more skilled compared with those talking to patients without encouraging them to ask questions. In addition, this tool had no negative impact on QoL or psychological symptoms, thus confirming results from previous studies.^{23,30} Concerning coping styles, we observed that self-distraction and behavioral disengagement were less frequently reported in the QPL arm. Faced with a medical situation that was initially perceived as being out of control, QPL patients may have felt more in control of the situation.⁴⁷ As already shown, using a QPL did not increase the length of the consultation, which appears as an interesting result, as the issue of lack of time is often raised by oncologists, feeling that they are unable to take the time to address patients' information needs or to initiate sensitive discussions about prognosis or EOL care.^{23,30}

The strengths of this study should be cited. This is the first randomized clinical trial testing a French QPL in the integrated PC setting, using a validated tool adapted to French-speaking cultures. It was given one month rather than a few days or just before the consultation, as was the case in previous studies, thus giving the patient and caregivers more time to read the brochure one or several times, to think about it, discuss sensitive topics with relatives, and prepare for the next consultation with the physician. However, several limitations should be noted. First, the high attrition rate (32%) confirms the difficulty in performing clinical trials among advanced cancer patients and did reduce the statistical power of the study. Second, other secondary outcomes could have been included: analysis of doctor-patient communication and patient parameters such as the desire for information, and cultural factors, to develop a wider implementation of this approach in clinical care.^{48–50} Third, no measures were undertaken to check that crosscontamination did not occur, that is potential changes in the physicians' communication behaviors in the control arm as a result of their participation in the study. Finally, we did not assess awareness of prognosis or treatment preferences. These are measures that could also have been relevant outcomes for use of the QPL.⁵¹

In conclusion, our study confirms the acceptability and helpfulness of a French-language QPL in PC consultations in oncology. However, our initial work on the translation and adaptation of the QPL to French culture highlighted the need to remove some difficult questions about EOL issues. This QPL is an efficient tool to foster discussion on supportive care and PC and advanced care planning, and it enables physicians to identify patients who are reluctant to address issues related to EOL care. This QPL is safe, with no negative impact on QoL or psychological symptoms, and it can be easily used in every cancer center. Further studies are needed to analyze QPL efficacy according to

factors such as the phase of the disease, awareness of prognosis, psychosocial characteristics, or oncologists' communication skills. It would also be helpful to use a shorter QPL focused on supportive care and PC and EOL issues, and to explore whether these terms have various meanings in the context of different centers and internationally. Future studies should also assess the impact of the QPL on promoting advance care planning during a longer period and the effect of staff and patient training on how best to use it.

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References

1. Gilligan T, Coyle N, Frankel RM, et al. Patient-clinician communication: American Society of Clinical Oncology consensus guideline. *J Clin Oncol* 2017;35:3618–3632.
2. Ferrell BR, Temel JS, Temin S, et al. Integration of palliative care into standard oncology care: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol* 2017;35:96–112.
3. Bernacki RE, Block SD, American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med* 2014;174:1994–2003.
4. Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* 2017;18:e543–e551.
5. Weeks JC, Catalano PJ, Cronin A, et al. Patients' expectations about effects of chemotherapy for advanced cancer. *N Engl J Med* 2012;367:1616–1625.
6. Enzinger AC, Zhang B, Schrag D, Prigerson HG. Outcomes of prognostic disclosure: associations with prognostic understanding, distress, and relationship with physician among patients with advanced cancer. *J Clin Oncol* 2015;33:3809–3816.
7. Raskin W, Harle I, Hopman WM, Booth CM. Prognosis, treatment benefit and goals of care: what do oncologists discuss with patients who have incurable cancer? *Clin Oncol (R Coll Radiol)* 2016;28:209–214.

8. Chen CH, Kuo SC, Tang ST. Status of accurate prognostic awareness in advanced/terminally ill cancer patients: systematic review and meta-regression analysis. *Palliat Med* 2017;31:406–418.
9. Brédart A, Bouleuc C, Dolbeault S. Doctor-patient communication and satisfaction with care in oncology. *Curr Opin Oncol* 2005;17:351–354.
10. Brighton LJ, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. *Postgrad Med J* 2016;92:466–470.
11. Innes S, Payne S. Advanced cancer patients' prognostic information preferences: a review. *Palliat Med* 2009;23:29–39.
12. Hagerty RG, Butow PN, Ellis PA, et al. Cancer patient preferences for communication of prognosis in the metastatic setting. *J Clin Oncol* 2004;22:1721–1730.
13. Parker SM, Clayton JM, Hancock K, et al. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life limiting illness: patient/caregiver preferences for the content, style, and timing of information. *J Pain Symptom Manage* 2007;34:81–93.
14. Buiting HM, Rurup ML, Wijsbek H, van Zuylen L, den Hartogh G. Understanding provision of chemotherapy to patients with end stage cancer: qualitative interview study. *BMJ Support Palliat Care* 2011;1:33–41.
15. Abdul-Razzak A, You J, Sherifali D, Simon J, Brazil K. 'Conditional candour' and 'knowing me': an interpretive description study on patient preferences for physician behaviours during end-of-life communication. *BMJ Open* 2014;4:e005653.
16. Clayton JM, Hancock KM, Butow PN, et al. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Med J Aust* 2007;186:S77–S105.
17. Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* 1998;279:1709–1714. Erratum in: *JAMA* 2000;283:203.
18. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;28:1203–1208.
19. Epstein RM, Duberstein PR, Fenton JJ, et al. Effect of a patient-centered communication intervention on oncologist-patient communication, quality of life, and health care utilization in advanced cancer: the VOICE randomized clinical trial. *JAMA Oncol* 2017;3:92–100.
20. Licqurish SM, Cook OY, Pattuwage LP, et al. Tools to facilitate communication during physician-patient consultations in cancer care: an overview of systematic reviews. *CA Cancer J Clin* 2019;69:497–520.
21. Dimoska A, Tattersall MH, Butow PN, Shepherd H, Kinnersley P. Can a "prompt list" empower cancer patients to ask relevant questions? *Cancer* 2008;113:225–237.
22. Bruera E, Sweeney C, Willey J, et al. 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* 2003;25:412–419.
23. Brandes K, Linn AJ, Butow PN, van Weert JC. The characteristics and effectiveness of Question Prompt List interventions in oncology: a systematic review of the literature. *Psychooncology* 2015;24:245–252.
24. Miller N, Rogers SN. A review of question prompt lists used in the oncology setting with comparison to the Patient Concerns Inventory. *Eur J Cancer Care (Engl)* 2018;27:e12489.
25. Brown RF, Bylund CL, Li Y, Edgeron S, Butow P. Testing the utility of a cancer clinical trial specific Question Prompt List (QPL-CT) during oncology consultations. *Patient Educ Couns* 2012;88:311–317.
26. Tattersall MH, Jefford M, Martin A, et al. Parallel multi-centre randomised trial of a clinical trial question prompt list in patients considering participation in phase 3 cancer treatment trials. *BMJ Open* 2017;7:e012666.
27. Zetzl T, Mann D, Gruner S, et al. Question prompts to empower cancer patients: results of a randomized controlled trial. *Support Care Cancer* 2020;28:2571–2579.
28. Henselmans I, van Laarhoven HWM, van Maarschalkerweerd P, et al. Effect of a skills training for oncologists and a patient communication aid on shared decision making about palliative systemic treatment: a randomized clinical trial. *Oncologist* 2020;25:e578–e588.
29. Levoy K, Salani DA, Buck H. A systematic review and gap analysis of advance care planning intervention components and outcomes among cancer patients using the transtheoretical model of health behavior change. *J Pain Symptom Manage* 2019;57:118–139.e6.
30. Clayton JM, Butow PN, Tattersall MH, et al. 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* 2007;25:715–723.
31. Brandes K, Butow PN, Tattersall MH, et al. Advanced cancer patients' and caregivers' use of a Question Prompt List. *Patient Educ Couns* 2014;97:30–37.
32. Best M, McArdle MB, Huang YJ, Clayton J, Butow P. How and how much is spirituality discussed in palliative care consultations for advanced cancer patients with and without a question prompt list? *Patient Educ Couns* 2019;102:2208–2213.
33. Fouquet C, Brédart A, Bouleuc C. French adaptation of a question prompt list for cancer patients and their carers in supportive and palliative care. *Bull Cancer* 2012;99:693–701.
34. Walczak A, Mazer B, Butow PN, et al. A question prompt list for patients with advanced cancer in the final year of life: development and cross-cultural evaluation. *Palliat Med* 2013;27:779–788.
35. Huberman MA, et Miles MB. *Analyse des données qualitatives*. Brussels: De Boeck, 1991.
36. Cohen SR, Mount BM, Bruera E, et al. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. *Palliat Med* 1997;11:3–20.
37. Razavi D, Delvaux N, Farvacques C, Robaye E. Screening for adjustment disorders and major depressive disorders in cancer in-patients. *Br J Psychiatry* 1990;156:79–83.
38. Brédart A, Bottomley A, Blazeby JM, et al. European Organisation for Research and Treatment of Cancer Quality

- of Life Group and Quality of Life Unit. An international prospective study of the EORTC cancer in-patient satisfaction with care measure (EORTC IN-PATSAT32). *Eur J Cancer* 2005;41:2120–2131.
39. Doron J, Trouillet R, Gana K, et al. Examination of the hierarchical structure of the brief COPE in a French sample: empirical and theoretical convergences. *J Pers Assess* 2014; 96:567–575.
40. R Core Team 2017. R: A language and environment for statistical computing. R Foundation for Statistical Computing, Vienna, Austria. Available from <https://www.R-project.org/>. Accessed August 26, 2020.
41. Walczak A, Butow PN, Tattersall MH, et al. Encouraging early discussion of life expectancy and end-of-life care: a randomised controlled trial of a nurse-led communication support program for patients and caregivers. *Int J Nurs Stud* 2017;67:31–40.
42. Rodenbach RA, Brandes K, Fiscella K, et al. Promoting end-of-life discussions in advanced cancer: effects of patient coaching and question prompt lists. *J Clin Oncol* 2017;35: 842–851.
43. Walczak A, Henselmans I, Tattersall MH, et al. A qualitative analysis of responses to a question prompt list and prognosis and end-of-life care discussion prompts delivered in a communication support program. *Psychooncology* 2015;24:287–293.
44. Hall A, Rowland C, Grande G. How should end-of-life advance care planning discussions be implemented according to patients and informal carers? A qualitative review of reviews. *J Pain Symptom Manage* 2019;58:311–335.
45. Arthur J, Yennu S, Zapata KP, et al. Perception of helpfulness of a question prompt sheet among cancer patients attending outpatient palliative care. *J Pain Symptom Manage* 2017;53:124–130.e1.
46. Yeh JC, Cheng MJ, Chung CH, Smith TJ. Using a question prompt list as a communication aid in advanced cancer care. *J Oncol Pract* 2014;10:e137–e141.
47. Morris N, Moghaddam N, Tickle A, Biswas S. The relationship between coping style and psychological distress in people with head and neck cancer: a systematic review. *Psychooncology* 2018;27:734–747.
48. McDermott E, Selman LE. Cultural factors influencing advance care planning in progressive, incurable disease: a systematic review with narrative synthesis. *J Pain Symptom Manage* 2018;56:613–636.
49. Aranda S, Jefford M, Yates P, et al. Impact of a novel nurse-led prechemotherapy education intervention (ChemoEd) on patient distress, symptom burden, and treatment-related information and support needs: results from a randomised, controlled trial. *Ann Oncol* 2012;23:222–231.
50. Brighton LJ, Koffman J, Hawkins A, et al. A systematic review of end-of-life care communication skills training for generalist palliative care providers: research quality and reporting guidance. *J Pain Symptom Manage* 2017;54: 417–425.
51. Tang ST, Chen CH, Wen FH, et al. Accurate prognostic awareness facilitates, whereas better quality of life and more anxiety symptoms hinder end-of-life care discussions: a longitudinal survey study in terminally ill cancer patients' last six months of life. *J Pain Symptom Manage* 2018;55: 1068–1076.

Asking Questions Can Help

Help for people in contact with the support care team.

Introduction

You will meet with a team of caregivers, whose objective is to help set up a comprehensive care plan, with the aim of improving your comfort and QoL, for you and your loved ones. This type of care allows us to take into account your physical symptoms as well as your family, professional and psychological difficulties, by offering you treatment, moral support, and social assistance.

We advise you to use this list of questions in consultation to help you get the information you need from your doctor. Most people undergoing treatment for cancer have questions and concerns, but these are often forgotten in the rush of the moment, or because of the stressful environment that can accompany the consultation.

Before the consultation, you should read the brochure and identify the questions you would like your doctor to answer or even add questions in the space provided. Your doctor will be happy to try to answer any questions you may have.

You can use this brochure list during this visit, as you may choose to use it later, or you can discuss these questions with another member of the health care team (e.g., a nurse). Do not feel obligated to ask any of these questions just because they are listed.

This booklet lists many questions, so that each patient can find some that are appropriate for him or her. For you personally, some of these questions are not relevant to you, so do not stop there.

There may also be topics that you do not want to hear about at the moment. We suggest that you refer to the topics first, so that you can decide if you want to read the questions about that topic.

About The Palliative and Supportive Care Service and Team

The care available

- What is the difference between supportive care and PC, particularly with regard to the provision of care?
- Who are the different members of the supportive care and PC team? And what is their function?
- What is the difference between the services provided by the supportive care and PC team and those provided by the oncology department?
- Can I see the supportive care and PC team at home?
- What kind of help can I get at home?
- What is the supportive care and PC day hospital?
- Is it possible for me to be admitted to the hospital for a short period (e.g., to control my symptoms or give my loved ones a break) and then go home?

Contact With the Care Team

- How do I contact the supportive care and PC team to access the services they offer?
- Under what circumstances can or should I contact them?
- How often can I contact them?
- Is the supportive care and PC service available outside business hours and in case of an emergency?

Coordination Between the Care Team and the Other Doctors Who Care for Me

- Does the supportive care and PC team communicate with my general practitioner and other specialists about my care?
- What is the role of my general practitioner now that I am under the care of the supportive care and PC team?
- Which health professionals responsible for my care should I contact first in an emergency?
- Who will see me on a regular basis now?
- Can you help me choose another general practitioner or cancer specialist?
- Can you help me formulate questions that I may wish to ask other doctors and cancer specialists?
- Can you advise me about my choice of chemotherapy treatments, which I am currently discussing with my oncologist?

My Physical Symptoms

- Can you help me feel less tired?
- Can you help me have more appetite?
- To relieve my pain, what medication and nonmedicinal means are available?
- What is the cause of my pain?
- If I have other symptoms, what can I do to alleviate them (e.g., constipation, shortness of breath, nausea, vomiting, dry mouth, edema, etc.)?
- Can you help me control my next symptom?

My Cancer Treatments

- How do cancer treatments work: chemotherapy? Hormonal therapy? Radiotherapy?
- How do I know if my cancer treatment is working?
- What are the side effects of my chemotherapy treatment?
- How do I deal with the side effects of my chemotherapy treatment?
- Is oral chemotherapy as strong as intravenous chemotherapy?
- Can I receive chemotherapy at home?
- Can I go on vacation while I am undergoing chemotherapy treatment?
- Can I take a break from my chemotherapy treatment?
- When can I stop my chemotherapy treatment?

My Symptom Treatments

- What are the side effects of my medication?
- Can these side effects be mitigated?
- Can a new drug interact with my current treatment?
- Are there any drugs I should not take because of my cancer or chemotherapy?
- What is the purpose of each of my medications?
- Are my old drugs still needed?
- How do I manage to take all my medications?
- Are there any natural or complementary therapies that could help me?

Morphine and Derivatives

- Will my body get used to the morphine if I start now?
- Will it still have an effect in the future?
- Is there a risk of addiction with morphine and its derivatives?
- Will I be able to stop taking it if my pain goes away?
- Will it make me disoriented? Constipated? Nauseated?
- What are the different ways to take morphine?

My Lifestyle, My QoL

- What is the right level of physical activity (what is too much exercise and what is too little)?
- How can I get the most out of my life despite my daily difficulties?
- What type of diet should I follow?
- How important is my diet?
- Can you advise me if—and when—I can return to work?
- Can you advise me about how long a holiday or trip I would like to take?
- Is it good for me to drive?
- How can I stay close and intimate with my spouse (physically and/or emotionally)?

The Evolution of My Illness and What To Expect

- What is the status of my illness?
- What are the chances of recovery?
- Can my condition get better or worse?
- What should I expect in the future?
- What symptoms might appear in the future, and what should I do if they occur?
- Will I suffer?
- Can my pain and other symptoms be controlled in the future?
- What will the worst days look like?
- What will the best days look like?
- How long can I expect to live?

The Support I Can Get

Support in Information Support

- What information is available about supportive care and PC and my illness?
- Are there any books, videos, or brochures available?
- Are there other organizations I could contact?

Practical Support

- Is there a program of activities offered by the supportive care service? (e.g., physiotherapy, massage, relaxation—sophrology?)
- Can you provide materials or equipment to make daily life easier?
- Can I benefit from disabled parking? Where do I apply?
- Are there volunteers available to visit me at home or at the hospital?

Financial Support

- What expenses will I have to bear during my illness (e.g., for any equipment or medication)?
- What financial assistance is available to me or my partner (e.g., pension/allowance)?
- Is there someone I can discuss financial matters with?

Psychological Support

- What are the possible emotional reactions, and what can I do about them?
- How should I deal with depression if it occurs?
- Who can I talk to about my fears and worries?
- When can I meet with a psychologist?
- How can I accept the changes or transformations in my body because of this illness?
- Is it possible to talk to a team member alone or for the person accompanying me to do so?
- Are there support groups?
- Can someone help me talk to other family members about what is happening to me?
- What support is there for other people in my family, such as my support person or my children?

Spiritual and Cultural Supports

- Is there someone I can talk to about my spiritual or religious needs?
- Can you arrange for me to meet with someone who shares my culture and who can understand me better?

About Quality of Care

- Who can I talk to if I am concerned about the care I am receiving?
- Is it possible for me to see someone else if I do not get along with my cancer doctor?
- Can I get a second opinion about any aspect of my cancer treatments?
- Can I choose which hospital or supportive care/PC team I am attached to? Can I change my mind if I am not satisfied?

For My Family and Friends

- What should my skills as a support person be?
- Do you think I can take care of my spouse, relative, or friend at home?
- Can I get help if I cannot do it on my own?
- What can I do if I cannot cope?
- How can I best support the person I am helping?
- What should I do if my spouse, relative, or friend does not want to eat enough?
- Will eating more food allow my spouse, relative, or friend to live longer?
- Who can I talk to if I am worried about the care my spouse, relative, or friend is receiving?

EOL Issues

The following questions may not apply to you or your stage of the disease. Please do not feel obliged or unwilling to read this section, but there may come a time when you feel the need to ask some of these questions.

Questions I Might Want to Ask

- How can I accept the fact that I am becoming more and more dependent on others?
- Will you be able to tell me when I am nearing the end of my life?
- How can I put my affairs in order or write a will?
- What should I expect during the last days of my life?
- Will I be able to choose where I will spend my last days of life: at home or in a hospital ward?
- Who do I talk to about the care I would like to receive and the care I do not want to receive when I am no longer able to express it?
- What is a trustworthy person?
- What are advance directives?

Poser des Questions Peut Aider

Une aide pour les personnes en contact avec l'équipe de soins de support

Introduction

Vous allez rencontrer une équipe de soignants, dont l'objectif est de contribuer à mettre en place une prise en charge globale, dans le but d'améliorer votre confort et votre qualité de vie, pour vous et pour vos proches. Ce type de soins permet de prendre en compte vos symptômes physiques comme vos difficultés familiales, professionnelles et psychologiques, en vous proposant des traitements, un soutien moral et des aides sociales.

Nous vous conseillons d'utiliser cette liste de questions en consultation, pour vous aider à obtenir auprès de votre médecin, les informations dont vous avez besoin. La plupart des personnes en cours de traitement pour une maladie cancéreuse ont des questions et des inquiétudes; mais elles sont souvent oubliées dans la précipitation du moment, ou en raison du climat de stress pouvant accompagner la consultation.

Avant la consultation, il vous est conseillé de lire la brochure et de repérer les questions auxquelles vous souhaiteriez que votre médecin réponde, voire d'en ajouter dans l'espace prévu à cet effet. Votre médecin sera ravi d'essayer de répondre aux questions que vous vous posez.

Vous pouvez vous servir de cette brochure-liste pendant cette consultation, comme vous pouvez choisir de l'utiliser plus tard, ou de parler de ces questions avec un autre membre de l'équipe de soins (une infirmière par exemple). Ne vous sentez pas obligé de poser une seule de ces questions, simplement parce qu'elles sont énumérées.

Cette brochure-liste recouvre un grand nombre de questions, pour que chaque patient puisse en trouver certaines qui lui conviennent. Pour vous personnellement, certaines de ces questions ne vous concernent pas: dans ce cas ne vous y arrêter pas.

Il se peut aussi qu'il y ait des sujets dont vous ne souhaitez pas entendre parler pour le moment. Nous vous suggérons de vous référer d'abord aux rubriques, afin de pouvoir décider si vous voulez lire les questions concernant ce thème.

Concernant Le Service Et L'équipe De Soins Support Et De Soins Palliatifs

Les soins disponibles

- Quelle est la différence entre soins de supports et soins palliatifs, notamment concernant l'offre de soins?
- Quels sont les différents membres de l'équipe de soins de support et de soins palliatifs? et quelle est leur fonction?
- Quelle est la différence entre les services fournis par l'équipe de soins de support et de soins palliatifs, et ceux fournis par le service d'oncologie?
- Puis-je voir l'équipe de soins de support et de soins palliatifs à domicile?
- Quelles aides puis-je avoir à domicile?
- Qu'est ce que l'hôpital de jour de soins de support et de soins palliatifs?
- M'est-il possible d'être admis à l'hôpital pour une courte durée (ex. pour contrôler mes symptômes ou permettre à mes proches de faire une pause), puis de rentrer chez moi?

Les contacts avec l'équipe de soins

- Comment contacter l'équipe de soins de support et de soins palliatifs pour avoir accès aux services qu'elle offre?
- Dans quelles circonstances puis-je, ou devrais-je, les contacter?
- Quelle est la fréquence à laquelle je peux les contacter?
- Le service de soins de support et de soins palliatifs est-il disponible en dehors des heures ouvrées et en cas d'urgence?

La coordination entre l'équipe de soins et les autres médecins qui me soignent

- L'équipe de soins de support et de soins palliatifs communique-t-elle avec mon praticien généraliste et d'autres spécialistes, à propos de mes soins?
- Quel est le rôle de mon praticien généraliste maintenant que je suis pris(e) en charge par l'équipe de soins de support et de soins palliatifs?
- Quels professionnels de la santé responsables de mes soins dois-je contacter en premier en cas d'urgence?
- Qui me verra de façon régulière à présent?
- Pouvez-vous m'aider à choisir un autre praticien généraliste ou un autre oncologue?
- Pouvez-vous m'aider à formuler des questions que je pourrais souhaiter poser à d'autres médecins et oncologue?
- Pouvez-vous me conseiller au sujet de mon choix de traitements par chimiothérapie, que je suis en train de discuter avec mon oncologue?

Mes Symptômes Physiques

- Pouvez-vous m'aider à me sentir moins fatigué(e)?
- Pouvez-vous m'aider à avoir plus d'appétit?
- Pour soulager mes douleurs, quels sont les moyens médicamenteux et non médicamenteux existants?
- Quelle est la cause de mes douleurs?
- Si je me trouve en présence d'autres symptômes, que puis-je faire pour les atténuer? (ex. constipation, essoufflement, nausées, vomissements, bouche sèche, œdèmes ...)
- Pouvez-vous m'aider à contrôler mon symptôme suivant ?
- Quelle est la cause du symptôme suivant: ?

Mes Traitements Contre Le Cancer

Mon traitement anticancéreux

- Comment agissent les traitements anticancéreux: la chimiothérapie? L'hormonothérapie? La radiothérapie?
- Comment savoir si mon traitement anticancéreux est efficace?
- Quels sont les effets indésirables de mon traitement par chimiothérapie?
- Comment traiter les effets indésirables de mon traitement par chimiothérapie?

- Est-ce la chimiothérapie orale est aussi forte que par voie intraveineuse?
- Est-ce que je peux recevoir la chimiothérapie à domicile?
- Est ce que je peux partir en vacances lorsque je suis en traitement par chimiothérapie?
- Est ce que je peux faire une pause dans mon traitement par chimiothérapie?
- Quand pourrais-je arrêter mon traitement par chimiothérapie?

Mes Traitements Contre Les Symptomes

- Quels sont les effets indésirables de mes médicaments?
- Peut-on atténuer ces effets indésirables?
- Un nouveau médicament peut-il interagir avec mon traitement actuel?
- Existe-t-il des médicaments que je ne dois pas prendre en raison de mon cancer ou de ma chimiothérapie?
- Quelle est l'utilité de chacun de mes médicaments?
- Mes anciens médicaments sont-ils toujours nécessaires?
- Comment puis-je me débrouiller pour prendre tous mes médicaments?
- Existe-t-il des thérapies naturelles ou complémentaires qui pourraient m'aider?

Morphine et dérivés

- Mon corps s'habituerait-il à la morphine si je commence maintenant?
- Aura-t-elle encore un effet dans le futur?
- Il y a-t-il un risque de toxicomanie avec la morphine et ses dérivés?
- Pourrais-je arrêter d'en prendre si ma douleur disparaît?
- Me rendra-t-elle désorienté(e)? Constipée? Nauséux?
- Quels sont les différents moyens de prendre de la morphine?

Mon Mode De Vie, Ma Qualite De Vie

- Quel est le bon niveau d'activité physique (qu'est-ce qui correspond à trop d'exercice et qu'est-ce qui correspond à trop peu d'activité)?
- Comment pourrais-je profiter au maximum de ma vie malgré mes difficultés quotidiennes?
- Quel type d'alimentation dois-je suivre?
- A quel point mon régime alimentaire est-il important?
- Pouvez-vous me conseiller si - et quand - je peux retourner au travail?
- Pouvez-vous me conseiller au sujet de la durée de vacances ou de voyage que je souhaiterais prendre?
- Est-il bon que je conduise?
- Comment puis-je rester proche et intime avec mon conjoint (physiquement et/ou sentimentalement)?

L'évolution De Ma Maladie Et Ce A Quoi M'attendre

- Où en est ma maladie?
- Quelles sont les chances de guérir?
- Mon état peut-il s'améliorer ou au contraire s'aggraver?
- A quoi dois-je m'attendre à l'avenir?
- Quels symptômes pourraient apparaître dans le futur et que dois-je faire s'ils surviennent?
- Vais-je souffrir?
- Ma douleur et d'autres symptômes pourront-ils à l'avenir être contrôlés?
- A quoi vont ressembler les pires jours?
- A quoi les plus beaux jours vont-ils ressembler?
- Combien de temps puis-je espérer vivre?

Le Soutien Dont Je Peux Disposer

Soutien dans le support d'information

- Quelle information est disponible au sujet des soins de support et des soins palliatifs et de ma maladie?
- Y a-t-il des livres, vidéos ou brochures disponibles?
- Y a-t-il d'autres organismes qu'il me serait utile de contacter?

Soutien pratique

- Existe-t-il un programme d'activités proposé par le service de soins de support? (ex. kinésithérapie, massage, relaxation-sophrologie?)
- Pouvez-vous fournir un matériel ou équipement pour rendre le quotidien plus facile?
- Puis-je bénéficier du stationnement handicapé? Où dois-je en faire la demande?
- Y a-t-il des bénévoles disponibles pour me rendre visite à domicile ou à l'hôpital?

Soutien financier

- Quelles dépenses devrais-je supporter au cours de ma maladie (ex. pour tout équipement ou traitement médicamenteux)?
- Quel aide financière est disponible est disponible pour mon compagnon ou moi-même (ex. pensions/allocation?)?
- Y a-t-il une personne avec laquelle je pourrais discuter de questions financières?

Soutien psychologique

- Quelles sont les réactions émotionnelles possibles et que puis-je faire pour y faire face?
- Comment dois-je réagir face à la dépression si elle survient?
- A qui pourrais-je parler de mes peurs et inquiétudes?
- A quel moment puis-je rencontrer un(e) psychologue?
- Comment accepter les changements ou les transformations de mon corps dus à cette maladie?
- Est-il possible de discuter avec un membre de l'équipe seul à seul ou que la personne qui m'accompagne puisse le faire?
- Existe-t-il des groupes de soutien?
- Quelqu'un peut-il m'aider à parler à d'autres membres de ma famille de ce qu'il m'arrive?
- Quel soutien existe-t-il pour d'autres personnes de ma famille, tels que ma personne de soutien ou mes enfants?

Soutiens spirituel et culturel

- Y a-t-il quelqu'un à qui je pourrais parler de mes besoins spirituels ou religieux?
- Pouvez-vous m'organiser une rencontre avec une personne partageant ma culture, susceptible de mieux me comprendre?

Au Sujet De La Qualite Des Soins

- A qui puis-je parler si je suis inquiet(e) au sujet des soins que je reçois?
- M'est-il possible de voir quelqu'un l'autre si je ne m'entends pas bien avec mon médecin oncologue? Comment dois-je m'y prendre?
- Puis-je avoir un deuxième avis concernant tout aspect de mes traitements anticancéreux?
- Puis-je choisir l'hôpital ou l'équipe de soins de support/de soins palliatifs à laquelle je suis attaché(e)? Puis-je changer d'avis si je ne suis pas satisfait(e)?

Pour Mon Entourage

- Quelles doivent être mes compétences en tant que personne de soutien?
- Pensez-vous que je peux prendre soin de mon conjoint, proche ou ami à la maison?
- Puis-je bénéficier d'une aide si je n'y arrive pas tout seul?

- Que puis-je faire si je ne parviens pas à faire face?
- Comment puis-je soutenir au mieux la personne que j'aide?
- Que dois-je faire si mon conjoint, proche ou ami ne veut pas assez manger?
- Manger davantage permettra-t-il à mon conjoint, proche ou ami de vivre plus longtemps?
- A qui puis-je parler si je suis inquiet(e) au sujet des soins que mon conjoint, proche ou ami reçoit?

Questions Concernant La Fin De Vie

Les questions suivantes peuvent ne pas vous concerner ni correspondre au stade de votre maladie. Ne vous prions de ne pas vous sentir obligé de lire cette section ni vous n'en avez pas envie, mais il se pourrait qu'il ad-
vienne un moment où vous ressentiriez le besoin de poser certaines de ces questions.

Questions que je pourrais avoir envie de poser.

- Comment accepter le fait que je deviens de plus en plus dépendant des autres?
- Serez-vous capable de me dire lorsque l'on se rapprochera de ma fin de vie?
- Comment mettre mes affaires en ordre ou écrire un testament?
- A quoi dois-je m'attendre durant les derniers jours de ma vie?
- M'est-il possible de choisir le lieu de mes derniers jours de vie: chez-moi ou dans un service hospitalier?
- A qui dois-je parler des soins dont je souhaiterais bénéficier et de ceux que je ne veux pas recevoir lorsque je ne pourrai plus l'exprimer?
- Qu'est-ce qu'une personne de confiance?
- Qu'est ce que les directives anticipées?