

Brief Report

Perception of Helpfulness of a Question Prompt Sheet Among Cancer Patients Attending Outpatient Palliative Care



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Abstract

Background. Data on the use of question prompt sheets (QPSs) in palliative care are limited. Our team previously developed a single-page QPS using a Delphi process. The main objective of this study was to determine the perception of helpfulness of a QPS in patient-physician communication among advanced cancer outpatients.

Methods. Hundred of 104 (96%) eligible patients and 68/68 (100%) caregivers received the QPS during their first palliative care clinic. Twelve palliative medicine specialists also participated in the study. Patient and physician perceptions about the QPS were assessed at the end of the visit. Patients' anxiety was also measured before and after consultation using the Spielberger State Anxiety Inventory.

Results. Among the responders, most agreed that the material was helpful in communicating with their doctor (77%), clear to understand (90%), had the right amount of information (87%), and they would use a similar material in the future (76%) and recommend it to other patients (70%). Overall, 92% were satisfied with their consultation visit. Physicians perceived that the QPS was helpful in 68% of the encounters and it did not prolong the consultation in 73% of the encounters. Physician agreement on helpfulness of the QPS was not significantly different from that of the patients ($P = 0.3$). Patient anxiety improved after consultation from a mean (SD) Spielberger State Trait Anxiety Inventory score of 39.2 (12.8) to 33.8 (10.7), $P < 0.0001$.

Conclusion. The QPS was perceived as helpful in patient-physician communication among advanced cancer outpatients and it did not increase patient anxiety. Physicians similarly reported that the QPS was helpful and it did not prolong clinic visits. Further research is needed for its widespread adoption and integration into routine clinical practice. *J Pain Symptom Manage* 2017;53:124–130 © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Question prompt sheet, advanced cancer, helpfulness, palliative care

Introduction

Patients with advanced cancer develop severe physical, psychological, social, and spiritual symptoms that require a multidimensional and interdisciplinary management.¹ An effective communication strategy is fundamental in delivering such care. Greater patient participation during physician-patient encounters has been associated with positive patient

psychological outcomes.^{2–4} However, patients and family members may be uncertain about what type of questions to ask their physicians, may forget to ask certain pertinent questions, or may feel too embarrassed to ask them.^{5,6} Similarly, physicians may be unsure about the type and extent of information to provide their patients, when to convey them, or whom to have those conversations with.^{7,8}

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The use of a question prompt sheet (QPS) might address some of these barriers. It is a structured list of potential questions available for the patient to ask the physician during a clinical encounter.⁹ Various versions of QPS have been developed in different fields of medicine including general medicine,¹⁰ geriatric medicine,¹¹ gynecological and dermatological conditions,¹² surgery,¹³ diabetes,¹⁴ and cancer.¹⁵

There are limited data on the use of a QPS in the advanced cancer or palliative care setting. Clayton et al.¹⁶ in a thoroughly conducted study developed a comprehensive booklet that contained questions addressing various topics in palliative care. However, one limitation was that it was about 20 pages long containing 112 questions, and therefore impractical for routine use by patients and caregivers at a busy outpatient clinic with constraints of time availability. An expert panel from our team developed a single-page, 25-item QPS using a Delphi technique (Appendix A).¹⁷ The main objective of our study was to determine whether the QPS was feasible, defined as greater than 70% of participants who agree or strongly agree that it was helpful in communicating with their physicians.

Methods

Patient Selection and Procedure

The study was conducted from October 8, 2015 to February 24, 2016 at the University of Texas MD Anderson Supportive Care Center. Patients were eligible if they were 18 years or older, had a diagnosis of cancer, were attending their first outpatient consultation visit with a palliative care specialist, and were able to read and communicate in English. They were also required to have normal cognitive status, defined as a normal state of arousal and an absence of obvious clinical findings of confusion, memory deficits, or concentration deficits.

When a potentially eligible candidate was identified, a verbal consent was obtained from the attending physician for the patient's participation in the study. Eligible patients were then asked to provide a written consent and to complete the Spielberger State Trait Anxiety Inventory (STAI) questionnaire. Caregivers who were willing to participate in the study also provided consent. All the participants were then given the QPS and encouraged to identify the questions that they would like to discuss with the physician. At the end of the patient-physician visit, the patients again completed the STAI questionnaire and a patient satisfaction assessment questionnaire. All QPS forms were collected from the participants after the consultation but those who indicated the desire to keep them were given a copy of their forms for future use. The physician who saw the participating patient was also asked to complete a physician assessment form.

Patient demographic and clinical characteristics were obtained from the patients' charts by the research nurse. These included age, gender, race, marital status, religious affiliation, educational status, employment status, caregiver presence, cancer diagnosis, cancer stage, and performance status.

The Supportive Care Clinic Process

The Outpatient Supportive Care Clinic at the University of Texas MD Anderson Cancer Center provides five full-day services a week at two different locations in the hospital. It is staffed by 18 board-certified palliative care physicians, together with palliative care-trained registered nurses, pharmacists, social workers, counselors, and psychologists. It predominantly sees patients with advanced cancer and a relatively smaller number with early-stage disease or in early remission.¹⁸ The clinic nurse first assesses patient and his or her family and gathers pertinent clinical information. The findings are then discussed with the palliative care physician, who then conducts an interview with the patient and family, does a physical examination, and subsequently formulates the assessment and plan. The physician will involve other members of the team in the patient's care as and when necessary.

Study Assessments

Question Prompt Sheet. This is a single page, 25-item list of questions that was developed by an expert panel of clinicians in the Department of Palliative Care and Rehabilitation Medicine at the University of Texas MD Anderson Cancer Center using a three-round Delphi process.¹⁷ Some of the questions were adapted from previous studies like the one by Clayton et al.¹⁶ The QPS consists of some of the most relevant questions in diverse aspects of palliative care and is intended for use by patients and caregivers attending an outpatient palliative care clinic (Appendix A).

Spielberger State Anxiety Inventory. This consists of two widely used 20-item self-report scales measuring situational (state) or general (trait) anxiety. Form Y, its most popular version, was used in this study to measure participants' situational anxiety before and after the consultation visit.¹⁹ Scores range from 20 to 80, where higher scores indicate greater anxiety. The inventory's simplicity makes it ideal for evaluating individuals with lower educational backgrounds. It's been found to have high reliability ($r = 0.93$), internal consistency, and validity.¹⁹

Patient Perception of Helpfulness. Patients were asked questions about their perception of helpfulness of the QPS using a Likert scale from "strongly disagree" to "strongly agree." These questions have been used

in previous studies.^{20,21} We also asked a question adapted from Rotor et al.⁵ about patient satisfaction with the overall consultation visit.

Physician Perception of Helpfulness. This consists of two questions soliciting the opinion of the physician regarding the helpfulness of the QPS to the patient and its effect on the duration of the clinic encounter.

Statistical Analysis

We considered the prompt sheet to be feasible if more than 70% of participants agreed or strongly agreed that it was helpful in communicating with their physicians. With a total of 104 patients enrolled in the study, we were able to estimate the percentages of participants who agreed or strongly agreed that the QPS was helpful, was easy to understand, had the right amount of information, was recommendable to other patients, did not make them anxious, enabled them to think of questions or concerns they had not thought of before, or that they would use a similar material in the future, or were satisfied with the overall consultation, with a standard error not larger than 0.05.

Data were summarized using standard descriptive statistics such as mean, standard deviation, median,

and range for continuous variables as well as frequency and proportion for categorical variables. Agreement of “perception of helpfulness” of the QPS from patients’ and physicians’ answers was examined by McNemar’s test. A paired t-test was used to examine the change in state anxiety total score before and after the QPS. Association between “patient perception of helpfulness” of the QPS and the variables of interest including age, gender, race, marital status, religious affiliation, educational status, employment status, caregiver presence, cancer diagnosis, cancer stage, and performance status was examined by chi-squared test or Fisher exact test when appropriate. Both univariate and multivariate logistic regression models were applied to assess the effect of variables of interest on patient perception of helpfulness of the QPS. All computations were carried out in SAS 9.3 (SAS Institute Inc., Cary, NC).

Results

Between October 2015 and February 2016, 104 patients were enrolled in the study. Hundred of 104 patients (96%) completed it and were included in the primary analysis (Fig. 1). Twelve palliative

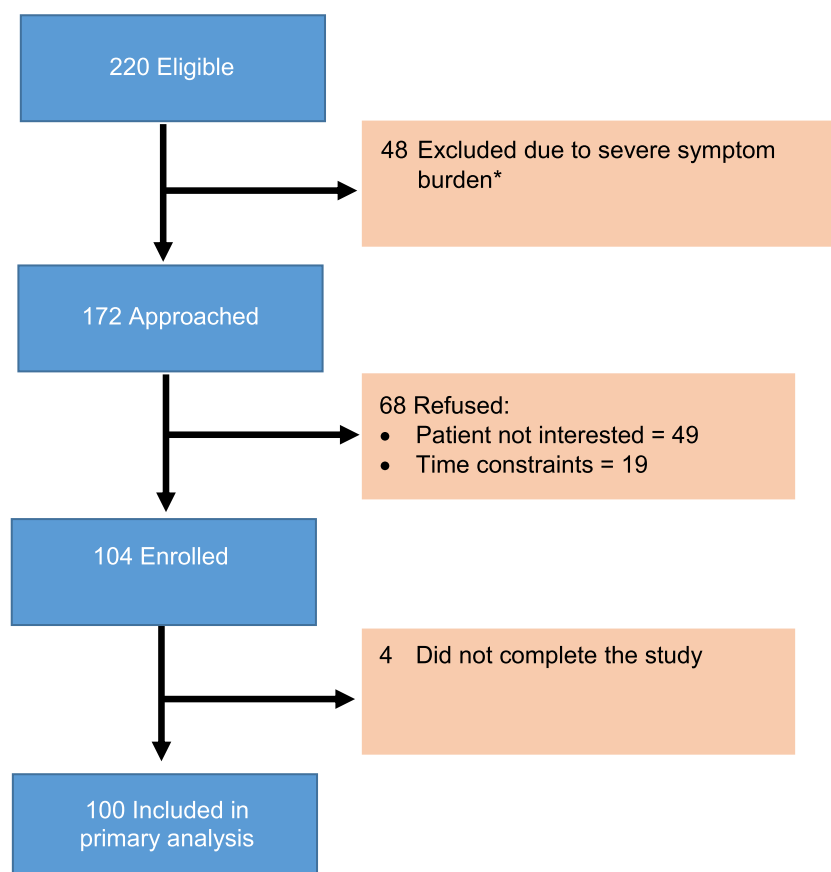


Fig. 1. Flow diagram of participant accrual information. *As determined by the physician.

medicine specialists and all 68 (100%) caregivers who accompanied patients participated in the study. The median (interquartile range) number of patients seen per physician was 6.5 (4.3–12.0). Table 1 summarizes the demographic and clinical characteristics of the study participants. The mean age was 59.7 years. Half of the participants were males. Seventy one (71%) were white, 64 (64%) were married, 87 (87%) were Christian, and 82 (82%) had college or higher education. Sixty-eight (68%) of the participants were accompanied to their clinic visit by a caregiver.

Table 2 summarizes the frequency of questions chosen by patients and caregivers to discuss with their

doctors during the consultation. Five of the top 10 patient questions (50%) selected by patients were about physical symptoms and treatment.

Patient and Physician Perception of the QPS and Consultation

Table 3 reports the patient and physician evaluations of the QPS and the consultation. Overall, patients had a positive perception about the QPS. Most of them agreed that the material was helpful in communicating with their doctor 75 (77%), clear to understand 87 (90%), had the right amount of information 81 (87%), and would either use a similar material in the future 74 (76%) or recommend it to other patients 67 (70%). Overall, 90 (92%) patients said they were satisfied with their consultation visit. Physicians also perceived the QPS as helpful to 68% of the patients in communicating with them. Moreover, they agreed that the QPS did not prolong the consultation visits in 69 (73%) of the clinic encounters. The physician agreement on helpfulness of the QPS was not significantly different from that of the patients (75% (70/93) vs. 69% (64/93), $P = 0.3$, McNemar's test).

Patient Anxiety Over the Course of Consultation

Table 4 summarizes the change in patient anxiety (STAI) scores before and after the consultation. The mean (SD) STAI anxiety score decreased significantly from 39.2 (12.8) preconsultation to 33.8 (10.7) postconsultation, $P < 0.0001$. Seventy-three (75%) patients disagreed that the QPS made them anxious.

Predictors of Patient Perception of Helpfulness of the QPS

In a univariate logistic regression analysis, presence of a caregiver (odds ratio [OR] 3.83, 95% CI 1.45–10.16, $P = 0.007$) and history of smoking (OR 3.35, 95% CI 1.04–10.80, $P = 0.04$) were the significant factors associated with patient perception of helpfulness of the QPS. However, in the multivariate analysis, caregiver presence was the only predictor of patient perception of helpfulness of the QPS (OR 3.45, 95% CI 1.28–9.33, $P = 0.015$).

Discussion

This is a prospective study evaluating a 25-item, single-page QPS developed using a Delphi technique and specifically designed for cancer patients attending outpatient palliative care.¹⁷ The patients' positive responses about the QPS and the high percentage of successful patient completion of the study (96%) suggest its feasibility in advanced cancer care

Table 1
Baseline Patient Demographic and Clinical Characteristics (N = 100)

| Covariate | Levels | n (%) |
|----------------------------------|----------------------------------|-------------|
| Mean age, years (SD) | | 59.7 (13.1) |
| Gender | Male | 50 (50) |
| Race/ethnicity | Caucasian | 71 (71) |
| | African American | 13 (13) |
| | Hispanic | 8 (8) |
| | Asian | 6 (6) |
| | Other | 2 (2) |
| Marital status | Married | 64 (64) |
| | Single | 16 (16) |
| | Divorced/separated | 13 (13) |
| | Widowed | 7 (7) |
| Highest education level | Less than high school | 2 (2) |
| | High School/vocational/technical | 16 (16) |
| | Associate degree/some degree | 29 (29) |
| | Bachelor's degree | 35 (35) |
| | Advanced degree | 17 (17) |
| | Other | 1 (1) |
| Employment status | Full time | 29 (29) |
| | Part time | 4 (4) |
| | Unemployed/disability | 24 (24) |
| | Retired | 38 (38) |
| | Other | 5 (5) |
| Performance status | 0–2 | 79 (79) |
| | >2 | 19 (19) |
| Presence of a caregiver | Yes | 68 (68) |
| | No | 32 (32) |
| Relationship to patient (n = 68) | Spouse | 40 (59) |
| | Child | 8 (12) |
| | Parent | 3 (4) |
| | Sibling | 6 (9) |
| | Other | 11 (16) |
| Religious preference | Christian (Protestant/Catholic) | 87 (87) |
| | Non-Christian | 8 (8) |
| | Not specified | 5 (5) |
| Cancer diagnosis | Gastrointestinal | 22 (22) |
| | Head and neck | 17 (17) |
| | Thoracic | 14 (14) |
| | Breast | 13 (13) |
| | Genitourinary | 12 (12) |
| | Gynecologic | 10 (10) |
| | Leukemia/lymphoma | 3 (3) |
| | Other | 9 (9) |
| Cancer stage | Advanced | 92 (92) |
| | Early | 8 (8) |

Table 2
Frequency of Questions Selected by Patients and Caregivers as Relevant to Discuss With Their Doctors During the Consultation

| | Question | n (%) |
|----------------------------|---|---------|
| Patients (N = 100) | | |
| 1 | If I have symptoms, what can be done to improve them (pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)? | 72 (72) |
| 2 | What symptoms may occur in the future and what should I do if they arise? | 55 (55) |
| 3 | What is the role of my primary care physician now that I have been referred to the palliative care team? | 48 (48) |
| 4 | What are the common side effects of my medications? | 44 (44) |
| 5 | How do I access the services by the palliative care team? | 42 (42) |
| 6 | How and when can I contact the palliative care team? | 42 (42) |
| 7 | How can I cope with the changes in my body as a result of this illness? | 40 (40) |
| 8 | Are there any medications that I should stop taking because of their interactions with the newly prescribed medication? | 39 (39) |
| 9 | What support is available for other people in my family, such as my caregiver or my children? | 38 (38) |
| 10 | Can I stop taking the pain medication if my pain goes away? | 37 (37) |
| 11 | Who are the members of the palliative care team and what do they do? | 32 (32) |
| 12 | What can I do if I am not coping? | 30 (30) |
| 13 | Who can I talk to about the medical care that I want in the future when I am no longer able to speak for myself? | 25 (25) |
| 14 | Is it feasible for me to die at home rather than in the hospital? | 22 (22) |
| 15 | What can I expect in my last days of my life? | 22 (22) |
| 16 | How do I get information about hospice? | 19 (19) |
| 17 | Can someone help me to communicate with other members of my family about what is happening to me? | 17 (17) |
| 18 | Is there someone I can talk to about my fears, concerns, spiritual, or religious needs? | 17 (17) |
| 19 | How do I get information about advance directives? | 17 (17) |
| 20 | How do I get my affairs in order and write a will? | 14 (14) |
| Caregivers (N = 68) | | |
| 1 | How can I best support the person that I am caring for? | 18 (27) |
| 2 | How do I get help if I am no longer able to take care of my loved one? | 14 (21) |
| 3 | Will you be able to tell me when it is getting close to the time that he/she will die? | 12 (18) |
| 4 | What skills will I need as a caregiver? | 11 (16) |
| 5 | What should I say when the person that I am caring for asks, "am I dying?" | 9 (13) |

consultations. The participating physicians also found the QPS as helpful in a high number of clinical encounters. Our study demonstrates the feasibility of a simplified and concise QPS developed using a rigorous methodological process.

Table 3
Patient and Physician Evaluation of the QPS and the Consultation (N = 100)

| Question | n (%) |
|---|---------|
| Patient assessment | |
| Agreed/strongly agreed that: | |
| The material helped me to communicate with my doctor. | 75 (77) |
| The information was clear to understand. | 87 (90) |
| The amount of information in the material was about right. | 81 (87) |
| I will recommend the material to other patients. | 67 (70) |
| I will use similar material or write questions down before I see my doctor in the future. | 74 (76) |
| The material helped me to think of questions or concerns I hadn't thought before. | 60 (63) |
| Overall, I am satisfied with the consultation visit. | 90 (92) |
| Disagreed/strongly disagreed that: | |
| The material made me anxious. | 73 (75) |
| Physician assessment | |
| Agreed/strongly agreed that: | |
| The question prompt sheet was helpful to the patient in communicating with me. | 64 (68) |
| The question prompt sheet did not prolong the consultation visit. | 69 (73) |

QPS = question prompt sheet.

The finding that patient anxiety significantly decreased immediately after the consultation is reassuring to clinicians who may be concerned about a seemingly negative impact the QPS can have on patients' psychological outcomes. It is difficult to determine whether this finding was specifically as a result of the use of the QPS, the actual physician interaction with the patient, or both. Similar studies showed that patient anxiety decreased immediately after^{20,22} six weeks²³ and four months²⁴ after initial consultation with the use of a QPS. Other studies showed that the QPS did not have any effect on patient anxiety immediately after consultation,^{4,20} one week after,²⁵ or one month after consultation.^{16,26} Brown et al.¹⁵ found that among patients who received the QPS, anxiety levels increased immediately after consultation but when the oncologist specifically addressed the QPS questions, the anxiety levels significantly reduced.

There is always the predictable apprehension among clinicians about adding another tool to an already significant number of existing ones for use in patient care, especially given the constraints of time availability at a busy outpatient clinical practice. It was therefore encouraging to find that a majority of physicians did not perceive the QPS as prolonging the consultation visit. Our group previously found that a QPS did not prolong the duration of visit,

Table 4
Patient Anxiety State Before and After Consultation

| | N | Median (Range) | Mean (SD) | PValue |
|---------------------------------------|-----|----------------|-------------|---------|
| Preconsultation anxiety (STAI) score | 100 | 41 (20–66) | 39.2 (12.8) | <0.0001 |
| Postconsultation anxiety (STAI) score | 98 | 32 (20–57) | 33.8 (10.7) | |

STAI = Spielberger State Trait Anxiety Inventory.

neither did it increase the physician or patient speaking time among patients attending a breast oncology clinic.²¹ This suggests that the QPS is a simple tool which may be used effectively to improve communication quality without increasing clinician burden. It also suggests that patients might be asking their most meaningful questions rather than simply asking more questions.

Our study showed that patients who were accompanied by a caregiver to the clinic were 3.5 times more likely to find the QPS helpful than those who were not accompanied by a caregiver. We are unable to determine the reason why this was so, but it is possible that the caregivers might have assisted the patients in using the QPS and hence impacted the patients' views about the QPS. More research is necessary to further investigate this finding. Caregivers play a vital role in the care of patients with advanced disease because they provide a complex array of tasks including personal and medical care, psychosocial support, and assistance with end-of-life decision making.²⁷ Hence, enlisting their participation in the care of the patient is essential in effective cancer management.^{28,29} None of the other potential factors was found to be associated with how helpful the QPS was. To our knowledge, our study is the only one that sought to examine the potential predictors of patients' perception of helpfulness of a prompt sheet in advanced cancer consultations.

We also found that patients were more interested in asking more questions about their symptoms and treatment and fewer questions about end-of-life issues. This may be because patients were meeting the supportive care specialist for the first time and preferred to first have their acute physical symptoms addressed. It is likely that once their acute physical symptoms were addressed and they got to know and build a therapeutic patient-doctor relationship with their physicians in the course of their care, they eventually discussed more sensitive topics such as end-of-life issues openly. In a study by Clayton et al.,²² patients and caregivers perceived the end-of-life questions as helpful in facilitating hitherto difficult discussions regarding the topic and readily endorsed them.

One limitation of this study is that it was a single-arm trial and hence the possibility of a significant placebo effect with this intervention could not be

eliminated. Future studies will need to be conducted in a randomized control fashion comparing the QPS with an attention control intervention such as a general information sheet. Second, study participants were recruited from a single tertiary academic palliative care center and had a higher level of education than the general cancer population. They may therefore not be fully representative of patients in other clinical settings. In future studies, it may be important to broaden participant invitation to include other palliative care patients with more diverse educational backgrounds and in different clinical settings. It might also be necessary to develop customized prompt sheets that are tailored to address the very specific issues in those clinical settings such as the intensive care unit, inpatient palliative care units, home hospice, and pediatric clinics. Another limitation of the study was that we were unable to record the number and type of questions that participants actually asked during their clinical encounter with their physicians. Future studies should record the details of the encounters to better understand how participants use the QPS in real time and which subject domains are of the greatest information needs.

Conclusion

In this study, we found that patients perceived the QPS as helpful in communicating with their doctors, clear to understand, having the right amount of information, and that they would either use a similar material in the future or recommend it to other patients. Patient anxiety significantly decreased immediately after consultation. Physicians also felt that the QPS was helpful in patient communication and it did not prolong clinic visits. Further studies are needed to further validate its usefulness and help facilitate its widespread adoption and integration into routine clinical practice.

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and Hilda Cantu contributed to the acquisition of data. Joseph Arthur, Jimin Wu, Diane Liu, and Eduardo Bruera contributed to data analysis and interpretation. Joseph Arthur, Eduardo Bruera, and Sriram Yennu contributed to article writing and revision. Joseph Arthur, Sriram Yennu, Kresnier Perez Zapata, Hilda Cantu, Diane Liu, Jimin Wu, and Eduardo Bruera contributed to the final approval of the article.

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Appendix

Palliative Care Question Prompt Sheet

The following are common questions that people with life-threatening illnesses sometimes ask their doctors. Please indicate the ones that you may like to ask today and the doctors will do their best to answer them.

The Palliative Care Team and Services

1. Who are the members of the palliative care team and what do they do?
2. How do I access the services offered by the palliative care team?
3. How and when can I contact the palliative care team?
4. What is the role of my primary physician now that I have been referred to the palliative care team?
5. Can someone help me to communicate with other members of my family about what is happening to me?
6. Is there someone I can talk to about my fears, concerns, spiritual or religious needs?
7. What support is available for other people in the family, such as my caregiver or my children?

Symptoms, Treatment, and Lifestyle

8. If I have symptoms, what can be done to improve them? (e.g., pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)?
9. What are the common side effects of my medications?
10. Are there any medications that I should stop taking because of their interactions with the newly prescribed medication?
11. Can I stop taking the pain medication if my pain goes away?
12. What can I do if I am not coping?
13. Who can I talk to about the medical care that I want in the future when I am no longer able to speak for myself?
14. What symptoms may occur in the future and what should I do if they arise?
15. How can I cope with the changes in my body as a result of this illness?

End-of-Life Issues (The Following Questions May or May Not Be Relevant to You or Your Stage of Illness. If You Would Like to Discuss Any of Them Today, We Will Encourage You to Ask Your Doctor)

16. How do I get my affairs in order and write a will?
17. How do I get information about advance directives?
18. How do I get information about hospice?
19. Is it feasible for me to die at home rather than in the hospital?
20. What can I expect in my last days of my life?

For Caregivers (If You Have a Caregiver, the Following Questions May or May Not Be Useful for Them)

21. How do I get help if I am no longer able to take care of my loved one?
22. What skills will I need as a caregiver?
23. How can I best support the person that I am caring for?
24. What should I say when the person that I am caring for asks, "am I dying?"
25. Will you be able to tell me when it is getting close to the time that he/she will die?