

**Introduction and Informed Consent:**

*Hello this is RM/LB from the University of Pittsburgh Medical Center. May I please speak with Mr./Mrs. \_\_\_\_\_?*

Hello, my name is RM/LB. I am a researcher at the University of Pittsburgh working with Dr. S from the Department of Medicine. How are you today?

Great. I am calling you to talk you about a research study we are conducting and to see if you would like to participate. We sent you a packet about the study in the mail. Did you receive a packet from your oncologist with information about Dr. S's "Caring for Patients with Cancer" study?

*(If Yes)* Great! The packet explains the study, but as a reminder

*(If no)* Okay, no problem. Let me tell you a little about the study.

The purpose of this study is to better understand the needs of people with cancer. If you choose to participate, the study involves a single phone interview. The interview will take about 30 minutes.

We can conduct the interview now or at a time that is more convenient for you. Would you be willing to help us by participating in the study?

*(If no)* Thank you very much for your time.

*(If Yes):* Great. Before we begin I need to tell you what the study will involve from you. Is that okay?

*(If now is not a good time):* Can we set up a time when I can call you back?

Information gained from this study will help us learn how to better meet our patients' needs. Your participation is completely voluntary. Choosing not to participate will not affect your medical care in any way.

The study is a 30-minute interview. I will ask you about some of the services that are available to people with cancer and about some of the things that people with cancer sometimes need from their health care providers. You can decide to stop the interview at any time. Also, it is possible that some of the questions I ask will make you feel uncomfortable or distressed; if so, please let me know. You are free to decide not to answer any question.

We will not share your answers with your doctor or anyone outside of the research team. Your name will not be used in any published reports about this study. All the information gathered will be associated with an ID number only, not your name. If you have questions about the study you can ask me or talk with Dr. S at any time. Our contact information is in the letter your oncologist sent you or I can provide that for you again now if you prefer.

Do I have your permission to begin the interview now?

*If yes:* Great, thank you for participating. So let's begin.

*If no:* Okay. Is there a better time for me to talk with you and conduct the interview?

*If yes—record that time* (thank you, I will give you a call then.)

*If no—Okay.* Thank you for your time.

**A. Palliative/Supportive care Awareness, Knowledge, Previous Experiences**

**Interviewer: I want to ask you about one of the services that is available to people with cancer. Please answer the questions to the best of your ability, okay? Great, let's begin:**

1. Have you ever heard the term palliative/supportive care?    Yes    No

2. How did you hear about palliative/supportive care? *(ask only if Yes to 1)*

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3. I realize you may have never heard of or have not heard much about palliative/supportive care, but can you please describe in your own words what you think palliative/supportive care is?

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4. For this question you can refer part one of the interview guide that came in the mail if you have it. Do you have it?

*(If yes:* great, it will be helpful. You can look at the guide to help visualize the scale for the answer choices)

*(If no:* oh don't worry, that is no problem).

Please rate your overall understanding of what palliative/supportive care services offer with a number from 0 to 10. Zero means that you do not understand at all what palliative/supportive care services offer and 10 means you completely understand what palliative/supportive services offer.

5. (If the patient has the interview guide: You can refer to section two of the interview guide for help).

Please rate how favorable your overall impressions of palliative/supportive care services are on a scale from 0, which means not at all favorable, to 10, which means most favorable.

6. Have you ever seen a specialized palliative/supportive care doctor or nurse?      Yes      No

7. Tell me about why you saw a palliative/supportive care doctor or nurse? (ask only if Yes to 6)

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8. Under what circumstances would you be interested in seeing a palliative/supportive care doctor or nurse (ask only if No to 6)

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## **B. Palliative/Supportive Care Description**

*Randomized to traditional of patient-centered description*

**Great, Thank you for answering those questions.**

B2. Description:

**Interviewer:** There is a palliative/supportive care clinic here at XX. I would like to tell you a little bit about palliative/supportive care and then ask you a couple more questions.

**[Traditional Description]:** Palliative/Supportive care is specialized medical care for patients with life-limiting illness. This type of care is focused on the management of symptoms such as pain, nausea, anxiety, and stress for patients with advanced cancer. The goal is to improve patient’s quality of life. Emphasis is placed on communication and coordinated care with the patient’s cancer doctors. Palliative/Supportive care is appropriate from the time of diagnosis with a life-limiting illness and can be provided together with other cancer treatments such as chemotherapy or radiation.

**[Patient-Centered Description]:** Palliative/Supportive care is specialized medical care for people with serious illness. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient’s cancer doctors to provide an extra layer of support. Palliative/Supportive care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

## **C. Palliative/Supportive Care Impressions, Perceived Needs, and Intended Actions**

Now, I would like to ask a few more questions about this definition of palliative/supportive care. For these questions your answers will be a number from 0 to 10.

*(If the subject has the interview guide: You can refer to the interview guide to help you understand the answer choices)*

**I will explain the answer choices. Are you ready to begin? Okay great.**

1. Please rate your overall understanding of what palliative/supportive care services offer on a scale from 0—do not understand at all to 10—completely understand)

2. Please rate how favorable your overall impressions of palliative/supportive care services are on a scale from 0—not at all favorable to 10—most favorable)

**For the following statements about palliative/supportive care, please rate how strongly you agree or disagree on a scale from 0, which means you strongly disagree with the statement, to 10, which means you strongly agree with the statement.**

3. Palliative/supportive care services would be helpful to me or my family now.  
(0—strongly disagree to 10—strongly agree)
4. Palliative/supportive care services would be helpful to me or my family in the future.  
(0—strongly disagree to 10—strongly agree)
5. I am likely to ask my oncologist if I can see a palliative/supportive care doctor.  
(0—strongly disagree to 10—strongly agree)
6. I would be willing to see a specialized palliative/supportive care doctor if my oncologist recommended it.  
(0—strongly disagree to 10—strongly agree)

#### **D. Needs Assessment**

##### **Interviewer:**

**Thank you for answering those questions. You are really helping us to better understand the needs of people with cancer. Now, I am going to read you a list of things that people with cancer sometimes need from their healthcare providers. These needs can be medical, emotional, social, or spiritual. We are interested in knowing if you have needed any of these items in the last month.**

**So first, I am going to read you the list of things that people with cancer sometimes need. If the item is something you have needed in the past month, regardless if the need has been met by anyone—please say yes. If the item is not something you have needed in the past month, please say no.**

**Do you understand?**

**We are also interested in how well we are meeting your needs. So, if you state that you have needed help with an item I will ask you if that need has been met fully, partially, or not at all.**

**As a reminder, all of your responses will be kept completely confidential. This information will NOT be shared with your cancer doctors and will not affect your treatment in any way. Do you have any questions before we begin?**

**OK, let's begin. For each item I read, please tell me whether it is something you have needed in the past month by simply answering Yes or No.**

In the last month, have you needed:

Medical Communication (*do not read title*)

1. Information about factors that could affect the course of your cancer
2. Quick information about your medical test results
3. Information from doctors about your prognosis
4. Information from doctors about your treatment
5. Information from doctors about side effects from your treatment
6. Information from doctors about potential complications from your cancer

In the last month, have you needed:

Psychological/Emotional (*do not read title*)

7. Help coping with fears about the cancer spreading
8. Help coping with frustration about not being able to do the things you used to
9. Help dealing with concerns about your family's fears and worries
10. Help dealing with fears about what is going to happen to you
11. Help dealing with feeling dependent on others
12. Help coping with fears about pain or suffering
13. Help dealing with concerns about your family's ability to cope with caring for you
14. Help dealing with anxiety or stress

**Okay, thank you we are about halfway through the list.**

In the last month, have you needed:

Symptom (*do not read title*)

15. Help dealing with lack of energy or tiredness
16. Help dealing with loss of appetite
17. Help coping with difficulty eating and/or swallowing
18. Help coping with lack of bladder or bowel management (e.g., constipation)
19. Help dealing with pain
20. Help dealing with feeling unwell a lot of the time
21. Help coping with breathing difficulty
22. Help dealing with having trouble concentrating

In the last month, have you needed:

Daily Living (*do not read title*)

23. Help doing work around the house
24. Assistance with preparing meals
25. Help finding transportation to medical appointments, shopping, or work

Ok, just a few more items. Thank you for your participation.

In the last month, have you needed:

Spiritual/Existential (*do not read title*)

26. Help setting new priorities for your life
27. Assistance with having your spiritual needs met
28. Help finding support from a religious group
29. To talk about religious or spiritual needs with your doctors

In the last month, have you needed:

Social (*do not read title*)

30. Help being able to express your feelings with friends and/or family
31. Help dealing with the reactions by your family and/or friends to your illness
32. Help dealing with maintaining relationships with family members

## **E. Demographics/Clinical**

**Great we are almost finished. I just have a few more questions to ask you about yourself.**

1. How long ago were you first diagnosed with cancer? \_\_\_\_\_
2. How long have you been receiving care from your current oncologist (insert Dr. name)?
3. Do you identify as:
  - Hispanic or Latino
  - Not Hispanic or Latino
  - Unknown
4. How do you describe your race or ethnicity? \_\_\_\_\_

*[Interviewer should categorize the patient's answer into one of the following categories. If no spontaneous response, say:]*

Are you:

- White
- Black or African American
- Asian
- Native Hawaiian or Other Pacific Islander
- American Indian/Alaska Native
- Unknown or Not reported

5. What is the highest level of education you have completed?  
[If no spontaneous answer, say: choose from one of the following]  
Less than high school  
High school diploma or GED  
Some college  
Completed college  
Some graduate study  
Graduate or professional degree
6. What is your total household income, including all earners?  
[if no spontaneous answer say: choose one of the following]  
Less than \$10,000  
\$10,000–\$29,999  
\$30,000–\$49,999  
\$50,000–\$69,999  
\$70,000–\$99,999  
\$100,000–\$149,999  
More than \$150,000  
Decline to answer

7. How important is religion or spirituality to you?  
Please choose (*read answer options*):  
Very important      Somewhat important      Not important

8. What is your religious affiliation? \_\_\_\_\_  
(if no spontaneous answer say: choose one the following)  
Catholic  
Non-Catholic Christian  
Jewish  
Muslim  
Buddhist  
Hindu  
Unaffiliated (atheist/agnostic)

9. In general, would you rate your quality of life?  
(*read answer options*):  
Excellent      Very Good      Good Fair      Poor

Great! We are finished with the interview. Thank you very much for participating in our research. If you have any questions feel free to contact Dr. S or me. Our contact numbers are on the packet you received in the mail. Okay? Great, have a good day. Goodbye.