

SUPPLEMENTAL FILE

A. PATIENT FOCUS GROUP DISCUSSION GUIDE

[Moderator introduces focus group and welcomes participants]

SECTION I: I would like to start by having you all take a moment to think about what good quality of life means to you.

1. What does good quality of life mean to you?
 - What types of things come to mind when you think of having a good quality of life?

2. Now I want you to focus specifically on the last month. Over the last month, how would you describe what good quality of life means to you?
 - In the last month, what have been your most important needs related to maintaining the quality of life you want?

 - Can you describe the ways, if any, in which you are trying to meet those needs?

 - Can you describe any ways in which meeting these needs has been difficult?

3. What, if anything, have you found to be most helpful in supporting your quality of life?

4. What role, if any, does family, community, play in meeting your needs?

5. What role, if any, do home care services, play in meeting your needs?

6. Are there additional support or services that helped with meeting your needs that we have not mentioned?

7. Can you describe what role, if any, your oncologist has played in addressing the needs you described above related to your quality of life? (*probes: what was most helpful? What was most difficult?*)

SECTION II: Now I would like to focus a bit more on some issues related specifically to patients with blood cancers.

Sometimes patients with blood cancers need blood transfusions during the course of their illness. There isn't a lot known about how patients feel about transfusions, and we are interested in better understanding the relationship, if any, between transfusions and quality of life.

8. Have you ever received a blood transfusion?
 - If yes → can you describe any ways in which the transfusion impacted your quality of life?
 - o For example, has it impacted your QoL for better or for worse? (*probes: tiredness, energy, time-consuming waiting for labs and transfusion, traveling to clinic as a burden*)
 - How did the impact of the transfusion compare to your expectations regarding the transfusion and its effect on your quality of life?
 - o Were there any impacts/aspects associated with transfusions that were surprising or unexpected?
 - Based on your experience, overall, how do the benefits of transfusions compare with the drawbacks? (*probe: do you feel benefits [quote their earlier responses on positive impact] outweigh drawbacks [quote their earlier responses on negative impact]*)
9. When you consider your quality of life right now, how important or unimportant is it for you to have continued access to transfusions?
10. Is there anything else about transfusions and QoL that you think we should know or consider?

SECTION III: Now I would like to ask for your feedback about a program to address quality of life needs of patients with blood cancers.

11. From your perspective, what should be the top priority of the program?
 - What specific services do you think should be included in this program?

[Moderator gives participants a handout with a list and description of the following services: home health aide, visiting nurse, social worker, chaplain, virtual visits with

oncology team, access to transfusion, nutrition service, respite care].

Now, we would like to get your perspective on a few different services. On this handout, you will see a table that lists eight services. Please take a moment to consider and rank the services listed in terms of how they relate to your quality of life with #1 being the most important and #8 being the least important.

12. What did people select for their #1?
 - What do you like about this service?

 - What makes it a top priority for you?

13. What did people select for their #8?
 - What don't you like about this service?

 - What makes it a low priority for you?

 - Should it be removed from the list?

14. Are there any additional services that you think should be added to this list?
 - What type of additional support or services, if any, would be helpful for addressing needs related to your quality of life?

Thank you again for taking the time to share your experience and opinions, those are all the questions I have for you today. However, I would like to take a moment to ask if there is anything else that you think is important or that you would like to add to our discussion today.

B. BEREAVED CAREGIVER FOCUS GROUP DISCUSSION GUIDE

Guide for bereaved caregivers whose loved ones did not enroll in hospice:

[Moderator introduces focus group goal and welcomes participants]

SECTION I: First, I want you to think back to the last three months of your loved one's experience with his or her blood cancer.

1. In that context, what did a good quality of life mean to your loved one?
 - What types of things come to mind when you think about how your loved one would describe a good quality of life during the last three months of their life?
 - What were their priorities around quality of life during this time?
 - What were their most important needs related to maintaining the quality of life they wanted?
2. Can you describe the ways, if any, in which your loved one tried to meet those needs in their last three months of life? For example, what types of things did they try to do to maintain the quality of life they wanted?
 - What, if anything, did they find most helpful in supporting their quality of life?
 - What, if anything, did they find difficult, when it came to maintaining the quality of life they wanted?
3. What role, if any, did family or community play in meeting their needs?
4. What role, if any, did home care services play in meeting their needs?
5. Were there additional supports or services that helped with meeting your loved one's needs and maintaining their quality of life?
6. Can you describe what role, if any, that their oncologist played in addressing their quality of life needs? (*probes: what was most helpful? What was most difficult?*)

SECTION II: Now I'd like to focus a bit more on some issues related specifically to patients with blood cancers.

Sometimes patients with blood cancers need blood transfusions during the course of their illness. There isn't a lot known about how patients or their caregivers feel about transfusions, and we are interested in better understanding the relationship, if any, between transfusions and quality of life.

7. Did your loved one ever receive a blood transfusion during the course of his/her blood cancer?
 - If yes → can you describe any ways in which the transfusion impacted the quality of life for your loved one?
 - o For example: did it impact their QoL for better or worse? (*probes: tiredness, energy, time-consuming waiting for labs and transfusion, traveling to clinic as a burden*)
 - How did the impact of the transfusion compare to your expectations regarding its potential effect on their quality of life?
 - o Were there any impacts/aspects associated with transfusions that were surprising or unexpected?
 - Based on your experience, overall, how did the benefits of transfusions compare with the drawbacks? (*probe: do you feel benefits [quote their earlier responses on positive impact] outweigh drawbacks [quote their earlier responses on negative impact]*)
8. Based on your experience with your loved one's quality of life, how important or unimportant do you think it is for patients with blood cancers to have access to transfusions in the last few weeks and months of their life?

SECTION III: I now want to focus on the support services that your loved one used in their last few weeks of life.

9. Can you describe any supports or services that were most helpful?
10. Were there any additional support or services that you wished could have been available to your loved one during the last three months of life?
 - If yes → please describe such services.

11. If you had to design a program that would provide support to address the quality of life needs for patients with blood cancers in the last three months of life, what would be the top priority?

- What are the three most important features that you think should be available? Why are they important to you?

[Moderator gives participants a handout with a list and description of the following services: home health aide, visiting nurse, social worker, chaplain, virtual visits with oncology team, access to transfusion, nutrition service, respite care].

Now, we would like to get your perspective on a few different services. On this handout, you will see a table that lists a few services that may be helpful to patients with blood cancers. Please take a moment to consider and rank the services listed in terms of how they relate to quality of life with #1 being the most important and #8 being the least important.

12. What did people select for their #1?

- What do you like about this service?
- What makes it a top priority for you?

13. What did people select for their #8?

- What don't you like about this service?
- What makes it a low priority for you?
- Should it be removed from the list?

14. Are there any additional services that you think should be added to this list?

- What type of additional support or services, if any, would be helpful for addressing needs related to quality of life?

15. Is there anything else related to quality of life in the last weeks of life that you think is important to consider?

Thank you again for taking the time to share your experience and opinions, those are all the questions I have for you today. However, I would like to take a moment to ask if there is anything else that you think is important or that you would like to add to our discussion today.

Guide for bereaved caregivers whose loved ones enrolled in hospice:

Sections I, II, and III are included in this guide with an additional section focused on hospice as noted below:

As you all cared for loved ones who received hospice services during the course of their disease, I would now like to ask some questions about your loved one's experience with hospice care.

1. Think back to the decision to enroll in hospice. I would like you to walk me through the decision-making process and how your loved one and you made the decision to enroll in hospice.
 - What was that process like for you and your loved one?
 - Who made the final decision?
 - Who else was involved in the decision?
 - What was the most important factor in making the decision? Why? (*probe: what types of issues played the biggest role in this decision?*)
2. How would you describe the role of hospice, if any, as it related to your loved one's quality of life? (*probes: role as resource for pain control, helping to keep loved one out of the hospital, helping loved one and family feel comfortable with decision for no additional chemotherapy, helping to share responsibility of caregiving*)
3. Overall, how would you rate your experience with hospice care?
 - What did hospice do really well? (*probes: pain control, emotional support, practical support with bathing, toileting, and caring for loved one*)
 - What did hospice not do so well?
4. Did you face any obstacles in using hospice?
5. How did your experience with hospice care compare to your expectations of hospice?
6. Were there any additional support or services that you wished could have been available to your loved one during the last three months of life? If yes, please describe such services.