**Appendix: Semi Structured Interviews**

**Caregiver Video Diary Guidelines**

Introduction

As part of our study exploring patient and caregiver experiences with homebound stem cell transplantation, we are asking you to engage in a video diary exercise in order so that you can directly share your own unique views and experiences with caring and providing support to your loved one who has received a homebound transplant for his/her cancer.

We are providing you with a password-protected iPad that you will use to record your video diary entries, as well as instructions describing how to use the iPad to record your entries, and the password for the iPad.

We would like you to record a total of three video diary entries, at the following time periods: (1) one entry between days 1-5 following your loved one’s transplant; (2) one entry between days 6-9 following your loved one’s transplant; and (3) one entry between days 10-14 following your loved one’s transplant. Please video record all of your entries privately, and do not record other individuals in your entries. Also, when recording your entries, please do not mention your name, your loved one’s name, or the names of any other individuals. Instead, if necessary you can refer to such individuals as “the patient,” or by their relationship to you (e.g., my daughter/son/mother, etc.).

Please try to be as honest as possible in your responses to the prompts explored during the video diaries. There is no right or wrong answer to any of the questions that we are asking you to respond to. Please be assured that all information you share will be kept confidential and any comments that you might share about the care your loved one received at MSK will not in any way be shared with his or her MSK health care team, and will not affect your loved one’s medical care going forward.

If at any point you experience technical difficulties with recording your video diary entries, or would like any other assistance in regards to your diary entries, please contact a member of the MSKCC research team, at 646-888-0149.

Thank you very much for sharing your story.

Video diary prompts

If possible, please take about 15-20 minutes to record each diary entry; you can take more time if you would like. In response to each of the prompts below, please feel free to narrate your experiences and/or use a “show and tell” approach to illustrate any aspects of or items in the home environment that were important to you on the day of each entry.

For each of the three entries, please respond to the following prompts:

1. Please tell us what it was like to be a caregiver today.

2. What activities did you engage in today to take care of yourself and to assist you in your role to help your loved one?

3. What, if anything, was specifically challenging for you as you helped your loved one recover from his/her transplant today?

4. What, if anything, helped you in your role as a caregiver throughout your day?

5. Please show and describe to us anything in your home environment that was important to you as you provided care to your loved one today.

6. Please reflect on and describe today’s experience of handling nursing tasks necessary for the care of your loved one in the home environment.

7. Please share anything else that you think would be important for us to understand your experience as a caregiver today.

For entries 2 and 3, please respond to the following prompt:

8. How has your experience as a caregiver changed, if at all, since the prior diary entry that you recorded?

\*\*If you have any questions or concerns regarding your care, please speak directly to your caregiver and clinical team immediately.

**Caregiver Focused Individual Interview Guide**

*Discussion of caregiver video diary entries*

First, I would like to ask you some questions in regards to the video diaries that you generated during the study.

You recorded \_\_\_ (interview to indicate the number of video diaries recorded by caregiver) separate video diaries during the home care portion of the study. In orer to gain a better understanding of the homecare experience, we reviewed your entries, and looked for patterns of themes. A theme that seemed to emerge was “x” (interview to verbally indicate theme.) Can you talk a bit about that?

*The following question will be asked if applicable*

In reviewing your video diary entries, we had questions regarding certain content that you recorded that we are hoping that you can clarify. Can you clarify the following \_\_\_\_\_\_\_ (interviewer to prompt the participant to speak about a certain issue needing clarification identified prior to the interview)?

*Exploratory warm-up question*

In general, please share with me what your experience was like providing care to your loved one in the home environment during and following their stem cell transplant.

**Challenges experienced during the homebound process**

*If caregiver mentioned challenges in response to previous questions, begin with:*

You have talked about some challenges you experienced as you provided care to your loved one during and following their stem cell transplant in the home environment. Please tell me a little more about these challenges.

*If caregiver does not mention challenges in response to previous questions, begin with:*

What challenges, if any, have you experienced as you have provided care to your loved one in the home during and following their stem cell transplant?

*If caregivers have not already spoken about the issues below, please ask the following questions of all participants:*

What challenges, if any, have you had with your family? Your work? Your own health? If you do have any health problems, can you describe these and how you are able to manage your own health as well as the well-being of (insert name of patient)?

What has been most helpful for you in coping with these challenges? What has not been helpful or has made things more difficult?

Were there certain periods of the transplant process that were more difficult than others? If so, please describe which periods and why they were challenging for you

What have been the most difficult aspects of providing care in the home for someone who has been treated with a stem cell transplant that you have experienced? How did you attempt to cope with these challenges?

**Positive experiences during the homebound transplantation process**

Now I would like to turn to discuss whether you have had any positive experiences during the transplantation and recovery period at home.

*If caregiver mentioned positive changes in response to previous questions, begin with:*

You just spoke about challenges you’ve faced as a caregiver. You also spoke about some positive things that occurred since you began taking care of (insert name of patient) in the home during and following their transplant. Please tell me more about these positive changes.

*If caregiver did not mention positive changes in response to previous question, begin with:*

You just spoke about challenges you’ve faced as a caregiver. Now I’d like to ask you about whether there have been any positive changes that may have occurred for you since you began providing care of (insert name of patient) in the home during and following their transplant. What positive changes have you experienced, if any, during that time period?

***Assessment of their personal homebound transplantation caregiving experience and interactions with medical staff***

Now I would like to understand further the personal experiences you have had in providing care to (insert name of patient) during the homebound transplant process.

What feelings did you have surroundings providing care for your patient in the home? (probe specifically on degree of anxiety experienced in regards to this issue if not proactively offered by participant) (probe only if participant struggles to answer question above: For example, how did you feel about your need or ability to maintain a clean home environment?

To what extent did you experience any anxiety or stress during your caregiving experience in the home setting?

If you do feel you experienced any anxiety or stress, do you feel it was related to the fact that you provided the care in the home setting? If yes, how specifically? To what extent have you experienced any anxiety or stress after the home care portion of the study was completed?

*To be asked only if caregivers who reported feeling anxious in providing home-based care:*

How did your providers and interactions with your providers influence the extent of the anxiety that you experienced regarding the transplant process? Did they lower your anxiety?

**Overall assessment of the study**

Please comment on how the transplant and recovery afterwards compared to what you had expected prior to the transplant.

Reflecting back, how did you feel regarding your ability to complete the tasks (i.e. questionnaires, stool samples) asked of you during the study?

What was it like to create the video diaries as part of this study? Did you find them beneficial in any way? Why or why not?

**Conclusion**

We are extremely grateful for your openness and willingness to talk about these topics how was the experience of talking about the topics we discussed during this interview?

Is there anything else relevant to your caregiving experience that you would like me to know?

Thank you very much for your talking to me about your experience providing care to (insert name of patient) during his/her transplant today. We greatly appreciate it!