

## **APPENDIX: Semi-structured Interview Script**

### **Experiences of Caregivers of Individuals with Newly Acquired Stroke: A Qualitative Study in Inpatient Rehabilitation**

Below is a list of open-ended questions that will serve as a basis for our interview. Following the format of qualitative methodology, we may ask you additional questions to more fully understand your experience as a caregiver/support person of one of our patients. Should you choose not to answer any of the questions, your loved one's current and future care at The Mayo Clinic will not be affected. We intend to use your answers to develop a description of the lived experience of being a caregiver/support person participating in inpatient rehabilitation following stroke.

#### **Interview Questions:**

##### **Concerns/worries/fears:**

Prompt: These questions are targeted at understanding any concerns/worries/fears you may be experiencing related to your loved one.

Open-ended questions:

1. Since your loved one had a stroke, what has been your biggest concern or source of fear?
2. Describe a specific instance where you were concerned or fearful regarding your loved one.
3. What are you currently most worried about regarding your loved one?
4. What have you found to be helpful in dealing with these feelings?
5. What advice would you have for developing a program to help families address these?

##### **Understanding of the diagnosis and treatment:**

Prompt: Next, we would like to ask you some questions about your perception and understanding of your loved ones diagnosis and treatment.

1. How well do you feel that you understand your loved ones medical diagnosis of\_?
  - a. If you feel you have a poor understanding of their medical diagnosis how has this affected you?
  - b. If you feel you have a good understanding, what factors have contributed to your understanding?
2. How well do you feel that you understand what the medical team is doing to help your loved one?
  - a. If you feel you have a poor understanding of their medical management how has this affected you?
  - b. If you feel you have a good understanding, what factors have contributed to your understanding?
3. How well do you feel that you understand what the therapy team (PT's, OT's, and SLP's) is doing to help your loved one?
  - a. If you feel you have a poor understand of their medical diagnosis how has this affected you?
  - b. If you feel you have a good understanding, what factors have contributed to your understanding?
  - c. What, if anything, have they done to help you?

**Preparing For Home:**

Prompt: Next we would like to ask you questions about preparing to take your loved one home. Open-ended questions:

1. Describe your experience with this aspect of your family member's care?
2. Do you feel you are prepared for dismissal home with your loved one?
  - a. Are there specific experiences that have made you feel more prepared?
3. Are there certain aspects of preparing to go home that have been particularly challenging to you?
4. What, if anything, are you most worried about in regard to returning home?

**Caregiver Support**

Prompt: Last, I would like you to think about the physical and emotional support you have received while your loved one has been staying here at the rehabilitation hospital.

Questions:

1. Have you felt supported?
  - a. If so, how?
  - b. How has this impacted you?
2. If our staff were to improve in our ability to support you during this time, what would that look like?

**COVID-19 (Asked only of the participants who experienced the COVID-19 visitor policy restrictions; specifically participants 3-11)**

Prompt: Now I would like you to think about the effect of COVID-19 on your experience?

1. What is it like to go through two problems at the same time: the current health problems of your loved one along with the pandemic?
2. How do you think your experience would have been different if there was no pandemic right now?
3. Without visitation restrictions, what do you think your experience would have been like?