

APPENDIX A: SEMI-STRUCTURED INTERVIEW GUIDE

At the point of the interview, the respondents have already received a consent form during the first clinical encounter which details the study and research process in detail. Before starting the interview, the researchers paraphrase the most important points of the consent form content once again:

Thank you very much for agreeing to participate in this interview. As we explained to you when we first met you at the epilepsy center, we are interviewing you to better understand what patients and their caregivers think about experiences with surgical treatments for brain function. It is important to know that there are no right or wrong answers to any of our questions, we are interested in your own experiences and views. Also, your participation in this study is voluntary and your decision to participate, or not participate, will not affect the care you currently receive. You also have the right to withdraw from the study at any point, whether during the interview or afterwards, without penalty or loss of benefits to which you are otherwise entitled.

The interview should take approximately one hour depending on how much information you would like to share with us. And with your permission, we would like to audio record the interview. All responses will be kept confidential. This means that your de-identified interview responses will only be shared with research team members. We will also make sure that any information we include in our articles and reports does not identify you as the respondent. You may decline to answer any question or stop the interview at any time and for any reason. Are there any questions about what we have just explained? May we turn on the digital recorder?

1st INTERVIEW

Beginning of the interview

Please note that this guide only represents the main themes to be discussed with the participants and as such does not include the various prompts that may also be used (examples given for each question). Non-leading and general prompts will also be used, such as “Can you please tell us a little bit more about that?” and “What does that look like for you”.

1) Discussion of Observed Visit

Open the interview by discussing the observed clinic visit.

- 1.1. Ask the patient/caregiver to explain what happened during that visit in their own words.
- 1.2. Explore any notable aspects of the visit that made it into the field notes.
- 1.3. Explore the patient/caregiver relationship with their healthcare providers – not just the physician/neurologist but also the other members of the care team.
- 1.4. Also explore their feelings about the clinic as a place to get healthcare and how this compares to other places where they receive care.

Use the discussion of the visit to establish rapport and get a sense of the patient/caregiver comfort level discussing ethical concerns and issues of patient authenticity.

2) Personal Background

Explore any issues of personal background

- 2.1. Where did you grow up?
- 2.2. Go to school?
- 2.3. What about brothers or sisters?
- 2.4. What kind of work have you done in your life?
- 2.5. Spouses or partners?
- 2.6. What about children?

Use this portion of the interview to explore and document any previous discussions of what the patient/caregiver considers the patient's authentic self.

3) Illness History Get a detailed social history of the illness from the perspective of the patient/caregiver.

Get a detailed social history of the illness from the perspective of the patient/caregiver.

- 3.1. How was the illness discovered and diagnosed?
- 3.2. What types of treatments has the patient pursued?
- 3.3. Were there treatment options that were considered but not pursued?
- 3.4. What has been happening recently in terms of treatment?
- 3.5. How has it affected the patient's/caregiver's life?
- 3.6. Work?
- 3.7. Relationships with other people?
- 3.8. What about past illness experiences?

Be sure to explore the various ups-and-downs in the illness history, particularly if there were times when symptoms impacted day to day quality of life or turning points where management of the illness assumed different intensity.

Ask about significant past illness experiences of family or others.

4) Fears and Hopes for Medical Care

Focused discussion of the particular illness condition and health in general.

4.1 Explore what kinds of outcomes the patient/caregiver would consider “successful” management of the illness and why.

4.2. Discuss fears the illness raises and how the patient/caregiver manages or addresses those issues day to day.

4.3. Explore the roles of healthcare providers, family, and other caregivers as they impact hopes of success or fears of illness.

4.4. How are important (and everyday) treatment decisions made?

4.5. Are some types of decisions made more by the patient and others in discussion with caregivers?

4.6. What about the role of providers in decision-making?

Use this section of the interview to explore the dynamics of healthcare decision making.

5) Conclusion

Conclude the interview by inquiring whether there are any other issues that the patient/caregiver would like to discuss that have not yet been raised.

5.1 Is there anything else that you would like to comment on that we haven’t already asked you about?

5.2 Are there any questions you would like to ask us?

Thank you very much for your time and the information you shared today.

2nd INTERVIEW

Beginning of the interview

Please note that this guide only represents the main themes to be discussed with the participants and as such does not include the various prompts that may also be used (examples given for each question). Non-leading and general prompts will also be used, such as “Can you please tell us a little bit more about that?” and “What does that look like for you”.

6) Discussion of Observed Visit

Open the interview by discussing the observed clinic visit.

6.1. Ask the patient/caregiver to explain what happened during that visit in their own words.

6.2. Explore any notable aspects of the visit that made it into the field notes.

Use the discussion of the visit to re-establish rapport.

7) Experiences since surgery

Get a detailed history of the illness, treatment and recovery – since the surgery - from the perspective of the patient/caregiver.

- 7.1. How did the patient experience the surgery and the aftermath?
- 7.2. Where there differences in how the patient felt comparing their state before and after surgery
- 7.3. How was the experience of receiving stimulation for the first time?
- 7.2. Where there differences in how the patient felt comparing their state before and after stimulation
- 7.3. How have the seizure events changed since the procedure and since receiving stimulation
- 7.4. How has the treatment affected the patient's/caregiver's life?
- 7.5. Is the patient able to do certain things they were not able to do before?
- 7.6. How does the patient feel about having an implanted stimulation device in their brain?
- 7.7 How has the patient's environment, personal and/or professional, reacted to the patient's treatment?
- 7.8. Does the patient share if they are receiving brain stimulation and if so, with whom?
- 7.9. What changes have the patient/caregivers noticed since stimulation has been turned on?

Be sure to explore the various ups-and-downs in the recovery process and since stimulation, particularly if there were times when the stimulation impacted day to day quality of life or turning points where the management of the illness changed.

Use this portion of the interview to explore and document any previous discussions of what the patient/caregiver considers the patient's authentic self.

8) Experience with brain data

Explore how the patient/caregiver experienced seeing their brain data and how the data management is impacting their lives.

- 8.1. How did the patient feel when they first saw their brain data?
- 8.2. How, if so, is it changing how they think about their seizures and their epilepsy in general
- 8.3. How do the patients describe the process of managing (downloading, uploading, discussing) their brain data?

9) Fears and Hopes for Continuing Medical Care

Focused discussion of the future regarding their illness condition and health in general.

- 9.1. Explore if the patient/caregiver would consider the treatment a “successful” management of the illness and why.
- 9.2. Discuss fears and hopes the patient/caregiver have for the future of their continuing treatment.
- 9.3. Explore whether the patients are happy with the treatment choices they have made and with the support they have received.
- 9.4. Explore the future roles of healthcare providers, family, and other caregivers as they impact hopes of success or fears of illness and treatment.
- 9.5. Discuss any unwelcomed changes related to the surgery and stimulation treatment

10) Conclusion

Conclude the interview by inquiring whether there are any other issues that the patient/caregiver would like to discuss that have not yet been raised.

- 10.1. Is there anything else that you would like to comment on that we haven't already asked you about?
- 10.2. Are there any questions you would like to ask us?

Thank you very much for your time and the information you shared today.