

SUPPLEMENTARY MATERIAL:

INTERVIEW FRAMEWORK – PATIENT

I want to remind you that you can stop the interview at any time. You can also refuse to answer any questions. Again, we will audio-record this interview in order to transcribe it for analysis. Are you willing to proceed with the interview and recording?

1. Knowledge, prognosis & expectations

Objective: Explore the degree to which they know about the disease, the prognosis; explore their expectations for what's to come. .. We don't want to disclose information they don't know.

- I hear you have been seen by (Dr. X) at the MAC. Is that correct?

- About how many appointments have you had there?
- If yes, could you tell me why you initially came to be seen at the MAC?
 - What did the doctors at the MAC/your identified doctor tell you about these issues?
 - What do you call what you are experiencing?
 - When do you feel this began? [or: when did you receive this diagnosis?]
- Do you think your condition will [memory concern] change over time? How?
 - If needed, probe with: What is your understanding of the most likely scenario for someone with this condition as they age? (*objective: identify if diagnosis or prognosis information was surprising or disturbing*)
 - Where did you get this information from?
 - Would you have preferred to have received the information differently? How?
- Have you had a strong reaction to anything your doctor said? Please tell me about it.
 - How could your doctor have done this differently?
- Right now, who would you say is your main doctor? Who did you turn to the most right now? (e.g., the “captain” or “quarterback” of your medical care?)
- We are interested in learning more about your experience living with these memory changes. At this time, are there things in your life that you are finding difficult to handle or even distressing?
 - Probe: Thank you for those answers. I’m going to show you a list of aspects of life with which caregivers sometimes have difficulty. Do any of these feel difficult or distressing to you? *[[Discussion topic handout]]*
- We’ve talked about what you have experienced. Now I’d like to talk about the future. When you think about the future...
 - What are your biggest **concerns**?
 - [Probe into these]
 - What do you **feel good** about?
 - What do you **hope for**?
 - Possible probes:
 - You could think about your goals/values, or what will make life meaningful for you.
 - What feels most important to you?

2. Anticipatory Guidance

Objective: Explore the degree to which they know they are prepared or want to be prepared about the illness trajectory, knowledge and engagement in ACP, and the support they have for this. Also explore any needs they recognize that may be relevant to ACP activities.

- Did any of the concerns you mentioned above cause you to make any special plans or changes in your life?
 - Please tell me about these plans/changes.
 - Probe based on what they brought up- e.g. finances, family, symptoms

- When faced with news of a new illness or condition, some people think about future health decisions, such as what treatments they would or would not want, or who would make such decisions for them. Some may be near-term, some may be long down the road. Have you thought about anything like this?
 - Probes: e.g., about advanced care planning or advanced directives? What have you heard?
 - E.g., about palliative care? What have you heard?
 - What led you to start these conversations/making these plans when you did?
 - Probe for who initiated it.
 - Did you receive services/support for this?
 - If yes: Who/where?
 - If no: Would you want help with this?

- Have any clinicians been involved in these discussions or preparations? How so? If not, why not? If yes, who (PCP, specialist, how long have you known them for)?
 - What have you found helpful about their involvement?
 - What has been less helpful? What do you wish had gone differently?
 - Is there anyone [else] with whom you are comfortable discussing these plans and decisions with?
 - Have you discussed these with your family (spouse/child/caregiver)?

- Has any of this felt particularly difficult? How/please explain/Tell me more.

- Have any of these plans or changes felt valuable or helpful to you? Please explain/describe.

- Are there certain types of services or supports do you wish were available to you or your family?
 - Could the MAC provide any services or resources that would improve your quality of life right now? In the future?

Do you have any questions for me? [Answer any questions.]

If you have any additional thoughts or questions, feel free to contact me. If I need to ask any additional questions, may I contact you again? If so, how would you prefer that I contact you: by email or by phone? That is the end of our interview today. Thank you so much for your time.

INTERVIEW FRAMEWORK – ACTIVE CAREGIVER

I want to remind you that you can stop the interview at any time. You can also refuse to answer any questions. Again, we will audio-record this interview in order to transcribe it for analysis. Are you willing to proceed with the interview and recording?

3. Information about the Caregiver

Objective: Explore the CG's relationship to and the support they provide to patient; explore other people who help the patient and/or CG.

- First, please tell me how you are related to [____ name of patient]?
- Could you tell me a little bit about him/her?
- We know that your loved one is receiving care at the MAC. Before we go into specifics could you give me a brief overview of how you came to be at the MAC/your journey getting to the MAC?
- Next please give me a brief overview of the period between then and now.
 - Who would you say was the patient's main doctor in this period? (e.g., who did you turn to the most? Who was the "captain" or "quarterback" of their medical care?)

Now I'd like to ask you about your experience as a caregiver.

- What do you do with them or for [patient] in their day-to-day life?
- Does anyone else help you or your loved one?
 - Who helps?
 - How do they help?
 - Are there other people you could rely on in the future if you need more help?
 - Probe to get a sense of who/how many
- How would you describe your quality of life right now?
 - Social, emotional, physical

4. Knowledge, prognosis & expectations

Objective: Explore the degree to which they know about the disease, the prognosis; explore their expectations for what's to come. We don't want to disclose information they don't know.

- Please think back to your experience receiving care at the MAC.
 - About how many appointments have you had there?

- Does anything stand out as surprising?
 - a turning point moment?
 - source of frustration?
 - or especially helpful?
- What did provider[s] communicate to you and/or [name of patient] at the MAC about their concerns?
 - When? [was the patient diagnosed?]
- Can you describe to me what is happening with your loved one's brain/body?
 - Do you have thoughts about how this might change over time?
- Did you receive guidance about what to expect over time?
Where did you get this information from? Do you wish it had happened differently? How?
Probe: Did you receive it at a time that you found appropriate?
- We are interested in learning more about your experience caring for someone with memory concerns. At this time, are there things in your life that you are finding difficult to handle or even distressing?
 - What are they?
 - What could make this easier or better for you/[patient]?
 - Probe: Thank you for those answers. I'm going to show you a list of aspects of life with which caregivers sometimes have difficulty. Do any of these feel difficult or distressing to you? *[[Discussion topic handout]]*
 - What could make this easier or better for you/[patient]?

We've talked about what you have experienced. Now I'd like to talk about the future.

- What do you consider to be a good quality of life for [patient] in the future?
- What are your biggest concerns?
 - *[Probe into these.]*
- What do you feel good about?
- What do you hope for?

5. Anticipatory Guidance

Objective: Explore the degree to which they feel prepared for the future, have engaged in ACP, to which they've done any, and the support they have for this. Also explore any needs they recognize that may be relevant to ACP activities.

- Did anything you learned about [patient's] condition or how it will evolve over time cause you or [patient] to make any special plans or changes in [patient's/your] life?
 - Please tell me about these plans/changes.
 - Vacation? Jobs? Lifestyle? Living place?
- When faced with news of a new illness or condition, some people think about future health decisions, such as what treatments they would or would not want,

or who would make such decisions for them. Some may be near-term, some may be long down the road. Have you and [patient] thought about anything like this?

- Of these plans that you've tried to make, what has been the hardest?
- *[If anticipatory guidance-related activities are mentioned]*
 - What led you/[patient] to start these conversations when you did? Were you able to have them at a time where your loved one was able to participate meaningfully in these conversations and state their wishes? If not, how did you extrapolate what your loved one wished for?
 - Probe for who initiated it.
 - Do you/[patient] receive services/support for this?
 - If yes: Who/where?
 - If no: Would you want help with this? What kind of help?
- Have any providers been involved in these discussions or preparations? If yes, who (PCP, specialist, how long have you known them for)? How so?
 - What have you found helpful about their involvement?
 - What has been less helpful? What do you wish had gone differently?
 - Do you feel you can discuss [patient]'s feelings, hopes, emotions, with someone in the office (physician, nurse, care team navigator)? If not, why? What would allow for such a relationship?
- Has a clinician talked to you about palliative care at any point?
 - [If talked/provided:] Tell me about your experience and reaction.
 - What is your understanding of what palliative care is?
 - Would you be interested in palliative care? Why or why not?
- Are there certain types of services or supports do you wish were available to you or your family?
 - Could the MAC provide any services or resources that would improve your quality of life right now? In the future? *[refer to needs discussed earlier if relevant]*

[Transition question]

- Thinking about everything we have discussed that you do with and for [patient], do you feel there is anything from your background or education that has helped you with this?

Section 4: Caregiver as Expert

In this final section, we want to get your opinions as an expert. We're trying to build something to reduce suffering for people like you and [patient].

- What, if any, information do you wish you had known when [___patient] was first diagnosed?
- What advice or information would you give another caregiver starting out on this journey?

Do you have any questions for me? [Answer any questions.] If you have any additional thoughts or questions, feel free to contact me. If I need to ask any additional questions, may I contact you again? If so, how would you prefer that I contact you: by email or by phone? That is the end of our interview today. Thank you so much for your time.

INTERVIEW FRAMEWORK – BEREAVED CG

I want to remind you that you can stop the interview at any time. You can also refuse to answer any questions. Again, we will audio-record this interview in order to transcribe it for analysis. Are you willing to proceed with the interview and recording?

6. Information about the Caregiver

Objective: Explore the CG's relationship to and the support they provide to patient; explore other people who help the patient and/or CG.

- First, please tell me how you were related to [____ name of patient]?
- Could you tell me a little bit about him/her?
- Could you give me a brief overview of how you came to receive care at [neurology clinic]? Can you give me a brief overview of [patient's] journey there?
- And please give me a brief overview of the period of time between then and when [patient] died? [I'll ask more detailed questions next.]
 - Who would you say was the patient's main doctor in this period? (e.g., who did you turn to the most? Who was the "captain" or "quarterback" of their medical care?)

Now I'd like to ask you about your experience as a caregiver.

- Thinking about the last year of their life, what did you do with or for [patient] in their day-to-day life?
- Did anyone else help you or your loved one?
 - Who helped?
 - How did they help?
- How would you describe your quality of life at that time?
 - Social, emotional, physicals

7. Knowledge, disease course & experiences

Objective: Explore the degree to which they knew about the disease, the prognosis; how the disease would unfold.

Please think back to your experience receiving care at the MAC.

- About how many appointments did you and [patient] have there?

- Does anything stand out as surprising?
 - a turning point moment?
 - source of frustration?
 - or especially helpful?
- What did provider[s] communicate to you about their concerns?
- Did you receive guidance about what to expect over time?
 - Where did you get this information from? Do you wish it had happened differently? How? Did you receive it at a time that you found appropriate?
- Did different “stages” or emergence of new symptoms surprise you? Which ones? Why?
 - Were you supported throughout these stages and symptoms? How so? By whom?
- Were there aspects of your and the patient’s life that you found difficult to handle or even distressing? What were they?
 - What could have made this easier or better for you/[patient]?

Probe: Thank you for those answers. I’m going to show you a list of aspects of life with which caregivers sometimes have difficulty. *[[Discussion topic handout]]*

- Did any of these feel difficult or distressing to you? *[Map re timing to EOL.]*
 - What could have made this easier or better for you/[patient]?

8. End of Life Experience

Objective: Understand CG’s experience of patient’s end of life period; their needs; whether the needs were met.

- Please think about the months before [____patient] died. *[[3-6 mo. if clarification needed]]*
 - Could you tell me what that time was like for you and for your loved one?
- What needs did [____patient] have during this period [beyond those above]?
 - Probe: what did you need to take care of? What did you need help with?
 - Probe: *Refer to handout list.*
 - How did you handle these needs?
 - Where did you/[patient] receive services/support?
 - Who else was involved in these activities? (e.g. family, clinicians)
- What needs did you have during this period?
 - Probe: what did you need to take care of? What did you need help with?
 - Probe: *Refer to handout list, focusing on caregiver’s own experience.*
 - How did you handle these needs?
 - What helped you to do it?

- Where did you/[patient] receive services/support?
 - Who else was involved in these activities? (e.g. family, clinicians)
- Did you/[____ patient] have any [other] needs in this period that weren't met? Please tell me about them.
- Did you experience anything especially difficult that you didn't expect? How did you deal with it?
- Were there needs that surprised you?
 - i.e., What did you experience that you didn't expect at the beginning of the journey? when do you wish you had been informed about it?
- Are there types of services or supports that you wish were available to you or your family during this time?
 - Could the MAC provide any services or resources that would have improved your quality of life then?

9. Engagement with Palliative Care

Objective: Explore to what extent CG/patient engaged w/PC, how, why, and how that shaped the end of life period.

- Did you engage with anyone from services such as palliative care, symptom management or hospice during this time?
 - If yes: Please tell me about it.
 - Probes: What kind of services did they provide for you/the patient?
 - Why did you choose to engage them?
 - Would you make the same decision to engage this service/not engage this service again? Why/why not?
 - If no: Did you consider engaging with palliative care or related services at any point? Why/why not?
 - What is your understanding of what palliative care is?
 - Would you make the same decision to not engage PC again? Why/why not?

10. Preparations for End of Life

Objective: Explore how they planned for end of life (conversations and activities), their satisfaction with what happened, and what did/would have helped.

- When did you and [____ patient] begin having conversations about, for example, his/her goals for his/her care? Advanced care planning? Values or preferences for care at the end of life?
 - What led you to start these conversations when you did? Do you feel that timing was too early, too late, or just right?

- Were any clinicians involved in these discussions or preparations for them? How so? Who?
 - What did you find helpful about their involvement?
 - What was less helpful? What do you wish had gone differently?
- Were there other things we haven't discussed that you had to or wanted to take care of before [____patient] passed? Please describe.
 - Were any clinicians involved in these activities/preparations? How so?
 - What did you find helpful about their involvement?
 - What was less helpful? What do you wish had gone differently?
- Thinking back, do you wish any of these preparations would have gone differently? How? What would have made it easier or better?

[Transition question]

- Thinking about everything we have discussed that you did with and for [____patient], do you feel there is anything from your education or your personal background that helped you with this?

11. Caregiver as Expert

Objective: Elicit and explore what information, perspectives, etc., may have been helpful at the debut of caregiving; explore their perceived learning/growth. Conclude the interview on a positive/empowered note.

In this final section, we want to get your opinions as an expert. We're trying to build something to reduce suffering for people like you and [____patient].

- What information do you wish you had known when [____patient] was first diagnosed?
- What advice or information would you give another caregiver starting out on this journey?

Do you have any questions for me? Is there anything else I should have asked?

If you have any additional thoughts or questions, feel free to contact me.

If I need to ask any additional questions, may I contact you again? If so, how would you prefer that I contact you: by email or by phone?

That is the end of our interview today. Thank you so much for your time.