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ATTACHMENT 6A

Caregiver Interview Guide

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Caregiver in-depth interview guide

SDOH Caregiver Interview Guide

Introduction

Thank you for taking the time to speak with me today. We are interested in learning more about your experiences as a caregiver for a cancer patient or survivor. We are also interested in learning about any barriers you and your care recipient may have faced during their treatment and ways in which they may have tried to overcome them.

We have planned for a 45-60-minute call. With your permission, we would like to record the Zoom session to back up our notes. The recording will include both audio and video unless you turn your camera off. If you prefer not to be recorded on video, please feel free to turn off your camera at any time during the session. Turning off your camera does not preclude you from participating in the study, and you will still be audibly recorded if you have provided permission. Your name and the recording will not be shared with anyone outside of the core survey team who will analyze the findings. Your responses will be aggregated with responses we get from other caregivers to identify common challenges caregivers and their care recipients have faced along the journey from treatment to post-treatment/survivorship. These findings will be shared with CDC and other stakeholders and will not include any identifying information.

Please keep in mind that there are no right or wrong answers. Your participation in this interview is voluntary, and you can skip a question or stop me at any point. Joining this study has no more risks than everyday use of the phone or video calls. Some of the interview questions may be upsetting, but you don't have to answer them. Protections are in place to keep your data as safe as possible. Do you have any questions before we begin?

Do I have your permission to start recording the interview?

[If yes, start recording]

1. Could you describe for me what typical activities or responsibilities looked like for you as a caretaker? (e.g., types of activities/services/support you provide, trips to doctors, errands)

   This can include on treatment days as well as on days spent recovering from treatment and coping with side effects.

2. For [the care recipient], were you the sole caregiver? If not:

  a. How many other caregivers did [care recipient] have?
  b. Did each caregiver have different roles? What were the roles of each of the caregivers?

3. In your survey, you indicated that the following were the top issues the care recipient faced during their cancer treatment. [*Interviewer, please determine top 3 issues from survey and ask interviewee to provide more context and examples*.]

   Interviewer, ask: for each of the top 3 issues the care recipient faced during their cancer treatment: [insert patient's top barrier 1, patient's top barrier 2, patient's top barrier 3]

   [Probes]

   How did issue the impact the care recipient's ability to obtain treatment?

   Were you involved in helping the care recipient address this barrier? If so, how?

   Was the care recipient able to overcome the barrier?

   If the care recipient overcame this barrier, how? What factors were helpful?

   Can you suggest other solutions to this barrier? What resources would be helpful?

Ranking	**Top Issues**
	Afraid the treatment will be too painful or unpleasant
	Could not afford care (e.g., cost too much; other competing expenses)
	Could not afford food
	Lack of permanent, stable housing
	No insurance coverage, or insurance company would not approve, cover or pay for care
	Problems getting transportation to doctor's office for treatment or with long travel time to the doctor's office for treatment
	Could not get time off work for appointments and care (e.g., no paid sick leave, no flexible work schedule, no medical leave)
	Didn't know where to go to get care (e.g., no primary doctor or usual source of care to make referral; unfamiliar with local providers; local specialty practice closed)
	Was refused services (e.g., out of network provider, not accepting new patients)
	Took too long to get an appointment that worked for their schedule
	Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status)
	Unable to understand the doctor's language (e.g., different language without access to interpretation)
	Medical information was too hard to understand

	Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability)
	Could not get a friend or family member to go with them to appointment
	Other
	Did not encounter any issues / Not aware of any issues. [EXCLUSIVE SELECT]
	Prefer not to answer [EXCLUSIVE SELECT]

4. What were the top 3 barriers you faced while providing support as a caretaker? For example:

Ranking	**Barrier**
	Not enough money
	Could not afford food
	Lack of permanent, stable housing
	No insurance coverage, or insurance company would not approve, cover or pay for care
	Problems getting transportation
	Hard to get time off work for appointments and care
	Experienced discrimination (e.g., racial or ethnic discrimination, gender, weight, sexual orientation, disability status)
	Unable to understand the doctor’s language (e.g., different language without access to interpretation)
	Medical information was too hard to understand
	Couldn’t get dependent care (e.g., for child, elderly relative, or relative with a disability)
	Could not get a friend or family member to go with them to appointment
	Other
	Did not encounter any issues / Not aware of any issues. [EXCLUSIVE SELECT]
	Prefer not to answer [EXCLUSIVE SELECT]

Interviewer ask: for each of the top 3 issues that the caregiver faced:

[Probes]

Did this barrier impact the care recipient’s treatment?

How did this impact your ability to provide support to the care recipient during their cancer treatment?

Did you overcome this barrier? If so, how? What factors were helpful?

Can you think of other solutions to the barrier? What resources would be helpful?

**If caregiver indicated that they did not face any issue during the cancer treatment of the care recipient, probe to ensure that this is correct and ask about what factors were facilitators.*

5. In your survey, you indicated that the following were the top health issues <u>you</u> faced during the cancer treatment of the care recipient. [*Interviewer, please determine top 3 health issues from survey*.]

Ranking	**Health Issues**
	Stress
	Anxiety
	Depression
	Fatigue
	Poor diet
	Physical strain
	Isolation
	Poor sleep
	Other
	None*

Probe: [If health issues selected]:

How did you cope with the issue(s) you faced while providing support to your care recipient? Are you still dealing with this issue/these issues?

* If the respondent indicated no health issue:

What do you think was the single greatest contributor to you being able to cope?

6. As a caregiver, did you feel that you:
    a. Received enough information from providers about the care recipient's diagnosis? Treatment? After care plan? If not, could you give examples of information that you would have liked to have received?
    b. Were respected by providers? If not, could you give examples as to how you were not respected?
    c. Were respected by the family members of the care recipient? If not, could you give examples as to how you were not respected?

7. Looking at the care recipient’s entire journey with cancer, do you feel that the process from screening and diagnosis to treatment and after care could have been better? If so, please explain.
    a. Please provide any ideas you have that could have made the process better for the care recipient <u>and</u> for yourself.

8. What had the greatest positive impact on your ability to provide care for and support your care recipient during their cancer treatment? (e.g., nurse navigator, flexible schedule/retired, medical background/education, positive outlook)

Closing: Is there anything else you would like to discuss before we end the interview?

Wrap-up: Thank you for your time!