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QUALITATIVE PATIENT INTERVIEW GUIDE

Question order 1

Introduction and “consent”: Thank so much for participating in our study! When we first contacted you by mail, we sent you a little info sheet about the study. But that’s been a while ago. So let me quickly go through the basics before we start with the interview.

The study we’re doing is about how people take care of their diabetes and what makes that more difficult or easy. So we’ll be talking to people like you and get your take on that. I’ll be asking you a lot of questions, and there are no right or wrong answers. We really value what you have to tell us because you’re the real expert on what it means to take care of diabetes day after day.

If that’s okay with you, I’ll record the interview. We’ll then later have someone type out what you said so that we can be sure that we got everything right. I want to stress that whatever you tell us is strictly confidential. Only the researchers who are part of this project will see what you say. We won’t share anything with your doctors, your family, or anyone else. And if there are any questions that you’re not comfortable answering, just let us know. The interview should take us about an hour. Does that work for you? Do you have to be anywhere after this?

As a thank you for your time we can offer you a \$50 Amazon gift cards for participating. [Reassess by situation: phone, in person]. We will email you those Amazon gift cards in the next week or so if that’s okay. I have your current email address listed as (X), is that correct?

Do you have any questions?

Okay, great, then I’ll turn on the recorder now.

Introduction and Open Questions [do not read]

Just to get started, can you tell me a little bit about yourself? When were you diagnosed with diabetes?

If participant doesn’t know how to respond: Things like: Where do you live? How old are you? What do you do for a living?

Let’s talk about the basics on how you take care of your diabetes.

1. If you think of a typical day, what do you do to take care of your diabetes?
 - a. Is there anything else you’d do on a typical day?
 - b. Can you say more about ...
2. And what do you think are the most important things you do to take care of your diabetes?

So we’ve talked about a typical day. Let’s think back to the past month.

3. What difficulties have you experienced with taking care of your diabetes?
4. If you think back even farther, have you had any other difficulties with taking care of your diabetes?
 - a. So is that something you no longer experience now? Can you say more why this is no longer an issue?
5. Are there times when taking care of your diabetes is harder for you? Tell me about those.

In the survey that you sent us, you mentioned that you’re using a .../not using a ... Is that right?

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6. When did you first get that? Was it something you asked for or that your doctor suggested?
7. How has having a ... affected how you take care of your diabetes?

We've already talked a bit about how you've taken care of your diabetes in the past. Let me ask you specifically:

8. Were there times in your life when taking care of your diabetes was easier or harder than it is right now?
 - a. Can you say more about that?
 - b. What was it that made it easier or harder?
9. Have you had any major changes or events happen in your life?
 - a. *If participant has difficulty answering:* For example, having a child, changing jobs, or moving in with a partner?
10. Have any of those affected how you take care of your diabetes?
 - a. Can you tell me how they have changed things for your diabetes?
 - b. *If participant mentions event but doesn't say whether or not it had effect on diabetes:* You mentioned ... Is that something that has had an effect on how you take care of your diabetes?

I want to ask you about work. You said that you work as ...

11. What issues with your diabetes do you encounter at work?
12. Are there things about your work are helpful to taking care of your diabetes?
13. Have you worked in a different job before? Or a different position at your current job? Can you tell me if changes in your job situation have had an effect on how you take care of your diabetes?

I'd like to talk about health care and health issues now.

14. Can you tell me about the health care you are getting for your diabetes?
15. How has your doctor (or the care you receive) affected how you take care of your diabetes?
 - a. Is there anything about your doctors or health care in general that make taking care of your diabetes harder?
 - b. And are there things about your doctors that have made taking care of your diabetes easier?
16. Do you have any health issues other than diabetes? On the survey we sent you, you said you had ...
17. Does this affect how you take care of your diabetes? If yes: How so?
18. Can you tell me about any financial or insurance issues related to your diabetes care that you have encountered?
 - a. *If participant seems hesitant:* I know that sometimes people are uncomfortable talking about these issues, and that's okay. Whatever you say is strictly confidential.

Let's switch gears a bit. Let's talk about things you know or have learned about taking care of your diabetes.

19. When you think back, were there any pieces of information or skills you've learned that help you take care of your diabetes?
20. Is there anything you wished you'd learned sooner?
21. And is there anything you'd like to learn *now* about taking care of your diabetes?

I want to specifically ask about a couple of things. Let me start with food and food choices

22. Do you have any difficulties in taking care of your diabetes related to eating and food choices?

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23. Is there anything about eating and food choices that is helpful to taking care of your diabetes?
24. And when it comes to food choices, is there anything that you feel you'd need to know, or certain skills that would be helpful?
25. Has carb counting ever been a part of how you take care of your diabetes?
 - a. Again, with carb counting, is there anything you'd need to know, or skills that would be helpful?
26. Another thing is physical activity. Has physical activity ever been a part of how you take care of your diabetes?
 - a. *If participant seems to have difficulty with term "physical activity"*: Things like exercise, or also just taking the stairs instead of the elevator, or walking to the grocery store.
 - b. Do you think it could be helpful to you?
 - c. What are some of the things that make it hard for you to get physical activity?
27. Do you ever experience low blood sugars? How does that influence how you take care of your diabetes? Is that something that has changed over the course of your life?

Let's talk about something else now. We'd like to know more about how others influence how you take care of your diabetes. Or how diabetes impacts your social relationships. And that's can be in a good way or a bad way.

28. Are there people in your life who have an influence on how you take care of your diabetes?
 - a. What do they do? What kind of influence do they have?
29. Other people may sometimes make it harder to take care your diabetes. Is that something that you have experienced? Can you tell me more about that?
30. Who do you talk to about taking care of your diabetes? I mean other than to your doctors and health care providers?
31. Can you tell me how your diabetes affects your social relationships?
 - a. *If participant has difficulty answering*: Things like friendships, or romantic relationships.
 - b. What about family relationships?

Sometimes other people may have opinions on how you should take care of your diabetes.

32. Are there any people in your life who try to tell you how to take care of your diabetes? What kinds of things are they telling you to do?
33. Do you know anyone else who has type 1 diabetes? Is the way you take care of your diabetes the same or different from others? How so?
34. Do you ever feel judged by others about your diabetes or how you care for your diabetes?
 - a. Tell me about an example when that happened.

Okay, we're almost done. Just three more questions.

35. How do you motivate yourself to take care of your diabetes, day after day?
36. Are there any things about you as a person that make taking care of your diabetes easier or harder?
37. And finally, how much do you feel like you're in charge of your diabetes?

Alright, that's it! Thanks so much. Just to be sure,

38. Is there anything else about your diabetes that I haven't asked about? Would you like to mention anything else?

Interviewer comments

Overall impressions (e.g., tone, sophistication)
Non-verbal (e.g., comfort level, body language)