

Appendix A

Focus Group Guide 1: Pre-pandemic questions

Introduction:

Hello everyone, I want to thank you for taking the time to talk with me today about your experiences as a person with dementia. Today we are interested in hearing your experiences and thoughts about some of the challenging situations you experience, the feelings you have, and ways in which you react to these situations and feelings. Some of these situations, feelings and reactions may be challenging for you and your loved ones. I am interested in hearing about ways you handle these situations and feelings at home. During our conversation today I ask that you reflect on your experiences before the COVID-19 pandemic ramped up in March of this year.

This interview will be recorded and then transcribed for analysis. All information will be kept confidential. There will no names associated with the transcripts. For the sake of confidentiality, I also ask you to keep what is shared in the focus groups private and within the focus group session. I have a series of questions that I would like to ask to prompt your responses, examples, and stories; there are no right or wrong answers here, just your own thoughts and insights. Please feel free to refer to your prepared responses during this conversation. Again, thank you all so much for your participation, if everyone is ready, I will begin [start recording].

Focus Group Questions

1. If we could start by just going around and sharing your name, the type of dementia that you have, and when you were diagnosed.
2. Thinking back to a time before the pandemic, please describe an example where you experienced a particularly challenging situation since being diagnosed with dementia.
 - a. What made this situation so challenging?
 - b. How did you respond to this situation?
 - c. Do you think having dementia influenced the way you experienced this situation? If so, how?
 - d. Do you think having dementia influenced the way you responded to this situation? If so, how?
 - e. Can you describe any ways you try to handle challenging situations at home?
5. Thinking back to a time before the pandemic, please describe specific feelings you have had that are very challenging for you, particularly those that you have had since being diagnosed with dementia.
 - a. Why do you think these feelings are so challenging for you?
 - b. How do you respond, or react when you have these types of feelings?
 - c. Can you describe ways you try to manage or address feelings that are challenging?
6. Can you describe any actions or reactions you have had that are particularly challenging for your loved ones?
 - a. Why do you think these are so challenging for your loved ones?
 - b. Do you think having dementia has influenced how you act, or react in certain situations?

- c. How do you try to prevent, or manage actions or reactions that are challenging for your loved ones?

Conclusion

Thank you for participating today. I truly appreciate your time and unique insights; your contributions today have been truly valuable. Is there anything else that you would like to share? If not, again thank you for joining today and sharing. [recording will be turned off].

Appendix B

Focus Group Guide 2: During pandemic questions

Introduction:

Hello everyone, I want to thank you for taking the time to talk with me today about your experiences as a person with dementia, particularly during this time of the COVID-19 pandemic. Today we are interested in hearing about how your experiences as a person with dementia have been affected by the COVID-19 pandemic.

This interview will be recorded and then transcribed for analysis. All information will be kept confidential. There will no names associated with the transcripts. For the sake of confidentiality, I also ask you to keep what is shared in the focus groups private and within the focus group session. I have a series of questions that I would like to ask to prompt your responses, examples, and stories; there are no right or wrong answers here, just your own thoughts and insights. Please feel free to refer to your prepared responses during this conversation. Again, thank you all so much for your participation, if everyone is ready, I will begin [start recording].

Focus Group Questions

1. If we could start by just going around and sharing your name, the type of dementia that you have, and when you were diagnosed.
2. In general, how has your life been affected by the COVID-19 pandemic?
3. How has the COVID-19 pandemic affected the way you experience dementia?
4. Thinking about a time since the COVID-19 pandemic began, can you please describe an example where you experienced a particularly challenging situation?
 - a. What made this situation so challenging?
 - b. How did you respond to this situation?
 - c. Do you think having dementia influenced the way you experienced this situation? If so, how?
 - d. Do you think having dementia influenced the way you responded to this situation? If so, how?
 - f. How has COVID-19 affected how you experience and respond to challenging situations, if at all?
5. Please describe specific feelings you have had that are very challenging for you, particularly those that you have had since the start of the COVID-19 pandemic.
 - a. Why do you think these feelings are so challenging for you?
 - b. How do you respond, or react when you have these types of feelings?
 - d. Can you describe any new feelings you have experienced since the COVID-19 pandemic that are particularly challenging for you?
 - e. How have you responded to these new feelings?
 - f. Can you describe new ways you have tried to manage or address feelings that are challenging since the pandemic began?
 - g. Were any of the things you used to try to manage these types of feelings affected by the pandemic?

6. Thinking about a time since the COVID-19 pandemic began, can you describe any actions or reactions you have had that are particularly challenging for your loved ones?

a. How has COVID-19 affected these types of actions or reactions, if at all?

7. Can you describe any resources or support strategies that you used before to help with challenging situations, feelings, or reactions that were affected in some way by the pandemic?

Potential probe: Did you participate in any support groups, or use community resources that were modified, or cancelled due to COVID? If so, please describe these resources and how the changes have impacted you.

8. In general, has the COVID-19 pandemic made it more or less challenging for you to care for yourself?

a. If so, in what ways is it more (or less) challenging?

Conclusion

Thank you for participating today. I truly appreciate your time and unique insights; your contributions today have been truly valuable. Is there anything else that you would like to share?

If not, again thank you for joining today and sharing. [recording will be turned off].

Table S1 Major Themes, Subthemes, Codes, and Example Quotations.

MAJOR THEME: Humanizing dementia		
Subtheme	Code	Quotation
Early experiences with cognitive impairment	Changing awareness and emotional responses	<p>“We had gone, um, my husband and I and, um, our adult children had gone to a little small family reunion at a lake that was about, oh, I don’t know. It’s like about 40 miles away. So, we spent the afternoon, and it was a wonderful time, and um, my son and his wife were in the pickup with us, and it was my husband and I. And when we left, we were on this curvy road. I did not know where we were, why we were there, where we had been coming from. I didn’t say anything. I just kind of sat there, and I thought, oh well, we went floating on the river. And then, I looked at everybody and noticed they didn’t have that kind of gear. We didn’t have a trailer with a boat. We didn’t have anything. And so, I just got... worked harder and harder to figure out where we had come from, and I was actually in a panic silently. And um, oh my gosh, and then it just came to me. We had been at this little family reunion, and I knew who all was there. I could picture the whole thing, and that was over. And then, I just sat there in silence because everything in the beginning that happens you...I did anyhow; I instantly thought it was a sign of progression. Oh my gosh, I’ve slipped. And right about that time, in the silence, my son said, “Geez, mom, you seem like you’re doing really well.” And I just sat there, and I went, “Well, let me tell you about this little time traveling trip I just had over the last ten miles.” (giggle). And he’s like “Oh,” and at that instance... there’s others too, but that instance was probably my longest time travel at this time. That’s what I call them, time travels. And um, my most panicking one.” (P3, F, 60 y.o.)</p>
	Being diagnosed	<p>“That’s the biggest thing is trying to get that proper diagnosis, and the problem is a lot of times you’re primary caregiver blows it off, especially if they’re an older doctor and they start using the phrase “Oh, that happens to me all the time. You know, we’re both around that age. Those things happen to us.” or whatnot and stuff, so it’s really about pushing that doctor and finally getting to the proper one which is a neurologist.” (P6, M 60 y.o.)</p>
Healthcare experiences	Healthcare providers	<p>“At the end of the day, you need to get an appointment to see a neurologist and preferably someone that understands or specializes in dementia or Alzheimer’s because just because you’re a neurologist doesn’t mean that you also understand Alzheimer’s and dementia too.” (P6, M 60 y.o.)</p>

	Medications	"I have not slept just because I can't sleep even taking my medication, and they've increased my sleeping medication. I was already on two different medications to help relax me and calm me down, and then they just threw on 100 mg of trazodone to try to knock me out, and it's like, you better get a tranquilizer gun out pretty soon and shoot me in the butt because that's the only thing that's going to knock me down." (P5, M, 60 y.o.)
Overstimulation	In public	"Sometimes it feels like we are always asking for changes to be made to make the environment more manageable for us. But it often goes unheard; nothing changes. We are still suffering when in public. So even before the pandemic, I just didn't go out." (P3, F, 60 y.o.)
	Social events	"So, um, we're at my wife's Christmas party at her work at the end of the year. They have it at the principal's house. I mean, the house is completely full. You know, every teacher and their spouse is in there. It's loud, a lot going on. I just tell her, "Honey, I've got to step outside." Or if we're at a restaurant and it gets super loud, I just tell them, "I just need to step outside," and just get away from it. Um, if I'm at home, there's two things I'm going to do; one, is either I'm going to lay down, turn off the lights, and just kind of like recharge. I don't want any noise. I want it quiet." (P6, M, 60 y.o.)
	Needing to "unplug"	"The things that I used to be able to look forward to and do, I had to stop doing because it was adding more stress, and one of those is social media. Because of COVID but because of all the vitriol, you know, politics, no matter what side of the aisle you're on going back and forth. I had to stop. I had to unplug." (P5, M, 60 y.o.)
Activism	Identity	"You might as well say we're all activists. We're all very interested in working with people and spreading the word to bring hope to people who are living with dementia, and certainly, that has shown in the last year or so. We have really grown to be quite popular to be interviewed with a lot of people around the country." (P2, M, 68 y.o.)
	Educate	"You know, it's hard talking about knowing what's happening to you, but we also know that what we're telling you could possibly help others. It could help other people understand different types of dementia. It can help people understand why people with dementia do certain things, and if you didn't hear from people like us, then it would just kind of keep on going like it has been for decades where people don't understand anything about living with a dementia-related illness, so." (P1, M, 60 y.o.)
	Humor	"And by using humor and making... not making light of it but where people can see that I understand what I have, but yet I can accept it, and I can still enjoy the time." (P4, M, 68 y.o.)

Tools to live well with dementia	Support from others	“She’s (wife) like a comfort blanket in the sense that I never go anywhere and speak unless she can come with me (phone ringing). I always try to make sure that she’s with me so that if I’m up on stage reading whether she’s... they want her to speak or not, she’s back there just rubbing my back, kind of just consoling me, keeping me, you know, on pace. If I tell a story and get emotional, she’ll point back to where I was at to help keep it going and whatnot and such, so.” (P6, M 60 y.o.)
	Socialization	“I mean, I was on a call, a support group call, an hour ago with a group, and the lady was talking about how she feels, and she was asking, “Do you ever feel like you’re losing your mind?” You know, you’re just totally losing it. And we’ve all been there. We’ve all been there. And the thing I told her is that you know you have a place you can come to just... if you just want to vent, you just vent, and that’s what we all are. And then I told her. I said if you ever feel that you’re losing your mind, tell us. We’ll find it for you. And then, when it’s my turn, you can help me find it. But, you know, we have each other’s back. Without this group, you know... I’m trying to say it nice, but, you know, I’d be in a funny farm.” (P1, M, 60 y.o.)
	Cannabidiol products and medical marijuana	“We talked about it (cannabis) before, and I actually and a lot of people I know with dementia got away from their Aricept and their Namenda and some of those other medications because in my personal opinion, it’s not medication where it may help you for six months. It doesn’t stop or change or anything, so there’s too many side effects from that drug, like someone else was saying that they have hallucinations. I was having those when I was on the medication and when I got off of it, they went away. So, I use the CBD now, basically every day.” (P6, M 60 y.o.)

MAJOR THEME:
“Welcome to our world”

Subtheme	Code	Quotation
Loss	Loss of activity and engagement	“I’ve lost a lot of movement because I was involved with my little men’s group, and there’s always another organization that I went to which would break up my week and something that I’d look forward to. Like Wednesday, I’d look forward to Friday’s coffee with the men, our men’s group, and um, it helped things move along.” (P2, M, 68 y.o.)
	Loss of interaction	“You miss the comradery in other human beings. And even something like this, you know, with Zoom, yes, you get to see people’s faces but when, you know, when we’re asked to go to a conference to speak, you know, you’re standing in front of sometimes 500 or a thousand people and you feed on that interaction. You feed on

		the look on people's faces and so forth, but when you see somebody on Zoom, and you're talking, and you see them like this, you know, I'm thinking, okay, they're playing solitaire or, you know, they're doing something but they ain't listening to me." (P1, M, 60 y.o.)
Stress	Stress and living with dementia	"It was all really, really confusing to me, and my disease is controlled by zero stress, low blood pressure, keeping your cholesterol, you know, zero stress kind of a thing." (P3, F, 60 y.o.)
	Stress in society	"And it can really get to you and, you know, on top of everything else with all the stress of everything else going on right now on top of the pandemic, you know, it's... it shows why people are really, really stressed out." (P4, M, 68 y.o.)
Pandemic impacts on health	Dementia progression	"Yeah, and I ask (stated wife's first name) every now and then, "Do you see a change in me?" "Have I progressed?" Or "Can you see a progression?" And, you know, and she tells me the truth. And she'll say, "You're having trouble finding words. Um, you're getting a little bit more forgetful." (P1, M, 60 y.o.)
	Physical health	"I just wanted to add during this ordeal, I've had some medication changes, um, one for a blood thinner because of the new strokes and two, an increase in an anxiety medication. So um, you know, I just wondered. And I really truly don't think that I would have if things would have just stayed normal. And I did end up having a couple mild strokes in the last nine months. I can't even remember when. I think it was more like August, but I don't know for sure. And um, I knew that because I got up and I was stuttering again and stammering, but it corrected fairly quickly." (P3, F, 60 y.o.)
