SELECTED QUOTATIONS

Note: All quotations were provided by adults with stroke, unless otherwise indicated.

Theme 1: Stroke-related deficits impact participation

Physical Deficits

"I have to use a cane to walk so I have to be really careful when I'm walking and walk slow. So I can't exercise real fast; I'd fall all the time."

"My biggest problem is holding and slicing. I'm left handed but I can't hold [the knife] with my left hand [due to hemiparesis from the stroke] so I have to put it up against the refrigerator and slice it like this."

"I go to the store, but I'm not able to go as often. I have to wait for somebody to take me because I don't drive. I've gotten behind the wheel and there's just something about driving with that left foot, I don't feel comfortable. So, I can't drive as much to the store and buy the good things that I normally would have done."

Cognitive Deficits

"For me, the cognitive part was the [hardest]. My brain didn't process anymore, and actually with this weight loss thing – there was a program I was on – it was called being in nutritional ketosis – and I lost a lot of weight and it was really good, but I couldn't get back to it after I had a stroke because it was too complicated. And so I think the beginning stuff in here [the DPP program] would

be too complicated. For me, it would've been [too hard], just coming out of the stroke. I was not prepared for that."

"There's a time my brain – sometimes it wants to work good and other days it doesn't want to work so good [agreement by other participants]. So I do think that if you're just coming out of a stroke and getting into a group [like the DPP], this is jumping into a whole lot all at once to learn."

Sensory Deficits

"It's affected my eyesight, too. So, at the grocery store it's hard for me to see what stuff says because I'm looking; I want to lose some weight, too."

"Food doesn't taste the same [following stroke] and you don't even want to eat it."

Psychosocial Deficits

Care-partner: "It creates friction on both sides. Friction for him, you know, to remember to write it down and me to nag at him. It's also stressful for me to have to say to him "did you do this, did you do that, did you do this, did you write it down?"

"You lose so much with the stroke that you have to maintain some source of self-esteem. I can handle some of this, you know!"

"Depression is a big part of what happens. One neurologist told me, you have to remember that this is a marathon, not a sprint. As long as you keep working at it, you'll keep getting better."

Theme 2: Existing program characteristics facilitate participation

Program structure

"Repetition, because I've noticed that my attention span has gone down since the stroke. I do multitask more – if I get bored with one thing I have another thing to do right away. So, I'm thinking if maybe on the [proposed] website you have a lecture that presents the material and then in the program, you have application of that [information] and discussion about it.

Group-based format

"If you can get the same group coming all the time together there would be some comradery or support by getting to know the people that are in your group."

"Talking along with [reading the handout] is a lot of help. Just to put [handouts] in front of a person who just had a stroke and say, "read this, do this," that's just too much!"

Weekly homework

"Have homework so I've got to do it and bring it back the next week."

"Reinforcement is key; the more often we do something, the better it sticks. So that's where the homework comes in."

Supportive lifestyle coach involvement

"I think it's important for you to…make them [program participants] feel successful. I used to be the sharpest knife in the drawer, and not anymore. Stuff is hard for me and challenging, and it's really depressing. So, I think you build in things where they can…do this and feel successful."

Theme 3: Recommended stroke-specific adaptations to promote participation

Session content and format

"I'm thinking if maybe there's a website where you have a lecture that presents the material and then in the program meetings you have application of that and discussion about it."

"I think it's important for you to…make them [program participants] feel successful. I used to be the sharpest knife in the drawer, and not anymore. Stuff is hard for me and challenging, and it's really depressing. So, I think you build in things where they can…do this and feel successful."

"Say we were in the [program] and we're in month 7 or 8, and I'm like 'I'd like to remember what was going on in month 2.' We could download [a session] or have a DVD sent to us, and we could re-listen to it."

Physical activity and dietary behaviors

"The first thing I think when I see 'brisk walk' is that's not going to happen. I can sit down in this comfortable chair [recumbent step bike] and step for 40 min and get my heart rate up, but I'm not walking; it's just not happening."

"Most people use both hands to do what they have to. One of the biggest problems is pouring. There's a lot of things that people don't realize [exist, i.e. adaptive equipment] that would help if somebody talked about them."

"Because my hand writing is so bad, I think if I could set it up [a tracking app] on my phone it would be much easier [to track activity and food consumption]. You might get people more willing to participate if you can do it on an app, cause everything is computerized now."

Additional diabetes and stroke education

"The resources are there. It's just knowing about them. In a program like this, though, you should be able to gather those resources."

"I would think that definitely for those people who have had a stroke that whatever you would want to do to prevent a recurring stroke or to prevent becoming diabetic [should be included]. It would go hand in hand as far as the things you would want to do to prevent both of those from happening.

"Like, she [another participant] eats a lot of fruit, but they told me not to do that [because participant already has diabetes]. So, what can I eat? So knowing what to eat and how much to eat [would be helpful], you know I'm saying? It's like I'm afraid to eat apples, I'm afraid to eat orange because it will be bad for your diabetes, your heart, your cholesterol."

Care-partner involvement

"Caregiver[s], don't push them [indicating person with stroke] too hard. Give them flexibility [so they don't] feel like you're task master over them."

"You could actually go both ways, I think [regarding inclusion vs. exclusion of care-partners). Because part of it, you can see that you're doing something successful, that you are regaining some things, you are getting the ability to do some things again, so for some that would be a motivational thing. For others it would be more of a discouraging thing. But that's when that person needs a caregiver to come alongside and give the support that's needed."