M:

Hello. Thanks for participating in this interview, this session should take about 45 minutes to an hour. There are two sections to this interview. The purpose of the first section is needs gathering. The second section will dive more specifically into the research study. And information from this informal interview will be used towards an undergraduate research project which is mine. For the ubc course, cogs 402. And the cogs 402 is a largely independent research study conducted by a student in their final years of a cogs degree with a UBC lab. And the purpose of this interview is to discuss motor neglect and conduct a sort of needs assessment from professionals in the relevant field. With your permission, information gained from this session will be attributed to your identity as an OT or PT, I may use your name in this study your occupation and place of work, but this study will not be published. As well, this session will be recorded. At this point, do you wish to continue participating in this interview?

Julia 1:32

Yes.

M: 1:33

Okay. And do I have your permission to use your name and associated career information in this project? Or do you wish to remain anonymous? Okay, cool. Thank you. Then we can proceed. Can you tell me your name, occupation and where you work?

Julia 1:48

Right. I am Julia. I am occupational therapist and a research professor at the University of British Columbia.

M: 1:59

Thank you. Um, can you give me a brief definition to your knowledge of how you might define motor neglect from the view of a OT?

Julia 2:09

Yeah, so the general unawareness of one side of one's body or one's spatial neglect of not being aware of one's space on the one side, and yeah, I'm sure you'll get into but like limitations in all things of life, whether it has to do with that one side of the body.

M: 2:36

Yeah, um, on average, how many patients with motor neglect do you encounter in a year? An estimate is fine.

Julia 2:47

Yeah. Yeah. I mean, I don't see any patients one on one for therapy in my research. Maybe like 10 a year? So, not many.

M: 3:02

Yeah, and so, when you did work as a OT, a practicing OT, how often would you see motor neglect?

Julia 3:11

Yeah, often, like every week. There'd be somebody in our unit that would have it. Yes. So very frequently.

M: 3:21

And usually from a stroke, right?

Julia 3:24

Yes.

M: 3:25

And it would be, would it be motor neglect, or just kind of other forms of neglect? What kind of would you see?

Julia 3:32

Yeah, generalized neglect. Yeah. And I don't think we even differentiated it really. At that time, in clinical practice, we were just looking at the function of the issue, like functional impairment of the issue, as opposed to like, yeah, and some from like, traumatic brain injury as well.

M: 3:53

Yeah. So you'd say, people in your profession see motor neglect quite often.

Julia 4:00

Yeah.

M: 4:02

Can you tell me about what your experience was like working with individuals with motor neglect? Just in general?

Julia 4:08

Yeah, I think it was challenging. Given that you would, it's not something like strength. Like if somebody had impaired strength, then it's a pretty easy step by step approach to increase their strength because you increase the number of reps, and it's something that we can relate to. Because, you know, if I want to be stronger, I can just do more. But with neglect, it's not something that's easily relatable and it is complex, because it's like the mind, cognition that like, you know, neurobiologically the unawareness of it. So that's trickier because it's not something that you can just, like, do more of something to get better at it.

M: 4:52

Yeah, yeah, for sure. And how long on average would you say you work with a neglect patient?

Julia 5:00

Yeah, I mean, that was just dependent on how long they were in the rehab center for. And depending on what country I was at, it was dependent because in Australia that we kept people until either they plateaued or they got back got better. And so it could be months, but in the rehab hospital in Burnaby where I worked, we kind of saw them until they're able to go home. So more like, weeks instead of months.

M: 5:28

Okay, I see. How do you think neglect has impacted your patients when you saw them in their day to day life?

Julia 5:42

Yeah, greatly. And it's impacted carers as well as the person. So for the person, they might not be able to safely go out into the community. Because, you know, the unawareness of, you know, a site or an area or a movement pattern on the one side of their body, they couldn't safely like walk or cross the streets. And then I think for, like, yeah, indoors or doing like personal activities would also be hard because they, you know, either forget or can't do, like, they just don't, aren't attentive to the one side. So that's, like all things like eating, going to the bathroom, getting dressed, all things become challenging in life. Yeah, and as I mentioned, for the carers, it's tricky too, because the caregivers might have to do more, or might have to support more, remind more, maybe get frustrated a little bit more.

M: 6:51

Yeah, for sure. So specific to motor neglect kind of patient where they aren't using their neglected limb more, what kind of ADLs do you think would be impacted by this?

Julia 7:05

Yeah, well like, everything from like, when you start the day, like, trying to get up on the side of your bed, if they're not able to, like, use or move their one side of their body as effectively, they might, for example, like, you know, trying to get up to walk and only one side of their body is really activating then, you know, they just fall over, or sitting up on the side of the bed, they can fall over. Getting dressed as well. You know, putting one side of their shirt on and kind of forgetting and not moving or using the other side. Tricky. Yeah. Yeah.

M: 7:42

Um, and so what kind of current treatments for motor neglect have been used in your profession as an OT?

Julia 7:54

Yeah, well, a few things. So getting people awareness of their issue is helpful. Because, and that's sometimes the first step, to get awareness of the fact that the person does have it. And even if they have cognitive awareness, they might not be able to, like put it into action in the moment, of course, because that's neglect. But, but sometimes they go hand in hand that like, you know, unawareness of the issue, but also unawareness of that one side, so, and the inability to like, move that one side. So you know, people have done like paper and pencil activities to get them to either be aware, or also be reminded. So like, you know, the classic of like, having a red line on the one side of the paper for the person to scan over to that side, just to get that person like reminded that there is another side of the world, and that another limb that they can use. And then also, you know, community like mobilizing or walking around or using a wheelchair or whatever in the community or in the hallways, getting somebody to be aware of that spatial area like, where that spatial neglect, but also being aware of their limb that they can actually ensure it actually moves. So visually putting things around in their area so that they're more aware of like the visual space but also their limb that they could move. Some people have done like it's, more taxing, I guess, but like tapping

on the limb or like, standing on the one side that they're neglected to see, spatially, but just so that they can be more aware of that side of the body and like physically getting it, getting them to be reminded of it,

M: 9:52

But this would require like more cognitive load on their part to remember to do all these things, like tapping so on.

Julia 10:01 Yeah. Yeah.

M: 10:03

Which is difficult with neglect in the first place because of the whole awareness.

Julia 10:07

Yes. Yeah. There's a cognitive element to it, yeah.

M: 10:12

Thank you for that. Um, and what can you say about the effectiveness of these treatments that you've mentioned?

Julia 10:18

Yeah, I mean, I teach on this. So I know it's not, the effectiveness is not that high. And, I mean we do something, right. But like, it's not fixing the underlying problem. And some people are able to do their functional skills better, which is good, like they can, you know, get around to the community a little bit better with these things. But still, the problem is not solved. Not that I think we've necessarily fixed the problem. But sometimes the interventions are just for the activity as opposed to like globally addressing, like, globally giving a strategy. (<-- the answer to Riley!!)

M: 11:00

So they're very specific to the tasks, like, for example, the visual scanning task can only really be used for reading.

Julia 11:08

Totally. Yeah. And community mobilizing in GF Strong was like, making sure you look to the one side, they're like, step your foot every second. It like reminded of your one side of body every time you pass a door or whatever. Those are helpful just for GF Strong.

M: 11:26

Right. What improvements do you think can be made for motor neglect treatment, things that maybe you wish existed but don't in current treatment?

Julia 11:38

Yeah. Well, I think I know what you're thinking of, so I don't want to lead... but something that doesn't rely on a therapist. Maybe I'll try to be a bit more blunt. Something that doesn't rely on a therapist, and then something that can, isn't just limited to one activity, like it isn't activity specific, but is more broad or global? That would be helpful.

M: 12:13

Why do you think not being limited to just a therapist would be helpful?

Julia 12:18

Because the therapist is not gonna be there all the time. Neither will carers. And it's like, people value their independence and their autonomy. So by not having to have somebody around is helpful. I mean, sometimes for these people, they need to have somebody around anyways, for other reasons. But, you know, to have a little bit of more agency with the whole thing. Yeah.

M: 12:45

And you mentioned earlier, something about, we can't really solve the problem exactly with these treatments. What do you think is the problem? The central problem to this?

Julia 12:57

Yeah, like, if it's an-- I know neglect is multifactorial, so it's. But if there's like a neurobiological issue, then of course, neuroplasticity can happen. Of course, people can like fully recover from things. But for many people, that's not the, that's not the goal, or that's not the case. So having strategies and compensations are maybe the better way to way of doing it. Or not better, but it is the way for those people. But for some people that do completely improve and don't have a problem anymore, that's great too. (<-- answer to James!!)

M: 13:37

Yeah. And do you think technology has a place in motor neglect treatment? And in what way?

Julia 13:44

Yeah, I mean, technology. I'm like, I'm not a technology person. But technology is so useful in so many things. Like it is, it can take the place of a carer in some ways, and it can take the place of a... Yeah, it can be optimized versus like stickers on a wall. It can be better than that, you know.

M: 14:19

Personalized even.

Julia 14:21

Yes, totally. Yeah. So that's, I think the benefit of it.

M: 14:29

And is there some technology that already exists right now in your mind in neglect treatment currently in OT?

Julia 14:39

Um, I don't know. I think like vibrator things are like physical reminders, maybe? But I don't know.

M: 14:51

Yeah, so it's not very like, if they do exist, which in my research they do a little bit, they're not really used that much.

Julia 14:59

They're not used. Definitely.

M: 15:02

Yeah. Why do you think that is?

Julia 15:03

Um, maybe cost? Maybe. Yeah. Awareness. Also, you know, if it's a clinician thing, like, the clinicians are really skilled in the area that they're, they're working in, and maybe will have more difficulty in expanding and like, you know, thinking of new different options. Yeah, so I think that's the tricky thing.

M: 15:37

Thank you for all of that. That was the first half of the questions. If you have any other questions or further thoughts you want to add at this point, you are free to do so. Please feel free to take a break or grab a glass of water. And if you're okay with it, we can continue.

Julia 15:54 Yep, totally fine.

M: 15:56

Okay. I will begin the second half of this interview now. This research project is a design study looking into the development of a haptic cueing device for use in motor neglect therapy. Specifically, as neglect seems to be largely a problem of attention, this device seeks to act as an external attention reminder to remind patients to use their neglected side more using the haptics, which is things like vibration, touch things, you know. Taking advantage of both limb activation therapy and feedback training. Getting people to move using wearable haptics has been successfully done before, think Fitbits. But what I seek to do is apply activity motor theory to a unique population, stroke, and develop a device that would directly cater to them. How this device would work in our study, it would be worn on the wrist of the neglected side. So think compact, light and small like a watch. But without the complications of and requiring a learning curve to work a smartwatch. The haptic effects would send by vibro tactile feedback to the wrist when it senses uneven movement of the left and right side. And this design project is seeking to validate the question in a usability study with healthy participants of whether or not we can elicit non dominant arm usage in response to dominant arm usage. The advantage of using haptic effects like vibrotactile feedback is that it does not require effort on the side of the patient as it tackles their bottom up senses. And it can be transferable to various activities of daily living rather than a highly specific task. So people can go about their days wearing this device with the sort of reminders a therapist might give them in therapy. In other words, the device hopes to augment current therapy techniques, reduce caregiver burden and increase therapy time outside of therapy sessions. Do you have any questions so far?

Julia 18:08

No, I mean, that sounds very promising and great explanation. It's very helpful to hear packaged up that way. Yeah.

M: 18:19

Now that you've heard briefly about the purposes and general design of this device, oh, I guess I already asked you. What are your initial thoughts so far on the proposed idea?

Julia 18:29

Yeah. I mean, as I said, like, it's a very interesting idea. I would love to hear more, maybe you're gonna get to that.

M: 18:39

Um, yeah, I don't really go more into the details, because it was just going to be like, a brief overview. But um, yeah. Any general thoughts?

Julia 18:52

yeah. I mean, I have a couple questions. But that's yeah. Is this the space now for them, or?

M: 18:58 Sure, yes.

Julia 19:01

Yeah, it's more like, so the, do you, if, how do they measure uneven neven patterns of movement? Is it on both sides of the body?

M: 19:15

So right now, specific to the study, we would have them wear two wrist watches, or they're not watches but their wrist thingies. And we would be using either accelerometers to measure how much arm usage they are using or we've, we've also discovered in the lab, this, I forgot what it's called but it's like something that will measure the amount of muscle rotation usage. So I can send that to you later if you want, if you're interested. But yeah, and so we would be using one of those two things or maybe both to measure uneven usage, and then upon receiving that feedback, the device would emit a haptic effect. So for example, say you're about to grab hold of this water bottle, and then your neglected side is your left side and maybe say the water bottle is all the way on the left side of the table. So it would make sense for you to grab it if you're neurotypical to grab the water bottle with your left hand, because it's on the left side. But with neglect, you'd maybe go out of your way to reach it with the right hand. So upon sensing that you're about to do unilateral tasks like that, the device would be like, Hey, hold on a second, remind yourself to use your left hand in doing this task. So then maybe it would change the behavior of the patient to change their course of action.

Julia 20:41

Right. So it would sense you're moving with one hand, not the other, and then, like, remind that haptic feedback through that wrist? Yeah.

M: 20:52

And it wouldn't really activate so much in bilateral tasks. Because it wouldn't really make sense then, because it's like, you have to use two hands. For example, if you're carrying a tray, and you're already using both hands, it's not going to be like, use your left hand more, it doesn't make sense. But if you are you're carrying a tray with just your right hand, maybe it would be like, Hey, how about you use your other hand now.

Julia 21:12

Yeah, yeah, I guess. And so it might do like more false positives or false whatever it is. Because some hands are, some tasks are one handed. But that's okay. Because you're just, you're getting more reminders of that other hand, and maybe it could be used for stability or something like that. And then, like, but if the person is, say, having their arm down at the side, as opposed to swinging it normally, then it would also have feedback as well?

M: 21:49

Yeah. Which is why we're maybe thinking not the accelerometers and more the muscle rotation thing. But yeah, right now, it's like, early stages of the prototype. Yeah. So it's definitely not how the final piece I envision would be, I think, because I feel like it would be useful to just have it on one wrist, it's just easier to manage for the patient for sure. Yeah. But for at least the usability study, just to see if there is an effect. See if if we can make any sort of change in behavior using this thing, then we're using two wrists just to measure that. But yeah, in the future it would be just on one wrist, hopefully. But yeah.

Julia 22:33

Yeah. And then I guess the other question I had, sorry, I'm losing it. Yeah, about so, if say you're in like a dressing or an eating task, where limbs are doing different things, like, one is stabilizing the zipper and the other one is pulling up, or one is like reaching for the thing. Like they're doing different types of activities. But they should still be moving and they still should be activated. With the, would it consider, like if one of them is moving, the other one should be moving as well in some way. So they would it would be activated, the feedback would be activated if the other limb is, if the neglected limb is just not--

M: 23:25

-- is not doing its part, I guess. Yeah. So it wouldn't activate if if it senses that it is doing it's like a muscle rotation, like maybe it is stabilizing, it is still using like, something is still moving. So it wouldn't really activate then I guess. But yeah, yeah.

Julia 23:41

Yeah. So if it's not doing very much at all, or if it's doing nothing, then it would get an trigger. But if it's supporting or like, positioning, then that's great.

M: 23:55

Yeah, we figured this would be a bit more helpful than similar past neglect alert devices that have been used where they would just kind of emit a constant vibration that wouldn't really have any feedback. So it's just like, every five minutes, so it's like,

Julia 24:14

Exactly. Yeah. And it can be annoying.

M: 24:17

You habituate to that. So yeah, that's the device. Um, how do you think this device would work for treatment of motor neglect in a stroke population?

Julia 24:28

Yeah, I mean, I think it would, like you know, let's wait and see, it sounds like it's there's nothing overly, like red flags about it. You know, like, it sounds safe. Yeah, and it sounds like it's pretty low impact in terms of what you have to wear. Like it's not this huge robot, you know, that you have to put on.

M: 25:10

And if you could just, if you could design a device similar to this, say, like you had all the know how to do this kind of thing. What would you change about it?

Julia 25:22

Maybe the accuracy to improve a little bit. So then, and I don't think wearing two wrist things is, I think that's fine. Like, it isn't a big deal I personally think. But I think the accuracy of it is important so you know that it is the right, like it's giving feedback at the right time. Instead of like, oh, yeah, it might give the wrong feedback in the wrong time. I mean, that's okay. But just, and, or if there's a way that therapists can also like, override or like, increase it. So like, you're doing a task, and you're getting the person to, like, just making sure that it's like going where you when you want, so there's some therapists contribution, maybe that would help? And then maybe like a leg version as well. I'm thinking mobility might be an issue for some people.

M: 26:27

Hmm. And where would you put a device like this on the leg?

Julia 26:34

Just thinking an ankle like, same kind of reciprocal thing? That's one option, but I think I mean, had like, it's usually, it's often like the whole muscle group, right? So it's not just the arms, but also like the torso and the muscles there and the legs and everything. Hands and arms are so important, though, like that is your eating, your dressing, your like, everything with your hands. So it's like the helpful first step.

M: 27:04

So you would say that having it on both wrists would be okay for a patient to just go home with?

Julia 27:10

I think that it's not a huge issue. Like, assuming this is small anyways, it's like two bracelets, like it's not... I don't know, I'm not somebody with the condition, but I can have like, one or two. But yeah.

M: 27:43

Yeah. And, um, thinking about people with neglect, um, where on the body do you think is most suitable to deliver the effects as described?

Julia 27:58

Yeah, I mean, I think your answer about wrist is, is probably helpful, because that's where a lot of movement comes from in somebody's body.

M: 28:09

And we're used to wearing things on wrists.

Julia 28:11

Yeah, exactly. It's easy. Yeah, just like, depending on the sensation, if they don't have good sensation in their distal limb, like lower down then maybe, like, higher up, like the bicep area, but I don't think so I think low, like lower if you can, is better.

M: 28:37

And I guess the wrist would be most helpful in determining like, like muscle rotation, because rather than bicep, I guess.

Julia 28:45

Totally.

M: 28:45

Yeah. Yeah. And we have an option of either putting the sensors on the top of the wrist or the bottom. And in your professional opinion, where do you think is most useful?

Julia 28:58

I mean, I think to replicate something that people are already used to, like a watch, f you have the sensor on top, it seems to replicate a watch a little bit more, maybe? I don't know, though, because on the bottom might look a little bit more discreet.

M: 29:16

All right. And I just have a final question. What do you think improvement would look like with such a device for patients with motor neglect?

Julia 29:30

The outcomes kind of thing? Yeah. I think if they were able to function more independently, so have more autonomy, not having that as many reminders. So like in their daily tasks, if they can do them, either with less errors or more independence, then that would be that would be very beneficial.

M: 29:57

Okay, because we were thinking gain, oh, maybe full parity would be a goal in neglect treatment. So maybe the neglect arm is used just as much as the non neglect arm or the neglect arm is used more than the neglect arm. But you're saying it's more it's like about just general improvement and fewer errors.

Julia: In function, yeah. I mean it's probably the same, it'll probably end up correlating those things.

M: Yeah, I think we're trying to make, like the ideal device down the road would be able to make this data and make it available to the therapist they're seeing, so then the therapist himself can see the numbers and be like, oh yeah ok it's improving slightly. And maybe even personalizable, easy to manage for the therapist to learn and be like, ok maybe I want to use a different haptic effect. Maybe vibrotactile is not really helpful with this person, but maybe temperature might be easier, somehow. Or maybe I want to put it on their bicep instead of their wrist, so it's like adjustable. Yeah so that's the ideal goal down the road.

Julia: Yes, nice.

M: Yeah and you mentioned earlier something like, I guess, devices like this exist in the world but they're not really used practically in most clinics. So, would having a device that is wearable at home and more so patient specific instead of like, oh it has to be used in the hospital but actually is, you can just bring, get the patient to go home with it— would that be a bit more practical?

Julia: Yeah I think so. And like it might be more... anything that is able to integrate a bit more easily. So like, reduce cost, reduce size, you know, any of that stuff would be integrated more. Yeah and having somebody... yes, having it be able to be with the person and go home as opposed to just use at the hospital, for sure.

M: Thanks so much for your time, and that concludes the end of the interview.