

Interviewer: Okay, hello. Thanks for participating in this interview, this session should take about 30 to 45 minutes. There are two sections to this interview. The purpose of this first section is needs gathering or needs assessment, and the second second section will dive more specifically into the research study that I'm doing. Information from this informal interview will be used towards an undergraduate research project, mine, for the UPC course cogs 402. Cogs 402 is a largely independent research study conducted by students 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 needs assessment from professionals in the relevant field. With your permission information gained from this session will be attributed to your identity as a PT or former 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 I may use your name in this study, your occupation and place of work, but this study will not be published, as well, this session will be recorded.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?

P2: Sure.

Interviewer: And I have your permission to use your name and associated career information in this project or do you wish to remain anonymous?

P2: You can, yep.

Interviewer: Thank you. We can proceed with the interview then. Can you tell me your name, occupation, and where you work?

P2: Yeah, P2. I am a physiotherapist by training. I currently work at Providence Health Care as a practice consultant for Allied Health Education Strategy. Formerly, I was working as a physiotherapist at St. Paul's hospital on the Medicine Unit. And before that, I have about 10 years of experience in both clinical and research settings.

Interviewer: Can you give me a brief definition to your knowledge of how you might define motor neglect, from the view of an (OT/PT)?

P2: Yeah, you know, like, I might not get this fully correct. But neglect, to me is a condition that reflects the meaning of that word, but it's this condition wherein someone, let's say, with a brain injury or a stroke, due to the damage to the, you know, attention regions of the brain, have difficulty dedicating their attention to their affected side, and you can break that neglect down into various types of neglect, where some of it might be like what they see or perceive in their environment. And some of it could be, I guess, motor neglect would be, which would be the internal side of things of not really using one side of their body or their arm-- not because it's weak, although that might be part of the problem, but because it is not within that person's kind of internal seam of their body.

Interviewer: Thank you for that. Have you worked with patients with motor neglect?

P2: Yeah, I have. If it was just motor neglect, no one immediately jumps to mind because it's often paired, you often see like, multiple aspects of neglect shining through but definitely I have worked with people with neglect, who, in turn, do not use, let's say their arm because of neglect, as well as additional weakness and even behavior change. I think I'll just say one thing is that neglect sometimes it's hard to tease out from learned non use, which is a

behavioral change wherein someone kind of just like, opts not to use a limb because they've just learned to do everything with their stronger, faster, more effective side.

Interviewer: On average, how many patients with motor neglect do you encounter in a year or an estimate is fine, or when you work as a PT?

P2: Yeah, it depends on your settings. So I would say on the Medicine Unit at St. Paul's hospital, we would get people with brain injury with stroke, which would be where this neglected be associated with is with that brain injury. Like maybe 10% of the patients coming through the medicine unit would have a stroke or some other neurological deficit, but not everyone with the stroke has neglect, so maybe I bring that down to like 5%. On the other hand, when I was working in the private setting, I would have a lot of-- my entire caseload was neurological patients, and a good chunk of them were in brain injury and stroke. And at that point it would be like 20 or 30%.

Interviewer: And how often do people in general in your profession see motor neglect?

P2: It depends on the setting. So you'd have physiotherapists who work in a private clinic, which is like sports oriented, and they probably would never see neglect compared to people in the private setting who work in a rural community where they don't have specialized like sports, physiotherapist clinics versus like general. So they might end up seeing folks from all sorts of, you know, medical diagnoses or whatnot. Compared to where I was working in the private clinic, they would specifically target those individuals with neurological deficits. So like specialized neurological clinics would see a lot of neglect. And then there's the folks who work in like rehab, or in acute care in the public health care setting. So everyone who comes through with a stroke, who survives, ends up going through the hospital pathway, and the physiotherapist in those settings might see some neglect as well.

Interviewer: Can you tell me about what your experience was like working with individuals with motor neglect?

P2: It's quite challenging. Because you often have all these associated deficits at the same time, it's rare to see someone with some-- with just a neglect. And that's just their motor. Usually, there's like paralysis or paresis, so weakness of an entire half side of their body. And then on top of like weakness, there might be changes in how their body is able to move their muscles. So spasticity, this condition where it's a presentation where like, the muscles become really sensitive to stretching. So it changes with these movement patterns as well. And then, like I mentioned, with the behavioral side, have learned non use so just opting to use the side that they can trust because it's working as close to normal as it used to. And then on top of that, you have any kind of cognitive deficit that could come along with that brain injury that results in the neglect. So whether someone is able to, like carry over day to day learning, or or their ability to like stay, give their attention to a task or without interruption or without being distracted, that can be affected by brain injury as well. So I guess the question was, like, what, what is it like to work with someone? Yeah, it's -- increases the challenge of working with someone, because usually people don't come in to see a physiotherapist specifically for neglect. It's because they want to walk better. They want to enjoy certain activities that they need to use their arms for. Neglect happens to be one of the reasons why they're not able to do those things, as well as they would like. So it's, to me, it's

not something I treat directly, or specifically, it's something that I have to account for when I treat the whole person.

Interviewer: And how long on average would you say you work with a neglect patient?

P2: In the private clinic setting, it's driven by like finances and how frequently someone can come and how much they wish to come and whether or not they can afford to come through all that, all their sessions, because it's not cheap in the private sector. It's like \$150 for an hour session. And if you don't have extended health benefits, that's quite a lot to expend on your like average income. And then, but comparatively, if I were in like an acute care setting, or rehab setting where I did my research, you'd have a lot of time to work with, with patients in rehab. It's really good patient to therapist ratio, see therapists like four days a week for an hour at a time. In which case there would be a lot of time dedicated to that person. I would say maybe, for me, from my private setting, I would see people about six to 10 times. And some people like ongoing because maybe they had funding because of it came from, they happened to have a stroke on while working or they got hit by a car and have a brain injury that led to neglect.

Interviewer: So you'd say finances is a pretty big influence on how much therapy someone can get in the private setting?

P2: Yeah, and I guess I would further qualify private setting being like, in the long term after being in the chronic phase of, let's say stroke, because by then they're out of the hospital system.

Interviewer: How do you think neglect has impacted your patients in their day-to-day life?

P2: Yeah, quite a bit, right? Like it could... imagine if you only had the functional use of one arm instead of two. And if it was your dominant arm or not, right, the one you write with or do everything with, that could really impact your life. So it depends, I guess which side this neglect is affecting, I think generally, it is more likely to affect your left side, because I think it's more associated with your right hemisphere of your brain. So it depends, I guess, like more people are right handed than left handed. So maybe there's a bit of a ratio there. I don't know that off the top of my head, but I think it is quite... it's an added layer to this to the disability that comes with, like, brain injury that leads to motor impairment.

Interviewer: Thank you. What kind of current treatments for motor neglect have you heard of or used in your profession as a PT?

P2: This one's tough. Because, like I said earlier, I don't think I spent a lot of time dedicating treatment specifically for improving neglect, it was kind of something I accepted that the person had as part of their impairments or not. Almost seen as like an unchanging aspect based on where when I was seeing people was like, well along in the chronic phase of their brain injury, so kind of not sure how much they could change that at that point. Because, to me the like, the most. The best time window to see an effect change is often delineated. The first three to six months, and often in the chronic, in the private sector, we see people pass that point. Yeah, so I guess if I were to treat someone with neglect, though, and I have, like, sometimes I would build that into what I was doing. So let's say if someone wanting to have

better balance, I would position them so that they had, were forced to think about or use their neglected side more often. So it makes it so to make it more challenging to use their dominant, intact side. Yeah, maybe sometimes dedicating some time to bringing attention to that side as well through like, touch. External, like cueing. Yeah.

Interviewer: And so yeah, so some neglect treatments can involve things like exactly what you said, like cueing from the therapist saying verbally, hey, use your side more, or things like in visual neglect, where you put a red line on a piece of paper and they can draw their eyes there. What can you say about the effectiveness of these forms of treatment?

P2: Yeah, I have no clue. I know some people have improved in their neglect, but I've kind of logged that in my brain as kind of being like a natural progression and recovery that people generally can sometimes just have from the acute, after the acute injury, just like the brain taking some time to recover, and that's when you see this kind of improvement in neglect. Not necessarily associated with direct treatment, although I'm sure there is research to look at this I just haven't really brushed up on it.

Interviewer: And since there isn't much literature on the kind of treatments that are available for motor neglect. It's because it's a rather like un-- people don't really understand the underlying mechanisms of neglect fully, and it's hard to tease out and and it's also multi faceted. So what kind of improvements do you think can be made for this treatment? Because it is rather like under studied. Are there things you wish existed but don't exist currently?

P2: Um I guess what I would hope for is that there were more efforts to address neglect in hopes of having an impact and/or more research in that areas to drive the efforts in. But at the same time, I think if there's not a lot of research to support it, there won't be as much impetus or rationale for therapists to make an effort there, because it might not be worth the time and resources put in, especially if people are paying out of pocket in that private setting.

Interviewer: Do you think technology has a place in motor neglect treatment, and in what way?

P2: I think so if it were not harmful to the patient, and then it was like, you know, like not-- if it was accessible, so if the cost was not high, for an unscientifically proven device or approach, then it shouldn't call on the patient to bear like a super high financial burden in hopes that it might improve something that we're not sure of. So I think technology could play a role. It's just I think there's like the process that technology has to go through to be developed and then approved. From like, let's say, like, a FDA standpoint. That being said, though, I think a lot of clinician, so especially like OTS can make low tech devices, and do it all the time, not necessarily for neglect, but to improve someone's functional abilities. So whether they change how someone is like positioned in their wheelchair, to make it less likely to develop a pressure sore. I think it is fair to use technology to target neglect in this kind of like prospective, let's hope for the best kind of way, if it were like accessible and affordable. So maybe during a physiotherapy session, I might apply like electrical stimulation to the affected side as a way to have constant like neurological feedback to bring your attention to the side because this device already exists. And let's say it's in the clinic, and I can just have it on the

whole time. Great. So I think using technology is a good way to try and target neglect. I just don't know where we stand on like the efficacy of any methods clinic-wise.

Interviewer: Yeah, for sure. Um, I had something else I wanted to ask you and then it flew out of my mind so we're just gonna go ahead. That concludes the first section of my questions. If you have any questions or further thoughts you want to add at this point, you're free to do so now. You can feel free to take a break or grab a glass of water and if you're okay with it, we can continue.

P2: Okay. I have water.

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Interviewer: I will now begin the second half of this interview. 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 cueing device to remind patients to use their neglected side more using haptic feedback, taking advantage of both limb activation therapy and feedback training. Getting people to move using wearable haptics has been successfully done before, think Fitbits. What I seek to do is apply activity motor theory to a unique population which is stroke and develop a device that would directly cater to them.

How this device would work in our study is 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 vibrotactile feedback to the wrist when it senses uneven movement of the left and right upper limbs. This design project is seeking to validate this 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. And the advantage of using haptic effects like vibrotactile feedback, is that it does not require effort on the part 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 like visual scanning on a piece of paper. 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?

P2: Would they wear it on both sides if it's monitoring, comparing left and right?

Interviewer: Yes, so, um, for the purpose of the design study, in the usability study, we would have one on each arm. But only one of them would be delivering the Haptic effect. And that would be on the non dominant arm. And right now, we're just seeing, can we even change behaviors with this? Is there any effect with having the haptic feedback on one side? Um, yeah, and then the device down the road, like if it happens, it might just be on one side, or it might be on both. But yeah, we'll see. Like, I asked Julia. And she's like, I honestly wanted it just on one side, but um, Julia, I was telling Julia about this. And she's like, I think it's totally fine if patients go home with both on both wrists. It shouldn't be too much of a problem. But But yeah, for now, just for the study, it's two sides. Yeah. Um, yeah. Now that you've heard briefly about the purposes and general design of this device, what are your initial thoughts so far on the proposed idea?

P2: Because I come from a research background, it's hard not to think about the feasibility of like the study, or whether you'll truly, if your results will truly reflect what you're looking for, or the construct that you're trying to measure. And I've also worked with people who have been attempting to develop like an arm, like an arm activity monitor after stroke. So that can be, that in itself was quite challenging, because you have to like figure out how to track movements in individuals who already have like altered muscle activation patterns, or movement patterns. So I commend you for tackling this. I'm curious how that will like, if you'll be able to tease out like, unpurposeful or sedentary movement, compared to like, like supportive, non dominant, arm usage. So like, let's say, bimanual tasks like cutting something on the cutting board, like you need to use your non dominant arm, but it is stable, it's not moving the same way that your dominant arm is moving. Or like when you're walking like will that, if you're swinging both arms, does that count? Like-- so I think it's a hard comparison to draw.

Interviewer: It's definitely, yeah.

P2: Yeah, ` is a place for haptics to provide that feedback to someone who's like, not even neglect, but even someone who like has developed learned non use as well. I think some people just need a reminder to use this side after that brain injury or after a stroke, and maybe they have full function and they had no neglect or maybe they also have neglect, but having haptic feedback as a reminder, so it's not always a therapist telling them to. Some people know that they have to, and even then might just not. So I think there's definitely, like, a place for that type of technology to be developed, it's just gonna be hard to validate how effective it is.

Interviewer: Yeah. Would you say that the vibrotactile feedback can also help with the sensation problems? Or even, as you said that you put some electrodes or whatever on the side, and that would just have constant--

P2: Yeah, I think it's hard to-- like sensory deficits after a neurological injury, and the recovery of sensation is also not as well understood or, or even researched compared to like, motor recovery and movement recovery. Partly because it's also just like, the hierarchy of like, patient desires of what they want to improve, right? Usually mobility, over like sensation, even though there's like an interdependence between the two. So yeah, I think it could have an impact. I just don't know where we stand on, like, sensory recovery as well. Yeah, I wonder if it's, if at this age, it's even that important to have it be tailored haptic feedback to their movement patterns? Or if it's more of a like regular, every half hour, you get a reminder, every 10 minutes, you get a reminder? I'm not sure what frequency that is, but it might take some of that design, study design, confusion out.

Interviewer: And you mentioned that you, there was this device that you worked on? Or someone you knew that worked on something similar? How did that work? Was there any sort of like, besides monitoring activity, did it do anything?

P2: I don't think so. I think it was more of an activity monitor to track movements after stroke of an affected upper limb and trying to like be able to track different movements of an

affected, upper limb, based on like what muscles were being activated. Yeah I don't think it was like a feedback, bio feedback device so much as it was a monitor.

Interviewer: Yeah, the whole, how do we tease out with whether they're doing this sort of task or that or swinging their arms-- we are kind of, there were other two options to either use accelerometers to measure activity. But we also are kind of leaning towards this other kind of, I'm forgetting the name right now, but it's a sort of, it measures muscle rotation in the wrist, which would be maybe a bit more specific than just plain acceleration. And so we want to kind, the way the feedback works is that it will sense movement in the, let's say, right hand, which is the dominant arm or non neglected side, you will sense movement in that and then upon sensing the movement there, it will vibrate on the neglected side. So let's say you are about to reach out for your water bottle with your non affected arm, because that's what you want to do. Then upon sensing that movement, it will be the device would be like, hey, stop for a second and like, maybe use your left hand instead to do this task. So we're not really looking at bimanual tasks, because of course, you could do several movements with both hands, no problem. Like carrying a tray, you have to use both hands. But we're kind of more looking into unilateral tasks. So maybe you wanted to just carry the tray with one hand instead. But then we're like, hey, no actually why don't you use your left hand as well. So that's how we're kind of trying to work out that problem, which is of course a huge problem. How do you think this device would work for a neglect population?

P2: You know, if it were to work as perfectly as you described there, to like have a reminder to use your affected side anytime you go to do something with your dominant arm, I think that would be good because it takes one piece out which is the internal cognitive reminder, like that kind of accountability is more externally driven. So I think in that case, I think it'd be giving that person with neglect the best or higher consistency of attention to that side. I wonder how intense that haptic feedback would have to be to register? And then I think the other piece would be, how do you ensure it's not going to be something that like, annoys the person? Having some ways to turn it off, or for it to like, learn when it doesn't need to activate? With the right arm, like, sometimes you do need to use your unaffected side, for I don't know, safety or for speed, for like writing, for tasks that like that your non dominant arm never did in the first place, right? I think navigating those pieces are important to ensure that it's not like cumbersome.

Interviewer: And that's why one of the reasons why we're not-- we want to base it on also just feedback instead of just a constant, oh it will vibrate every 10 minutes, which would be quite annoying and also not very task specific to what the person is doing. But yeah that's really good feedback on that. If you could design a device similar to this, what would you change about it?

P2: It's tough because I wouldn't want someone to wear something on both arms if I didn't have to, but then how do we measure your-- like to have that bilateral comparison would be nice to have that individualised haptic... yeah it's hard to get past that specific haptic feedback. Um, I don't know that I would necessarily change your idea so much as, like, having different designs and then choosing which one would be the best one to put your best efforts towards, instead of investing necessarily so much energy into this, like, one specific avenue which might not be the most effective approach, and that's not me suggesting yours

would not be effective, it's just more I don't know which would be the most effective avenue to first explore.

Interviewer: Yeah that's fair.

P2: I mean, lessons will be learned regardless of which one you tackle first. Yeah, I guess things to think about though would be like, how strong that haptic feedback is because in healthy adults it wouldn't need to be very strong to be felt, but then for someone who has neglect they might also have sensory impairments and it would have to be quite strong. And maybe like can add like a gradient so then the first time someone reaches with their dominant arm it's like a very gentle reminder, but like by the third time in a row, it's like, hey it's time to like, use your other side. And how do you make sure that like, you know, are they doing it one and then they use the other side? Is it going to be like constantly reminding them to never use their dominant side? Yeah, things to consider. (← and that's where a therapist would be involved and determine how best to use the device for their patient)

Interviewer: For sure. I just have two more quick questions. For the proposed device, where on the body do you think is most suitable to deliver the effects as described?

P2: I think the wrist. I think if you go too high up, that sensation— I mean it's more material to go around someone's upper arm. I think your clustering of sensory neurons is more dense towards your fingertips. So the wrist is like a nice middle ground, it's somewhere that would be more aesthetically pleasing or like, less noticeable. Less eye-catching to the external...

Interviewer: And would the top or the bottom of the wrist be, would you say, for the sensors?

P2: Um, I've never worn an Apple watch, so I don't quite know what the vibration, what my personal sensation is like there. I would think that if the device had to have, like if it was not just a band, like there was a thicker side, I think from the dorsal, the back side of your arm, to then kind of mimic like a watch. I think if this were to be conceptualised and taken to market, I think you'd want it to kind of look like a watch as well.

Interviewer: Yeah, and the last question. What do you think improvement would look like with such a device?

P2: What do you mean?

Interviewer: Um, for example, would full parity be a goal in motor neglect treatment where the neglected arm is used just as much as the non-neglect arm, or that the neglect arm be used more than the non-neglect arm? What would improvement look like?

P2: That's hard to say, because there's not a lot of— again, this is to my knowledge, there's not a lot of research to show, like, how much impact we can have on neglect as a result of, like, intervention. So ideally, you would improve the use of a neglected side to what it's normal would be, which is not the same as your dominant side, but, you know, closer to 50% than 0. Yeah. I think improvement in that spot, in the use of that side, is key and it depends on where they're starting from and what their, or what a normal ratio of dominant to non

dominant arm usage is like, or that they complete bimanual tasks bimanually, as one normally would.

Interviewer: Thank you. Um, that is all my questions. Do you have any final remarks you'd like to make?

P2: No I'm really proud of you for, like, taking this with the intention to take this through to completion beyond the course, and I feel like, not knowing the cogs program, I feel like this is meaningful work that you probably don't necessarily see across the board in your undergraduate projects. Right, like, you're not— it's pretty clear you're not just doing this to get a grade, but because you genuinely have like desire to improve some things. So thank you for that. Yeah I'd be interested to hear how this goes. Because, I think that kind of work is needed, I just don't know who is doing that work, how much is being done already. Maybe that's something you and your team can pave the way on.

Interviewer: Thank you so much for your time. That concludes the end of the interview.