

**Prepared For: Anna Hurley-Wallace**

**University of Southampton**

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ANONYMISED

Int[[1]](#footnote-1): Just to double check you’re still happy to go ahead and you’re still happy to be audio and video recorded for this?

R[[2]](#footnote-2): Yeah.

Int: Great, okay. So, because my screen’s over here with my reference questions, I’ll look over there just as a reference point, but I’ll still be listening to what you’re saying at the same time, okay?

R: Yeah, yeah, sure.

Int: Some of the questions I’ll ask to start with are quite similar to things we discussed in the screening but I’ll just go through them as a warm up, so if there’s repeats, it’s fine.

So, could you start by telling me a bit about your experience of this chronic pain you’ve been having?

R: Yeah, so I have it now over two years, in my legs, in my thighs, in my calves and then went to my arms. And now it’s also in my chest.

Int: And you say it started two years ago?

R: Yeah, around that, yeah.

Int: And what kind of pain is it, can you describe it?

R: It’s like a cramping pain, like somebody’s holding me like on my muscle or something like that. It’s not stabbing pains, more like a dull pain.

Int: Okay. And do you think it’s changed in how it feels to you from when it first started maybe compared to now?

R: I think at the beginning it was lighter and then it got more intense. But it changes over, like some days it’s more intense, sometimes it’s just light, sometimes it’s not there at all. It just depends on the day.

Int: Your audio went a bit funny there but hopefully it won’t do that again.

R: Oh, okay.

Int: It should be okay. So, how does pain affect your physical abilities?

R: Physical abilities, so... I cannot exercise too much, when I exercise too much, like to a point that I’m really tired, it’s more intense. So, you know like when you over exercise and then you have this pain and the next day this is like 10 times worse then for me, so I’m trying not to get to a point where I’m very tired. But other than that, it’s more affecting me also mentally.

Int: Do you want to tell me a bit more about that, how does it affect you mentally?

R: Yeah, so it’s just constant pain, it’s just constantly I’m worrying about this, when I’m going to get this pain, like for example if I have an interview or anything like that or if I’m going to go work, am I going to have this pain again? how intense it’s going to be? am I going to go through a shift or not? and basically stuff like that. So, it’s a constant worry, yeah.

Int: A constant worry, okay. And you mentioned about going to work then, do you think it affects your work life?

R: Yeah, so now I’m on a zero hours contract, so I have this possibility that I might not go to work, but I cannot see myself going to a full time job because sometimes it just would not be possible for me to get up.

Int: Yeah, so probably a lot of time off, you think?

R: Yeah, definitely.

Int: And how about your education life before? I can’t remember if you said you went to university or …?

R: Yeah, now I’m doing PhD but before I did my undergraduate. So, this started when I was in my first year of university. So, it was quite alright in that because I didn’t have to, like usually it’s a lot of books and reading so I go to the library and stuff like that, but it didn’t really affect me. Now it affects me more in a stress wise thing, so yeah.

Int: Okay, so you don’t think it affected your university life too much?

R: No, no, I don’t think so, no.

Int: And how about your social life, do you think it’s been affecting that?

R: Yeah, sometimes, yes. If I don’t feel well, if I feel sick, if I feel it’s very painful then I just don’t go out. I just prefer to stay at home and just take some paracetamol or whatever and just go through this at home than [inaudible 04:50] for everyone else.

Int: And how do your friends react to that, how are they about it?

R: Yeah, they feel sorry for me but, at the same time, they don’t understand that it’s with me all the time, so sometimes I feel like misunderstood, because sometimes I feel like they think that I’m just making this up because they just tell me, ‘There’s nothing wrong with you, you went to so many doctors and you still have pain’, and yeah, definitely misunderstood me.

Int: Okay. And can you tell me about advice you’ve had from doctors, nurses or physiotherapists?

R: So, the main advice was to stress less, they told me that it might be stress related. The other advice was to rest more, to relax more, to have the warm baths more often or to have these kind of warmers, like warming pads. And then to buy this kind of, like a machine for massage, you know this vibrating stuff, so I bought this, and yeah, I think that’s it. And they told me to exercise more but actually exercising makes it more worse, to be honest.

Int: And have you seen a physiotherapist about it or is that just the doctors that have said that?

R: No, it was just the doctors, doctors told me, and they didn’t direct me towards the physiotherapist.

Int: And how about someone more like a psychologist, have you had any advice from them about it?

R: Yeah, so they told me that most likely it’s not stress related because I had therapy and I finished it and they told me that I could deal with stress properly, they were like young people don’t, right, and they told me that pretty much everything is okay with my mental health, that I don’t have any mental illnesses, and my anxiety level is at a normal level, nobody can eliminate all the anxiety, right, but they said there’s nothing wrong with me.

Int: Okay, yeah. And how about anyone else like an alternative therapist or specialist, have you had any advice from anyone like that?

R: What do you mean?

Int: Like alternative therapies, maybe like chiropractor or like meditation type things or some people use like energy healing therapies.

R: No, I didn’t try any of this, no.

Int: Okay, alright. And so, overall, how would you say your experience of these treatments for pain has been?

R: Some of them help, but you never went away completely, so I feel like it’s just good for the day, I don’t know, for a few hours maybe, so it helps but eventually it goes back to normal, so I have to repeat it over and over again, which is annoying.

Int: And when you’ve been trying to find out how to deal with the pain that you’re getting, who or where have you gone to first, where have you turned to first?

R: You mean doctor wise or …?

Int: Well, anyone or anything.

R: Okay, so first I start looking on Google, obviously, so it gave me a lot of like results, so it showed me it can be pretty much anything because pain muscle and chest pain is pretty much anything, right. So, then I message the auto GP. First GP just told me that just to don’t stress, that’s what they told me, and they didn’t give me any treatment. Then I went to the next GP, then they send me for all these x-rays, all this ECG and stuff like that. Then I went to a cardiologist, then I went to a neurologist, and they said everything’s fine. Then I was looking for more information online but I don’t know, I feel like maybe I’m overreacting but, at the same time, I still feel pain, if you know what I mean, so yeah.

Int: Yeah, no, that’s understandable, I think a lot of people feel the same way that you do.

R: Yeah.

Int: So, you say you went to Google or to search the internet before you went to the GP and afterwards as well, it sounds like.

R: Yeah, yeah.

Int: Can you tell me a bit more about the resources that you’ve used to try and find out information about the pain?

R: So, most of the websites that I went on, they were these medical websites, like some general one. I always look for websites with the actual sources where they got the information from, and I found one website where you just put your symptoms and it gives you the list of the illnesses which you can have, so that was quite useful. But I think that’s it.

Int: Why do you think you liked that one?

R: Because it didn’t give you sources straightaway, they just give you options of what maybe wrong with you. And when I could list all my symptoms, it just gave me like, because sometimes doctors, they don’t ask about your whole life, they don’t look at you holistically, they just look at you in one symptom and they just try to treat you for that. But sometimes I think it’s not the whole point, right, so I like this kind of search engine that I could put all my symptoms, whatever is wrong with me.

Int: Okay. It sounds like maybe something like WebMD or something like that?

R: I think something like that, yeah.

Int: Yeah, a symptom checker website, yeah?

R: Yeah.

Int: Okay, and have you been on the NHS website at all?

R: Yeah, yeah, yeah. So, I went on the NHS website for, because at some point I thought I had fibromy-galia, I think?

**Int: Fibromyalgia?**

R: Yeah, yeah, yeah. So I thought I had this, so I was reading about that. Then I was also reading about general muscle pains and stuff like that and about chest pains on NHS website also. But in there it always says, ‘Contact your GP or contact 111’, so …

Int: Okay, so overall, how would you say your experience of looking on the NHS website was?

R: I think it would be useful for me if I would be diagnosed officially, right, and then I’m going there, then I could find a lot of useful things. But if I’m not diagnosed then I don’t know if it’s going to apply to me, maybe in this way.

Int: I see, because it sounds like you went to the GP and then you went on there and because there was no diagnosis you got a bit stuck.

R: Yeah.

Int: Okay, and when you’re first looking on Google and you’re typing in the search, what are you hoping to find, do you think?

R: I’m hoping to find the least extreme diagnosis. I don’t want to see like cancer or something like that, if you know what I mean. I just want to see that this is something normal which can be cured. Yeah, I think that’s the biggest hope. And I’m trying to find also some kind of ways which I can deal with the pain which doctors didn’t tell me yet, because I think doctors, they still need to learn a lot, there’s a constant learning process in there, and they don’t know everything.

Int: Yeah, so you’re thinking about a few things then, so one is looking for a diagnosis that’s not too bad?

R: Yeah.

Int: The other thing, looking for ways to manage it better, yeah?

R: Mm.

Int: Okay, and have you had any experiences of looking for information on social media, like Facebook or YouTube, Instagram?

R: Yeah, I searched for information on YouTube.... But I’m not sure if I found anything there, I don’t think so. I think I searched for this kind of diagnosis of people, usually people will share information there what they had, but they usually have some kind of diagnosis already, so I was looking for people who have some kind of chronic pain and they were sharing stuff, how does it start with them, how did it develop, how they got the diagnosis, and eventually how they were better, if not completely well. So, yeah, but I didn’t use anything, I didn’t use Facebook, I didn’t use anything else than that.

Int: Did you find any videos that you liked on YouTube?

R: Yeah, I found a few people who have this kind of chronic pain, but they got diagnosed with something in the end. But I know it took them like a few years to get diagnosed because they were liked pushed and pushed like me, similarly. So, sometimes I felt like I could relate to their story, that in a similar way they had some kind of symptoms.

Int: Yeah, I’m just curious as well because you said before about having some stress management input as well, do you use social media for managing the stress side of things at all?

R: Do you mean like scrolling for …?

Int: Yeah, mental health stuff, do you look at anything on Facebook or Instagram, YouTube, to help you manage stress and mental health issues perhaps?

R: Actually, I’m trying to avoid it because there’s a lot of people who are saying stuff in there which is not true. I’m trying to stick to doctors, so what I was using is this app which is called Calm, so there’s a lot of just like stories, some mediation but I didn’t use it this much, but there’s a lot of reading stories for sleep and stuff like that, so I was using this quite a lot. But I don’t know if this relates but I was also using this kind of app which is, it’s like a scheduling app so this helped me with managing stress, that I could write everything that I need to do in a day and then sort it by the priority and stuff like that.

Int: Okay, so a couple of different things with the apps as well.

R: Yeah.

Int: Do you still use Calm now?

R: Yeah, yeah, I am.

Int: And do you think it helps you cope with pain, or not?

R: It helps me sleep better, so in some kind of way, yeah, because sometimes in the evening I also have these pains, so sometimes this app it helps me just fall asleep, so to get rid of pain, so in kind of way, yeah.

Int: And do you still use the …?

R: Yeah, the scheduling app, yeah, yeah, yeah, I am, yeah.

Int: And the same thing, do you think that helps with your pain management too?

R: It doesn’t make it worse, I would say in this way, but yeah, I wouldn’t say it makes it better but it doesn’t make it worse.

Int: Okay. And do you do any other kinds of things yourself, just when you’re at home or when you’re on your own, to help you cope with the pain?

R: Do you mean like some physical stuff like these hot baths and stuff like that? Yeah, so I’m trying to have at least once a week this hot bath, so this helps my muscles. And I’m using this massager thing for my arms and for my legs, so at least once a day I’m using this one. And when it’s really very bad pain I’m using paracetamol. I’m trying not to take it too often because I’ll have to take it all the time, but yeah.

Int: Okay, and what about relaxation and mindfulness more generally, do you use that at all just when you’re by yourself, to help you?

R: Yes, sometimes I’m trying to do yoga because after yoga I don’t have this pain of my muscles, yeah, so you can say that this is mindfulness, right, because I’m relaxing, so yeah, so yoga.

Int: You’re doing a yoga class?

R: No, like an online one with YouTube.

Int: Oh, you do YouTube as well?

R: Yeah, yeah, yeah.

Int: And you find that helps with your body pain?

R: Yeah, sometimes stretching helps with body pain, yeah.

Int: Okay, and not just online stuff but any of these coping strategies that you’re using to manage your pain, have you had any problems with anything you’ve tried?

R: Yeah, I had a problem with the kind of medicine which the doctor prescribed me. He told me to use ibuprofen but the stronger version of ibuprofen, which made me really sick, but that was more connected with my stomach, so it’s not really with the muscles but it made me sick. I would say most of stuff I think didn’t work at all or it made it better, nothing really made me feel worse.

Int: Yeah, so not too many problems, just that?

R: Yeah.

Int: So, what did you do then to overcome the issue with the ibuprofen? Did you stop taking it or …?

R: Yeah, yeah, I stopped taking it and then doctor told me just to stick to paracetamol, just safer.

Int: Okay.

And going back to the online, just the online resources, and we mentioned a few things that you said about YouTube as well as Googling things and WebMD, do you think your use of internet resources has changed from when you first started getting the pain compared to how you use it now?

R: Yeah, I think so. I would say at the beginning I didn’t really know how to describe my pain, and with the pain when it goes on, I learn words which is used in medicine. So, this helped me to search for stuff. And I would also say that I’m using this more often now, because I feel like, you know there’s new research coming out pretty much every single day, right, and I feel that maybe something is going to get discovered very soon, so yeah, I’m hoping [*laughs*].

Int: So, you’re keeping quite a close eye?

R: Yeah, yeah.

Int: Okay, and which internet resources would you say you’ve found the most helpful and why was that?

R: I would say Google, Google is a pretty good search engine, it is finding a lot of stuff which I read. So, I would say mostly websites from different places where they talking about some health issues. NHS website is also useful. And I think that’s it. YouTube is like my second place, but the most …

Int: YouTube’s like your second choice?

R: Yeah, yeah.

Int: Okay, and are there any internet resources that you found were unhelpful and why?

R: Instagram, Facebook I think is a bit of rubbish in this case, in a medical sense. Because I know there’s a lot of people on Instagram also who are doctors, right, but I can never check are they really doctors, is this really serious what they are saying, so I’m never trying to follow these kind of people, even on Facebook, yeah, so I’m just trying to be careful with that.

Int: And thinking about online resources, is there anything else that you think would be helpful or would have been helpful perhaps before for helping you manage with the pain?

R: Do you mean like if somebody would create some better tools online or …?

Int: Well, just what would be helpful for you, if there were new things.

R: I think maybe some kind of better diagnosis tools or maybe... some kind of apps which can give you solutions, but again, I think this kind of apps are connected because some apps give you solutions to your pain or whatever then it’s dangerous. But I feel like I would like to see more websites which are helping people with this kind of chronic pain which is not diagnosed, because if you don’t have a diagnosis then you are pretty much stuck into one place and I don’t know where to go from now. So, I feel like there should be more resources for people who just don’t know what’s wrong with them.

Int: Okay, and anything when you were looking before as well that you wish had been there when you were looking, apart from what you just said?

R: Um... Maybe more information about from genuine websites, if you know what I mean? Because not all websites are also good, I need to be very picky, because some websites, they’re just saying something and it can be just like taken out of air, so yeah.

Int: And is there anything else that you would like to add to anything that you’ve said so far?

R: Maybe... because at the beginning I remember at the beginning I said that exercise makes my pain worse, but actually this yoga makes it better, so I just wanted to clarify that. Yeah, so just yoga makes it better.

Int: Okay, and it’s interesting as well that you use YouTube for that.

R: Yeah.

Int: Lots of people do as well, especially now.

R: Yeah, yeah, it’s really good.

Int: Okay, unless you have anything else to add on then, that’s the end of my questions. So, yeah, if you’re happy then I’ll stop the recording and then you’ll have a chance if you want to ask me any questions about anything then you certainly can do, okay?

R: Okay.

[CLOSE]

1. Interviewer [↑](#footnote-ref-1)
2. Respondent [↑](#footnote-ref-2)