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ANONYMISED

Int[[1]](#footnote-1): Just to double check you're happy to go ahead with the study and you're happy to be audio and video recorded just for this?

R[[2]](#footnote-2): Yes, that’s okay.

Int: Thank you. Some of the first questions might be quite similar to what I asked in the screening interview but that’s fine, it’s just to help warm up so repeats are fine, okay?

R: Yeah.

Int: Can you start by telling me a bit about your experience with the chronic pain?

R: My pain has been mainly in my calves and upper back and neck, the pain in my calves has been like a dull ache every day that normally would come about after periods of strenuous exercise, but this has been a daily pain and then in my upper back, it’s like a weighted pain. Yeah.

Int: How long have you been having that for?

R: At least since March. So, seven months?

Int: Seven, eight, yeah?

R: Something like that.

Int: Can you tell me about what it was like when it first started compared to what it’s like now?

R: When it first started, I’d say it was very upsetting because I thought like I don't know where this has come from and now, it’s just about how to kind of manage life with the pain, so if I have to take any paracetamol or ibuprofen to ease the pain and then try and carry on with daily life with it, so it’s just about finding alterations to help.

Int: Okay. And, do you think pain affects your school life?

R: Yeah, it affects kind of how long it takes to get to school - so if I’ve got really bad pain in my legs, by the time I walk down to the bus stop, it might take longer because I’m a bit slower, because it’s more painful and it definitely affects when I’m sitting in school doing my work and moving to and from my classrooms, it’s painful then.

Int: Okay. What about the social side of things, how does your pain affect that?

R: So, my social life has kind of been not only limited by the coronavirus, but it’s been limited by… say if I went to get the train to London with my friends, I’d be absolutely exhausted afterwards and have a lot more pain, it would be more prominent for another couple of days. Whereas if I try and avoid that, then it’s more bearable.

Int: Yeah. So, you avoid some situations, do you?

R: Yeah.

Int: Okay. You said a little bit about physical abilities with the pain and walking, is there any other ways the pain affects your physical abilities to do day-to-day things?

R: I’m trying to kind of plan how to exercise because like running is just out of the question so trying to stay fit and healthy has definitely been more restricted by the pain, because it’s like already having the post work-out pain there and then kind of having that doubled. It’s just more than like I can handle basically.

Int: Mm, okay. What about your mood and emotions? How does your pain affect those?

R: It’s been really tough because you have to deal with the kind of depressing side of the pain, making you feel upset and then you feel like your whole time is consumed by how do I get it to go away? How can I make it better? How can I live with this? And then it’s just really upsetting, feeling like as a teenager, I should be able to do everything and then this is holding me back, so it is definitely really upsetting.

Int: Yeah. Feeling a bit low, you said.

R: Yeah.

Int: That’s understandable, a lot of people with pain of any type who are in their teenage years will feel like that - a lot of people feel the same way.

R: And it’s definitely quite isolating as well.

Int: Mm. Especially at the moment…

R: Yeah.

Int: You mentioned about taking some painkillers for it.

Could you tell me about advice you’ve had generally from doctors, nurses or physios, or even psychologists, if you’ve seen anyone like that?

R: So advice from doctors has just been to take the ibuprofen, if it is relieving my pain even just a little bit, my main worry was I don’t want to be dependent on it, to be taking it every day, so I’ve been trying to manage and then if it’s really bad then I’ll take the medication but just because I don't know how long the pain’s going to last, I don’t want to have to be dependent on it for the rest of my life.

Int: Yeah. That’s understandable as well. What about a physio, have you seen a physio about it?

R: No, I’ve not seen a physio about it.

Int: Okay. Or a psychologist, or anyone like that?

R: I saw an osteopath about the pain in my back and that did help relieve the pain, mainly in my neck, so that was beneficial.

Int: What did the osteopath say or do about it?

R: It was just kind of... I don’t really understand completely, because they were just doing it but they were just feeling like my joints and then yeah.

Int: It helped?

R: Yes.

Int: Have you had any advice or treatment from any other alternative therapists or specialists?

R: No.

Int: Okay. When you’ve been having this pain, when you've been trying to find out about how to deal with it, who or where would you say you’ve turned to in the very first instance?

R: Mainly social media and online, like the NHS website, because you do feel so alone, you want to find if there’s anyone dealing with the same thing and then if they’re having any successful methods of relieving it, kind of using that as inspiration to try and incorporate into your life.

Int: Do you think you could tell me a bit more about the internet resources that you’ve used to find out information? Come back to the social media in a minute.

R: With the NHS website, I’ve just been kind of looking at the chronic pain, chronic fatigue pages and just kind of seeing their solutions. It’s really difficult to kind of research it alone without a doctor being there to aid you and I do worry about being consumed by just constantly looking, but I’d say by looking at the NHS pages and similar pages like that, it’s made me think about what other... information is out there to help me kind of give myself a broader understanding.

Int: Yeah. When you're using the NHS website, do you click on other links they suggest?

R: Yeah, I think there was like a chronic pain charity, so I clicked on their link, just to see if they were giving any advice and I think through doing that, I’ve kind of felt not as alone and then really thought about how my lifestyle does affect it.

Int: Okay. So overall, how would you say your experience of using the NHS website was? How would you describe it?

R: I’d definitely say that they could have more information about... but I know it is just there as a guide, so I do think there are links to the charities are beneficial.

Int: What about other health advice websites like Healthline or WebMD? Have you used any of those to find out about pain?

R: Yeah, I think I looked at WebMD and, again, it was just, I was just looking for lifestyle changes and alternatives to using medication because my worry is: I don’t want to be reliant on that, and I know that they could be heavily addictive. I just don’t want to have to deal with that on top of the pain.

Int: Okay, and with WebMD, what is your experience of using that compared to the NHS website?

R: I’d say the WebMD website was probably not as useful as the NHS website because NHS gave links to charities that gave more insightful information, whereas WebMD was just kind of symptoms and then it was more “talk to your doctor” and I felt like the NHS website was a good alternative to not being able to speak to my doctor within the pandemic.

Int: Mm. It has been tricky as well for you, from when the pain started. Of course.

Let’s talk about social media. Can you tell me about any experiences you have of looking for information about pain on social media?

R: So, I mainly used Instagram and I was just looking for the charities to see if they had an Instagram page and from there, I found lots of accounts with people suffering from the same thing and then using Instagram to talk about their experience. So, I felt less alone and then at the same time, I felt informed from a person that was dealing with the same thing as me. It was definitely helpful to kind of put a face to other people going through the same thing as me.

Int: Okay. Do you ever interact with the other accounts?

R: No, I didn’t really interact with them, I just kind of followed them and then just looked at what they were posting. Yeah.

Int: Okay. What about other social media resources like Facebook or YouTube?

R: Yeah. I did actually use YouTube and I watched a TED talk about this woman that was suffering with chronic pain, and it was just about the changes she made to her lifestyle and it was just – I really use that as a reflection to kind of think about, “How am I making changes to my lifestyle, to benefit?”.

Int: So, it sounds more like that was for information, whereas Instagram sounds a bit different to that?

R: Yeah.

Int: So, what would you say the main thing is you're going on Instagram for, for pain?

R: Kind of the community side of it, to not feel alone.

Int: Okay. Other things - maybe Reddit - some people have mentioned that, do you use that at all?

R: No, I don’t use that.

Int: Or Pinterest?

R: No, I haven’t used that.

Int: And Twitter as well?

R: No, I haven’t used Twitter.

Int: Okay, fair enough.

When you're initially searching the internet, when you start in Google and you're looking for information or advice, what do you think you're hoping to find?

R: I think everyone’s hoping to find like this magical cure to stop it but realistically, I’m just looking for something that makes my quality of life a bit better and not feeling… so defeated by it, feeling like I can carry on with life and still be happy.

Int: Yeah – that makes sense.

Okay. I’m going to skip back to talking about coping for a minute.

R: Yeah.

Int: What kinds of things do you do yourself when you're just, either at home on your own or by yourself, to cope with the pain you’ve been getting?

R: I’ve been trying to talk to my mum about it, just to kind of feel like I’m not holding it within me and bottling up my emotions because I do feel, if I don’t talk to my mum about it, then I’m just suffering in silence whereas at least if I talk to my mum about it, she understands how much pain I’ve got and then she also helps me realise if like one day I’ve coped a bit better than I thought I had, so seeing someone else noticing that I am managing to cope with it, even though I am in pain, is definitely helpful to feel more optimistic.

Int: Yeah, that’s good.

Does your mum or anyone else in your family or friends’ group give you advice about what you should do about pain?

R: No, my mum just kind of says if it does feel really bad, take the medication like the doctors have suggested but apart from that, she doesn’t really have any other ideas.

Int: She’s supporting you more?

R: Yeah.

Int: Okay. What about things like relaxation and mindfulness, do you do any of that to help you with the pain?

R: Yeah, I have the Calm app, so I do like the guided meditations on there and they have one for dealing with pain as well, so I’ve given that a go just to kind of feel a bit more calm about it but then also, if I just do a normal mindfulness relaxation, it does help to try and take away from the pain for a little bit, which I think is also good because I don’t want my whole life to be consumed by it.

Int: What do you mean by a normal one?

R: So, it’s just about mindfulness, it more focuses on your breathing whereas the one to do with pain focuses on like your terms of pain and evaluation of that within your body.

Int: Okay. Are you still using that now - Calm?

R: Yeah.

Int: Any other apps or websites that you’ve used for that sort of thing?

R: No, just Calm.

Int: What is it that you like about that, or why is it you think you chose that one?

R: Because it has things to help you fall asleep as well, so sometimes if I’m laying there and I can really feel the pain, it’s another thing to help take my mind off of it so it doesn’t disturb my sleep as well. It’s just the multi tools within the platform.

Int: Okay – that’s good. What about exercising at home or doing any sort of physio type exercises? Have you done any of that?

R: I tried to do some yoga during lockdown and then walking my dog, if it’s not been too much, on days where the pain in my legs is more prevalent, my parents have taken my dog out for a walk instead of me, so I’ve tried to opt for a more easy form of yoga, just to kind of stretch and still do some exercise that isn’t too strenuous.

Int: That sounds good.

With any of these coping strategies that you’ve been trying yourself, have you had any problems with any of them?

R: Not too sure, I’ve just kind of been... I do feel like it has helped me cope, so I’m less upset about my situation than when I first started feeling the pain, and yeah, I suppose it’s just kind of given me a different outlook on how the pain’s affecting my life.

Int: Okay. So, thinking just about internet resources again, because we mentioned a few things - we talked about the NHS website and other websites like that, social media and using Calm as well –

How would you say that your use of internet resources and/or social media has changed from when you first started getting the pain to more recently?

R: I think when I first started getting the pain, I was more using the internet and social media to look at coping mechanisms, mainly on YouTube and the NHS website. Whereas now, it’s turned more to, viewing pages of similar people on Instagram, just to not feel as alone and I’d say that my usage of Calm has been pretty level throughout the whole time, because I’ve still been using it just to kind of take my mind off of it through the meditation, just to help me get some good night’s sleep.

Int: Yeah – that makes sense.

Which internet resource or resources would you say you found the most helpful, and why was that?

R: I would say Instagram, just because it puts a more personal feeling to the information, it’s coming from someone that’s dealing with the same thing as you so not only does it help you feel less alone, but it feels like this person’s using this to help them, it could help me as well.

Int: What kind of things - I’m interested to know - if you’ve seen things on Instagram, have you tried any of those and if so, which things have you tried?

R: It was mostly just kind of… like doing less strenuous exercise, so before I wanted to just kind of carry on with life as normal whereas through Instagram, where people have kind of been saying that you need to make exceptions that alter your life to make things easier with the pain, so it definitely has been trying easier forms of exercise – to still exercise – but not increase the pain.

Int: You mentioned that about your yoga, that you changed the type?

R: Yeah.

Int: Are there any internet resources that you’ve found were unhelpful, and why was that?

R: I would say that not every internet page can be completely trusted, which is why I just stuck to the NHS website.

Int: And... what kind of other things you were maybe seeing on Google?

R: They were mostly American websites but obviously, the health system doesn’t work in the same way as it does in America to England, so I just stuck to English websites, and then I didn’t know the legitimacy of these other websites, whereas at least I know with the NHS website, it’s coming from doctors and respected people of science, so I thought this was my best way forward.

Int: Yeah, yeah. That makes sense.

So - thinking about any of the online resources, is there anything else that you think would be helpful or would have been helpful in the past for helping you manage with the pain?

R: I think the only thing that would have been more helpful was more contact with my doctor, but given the circumstances, I knew that was impossible so I do think that the combination of the internet and social media was my next best option.

Int: Yeah.

Could I ask as well, because I didn’t ask before, have you seen your doctor in-person about it?

R: No, no.

Int: How did you contact them? What mode did you use?

R: Via phone call and that’s just been the only way I’ve been able to contact anyone apart from when I’ve had blood tests taken, that’s the only time I’ve seen someone in-person, but they were just taking the blood and not actually talking to me about it. So, yeah.

Int: Looking at all the advice and things you’ve found on the internet now, do you think you will go back to your doctor about it when the service is open for face-to-face again?

R: Definitely, I feel like they can’t get an accurate picture of everything I’ve been dealing with, without talking to me about it in-person, because I feel like I need the face-to-face contact with them as well as they need with me, because they don't know… how much is being conveyed from just a phone call.

Int: That’s really interesting, even though you’ve had lots of information, you still want to see them in-person. Yeah.

R: Yeah.

Int: Is there anything else you'd like to add to anything you’ve said about the pain in general or about internet resources?

R: I can’t think of anything else.

Int: Okay. That brings me to the end of the questions. What I’ll do now is stop the recording. Thank you very much, and if you want to ask me any questions you can as well.

[CLOSE]

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