

<Main purpose: to find out what mediums are most comfortable for sufferers to use in terms of their emotional struggles>

What are some of the challenges you face in school because of your chronic pain?

Physically I can't lift up heavy things. Can't stand too long and can't sit too long.

Are there any instances where you have been treated differently because of your condition?

A: not really. Because they don't know my condition. When it comes to workplace, sometimes you don't have to tell them, so they wouldn't know.

But if you stand or sit a lot they won't notice?

I have to do it on my own, or I have to walk around and go to the toilet. I didn't mention about my condition.

But did they ask?

No they didn't ask. (laughs)

They just stand and you didn't ask.

Yeah.

So have you ever had an instance where you feel embarrassed sharing about? Like you have pain, but you don't want to inconvenience anyone?

Yes.

If so, pick an instance you feel comfortable sharing about.

Previously I worked as a dental assistant, so my time, I have to stand for at least 3 hours. (knits brows) For some instances where I really feel the aching, I have to move around, because I have to hold the tube while washing the teeth, you can't move around. Because once you move around, you can't suck the water from the mouth. So sometimes I will just move around, so the dentist tells me "please do not move", so once you move right, you will actually trigger a lot of things, so you have to endure the pain. So that's a lot of difficulties. So that's actually an obstacle for me to work with stationary movement for too long. Like when you stand or sit for too long. This is one of the challenges I faced.

Is that why you quit the job?

(contemplating), yes, actually it's true. (smile) I have to stand for a long time, 4 to 5 hours straight, without sitting. (knits eyebrows). So this is the difficult part for people who have pain when you have to work.

How did the incident make you feel?

Very....um, how should I say... (contemplating)...of course you will feel suffering(laugh), or you will feel the pain, or I should say, agitated. Because you can't do the job because you feel the pain, there's no way that you can tell your boss that "oh I have to sit down, I can't do anymore." that's a...I should say the frustration. I feel frustrated. Yeah. (knits eyebrows)

Does it contribute to your inner feelings, like insecurities?

That means when you're looking for a job for the next round, you have to think so much. You can't find healthcare, where you're doing the heavy weight, and you can't climb up the stairs because of your arthritis, you can't sit for too long, you can't stand for too long... and uh, you can't stop at a motion for too long, and just like the dentist incident, you have to really hold the suction for 30 minutes. You can also feel the aching. So there's a lot of problems when looking for jobs. Even for office jobs, you can't sit for too long. Every now and then you have to stand and walk around. (objective frown) some bosses might not be happy, like "hey you're going to the toilet again, you're getting water again, you're walking around again?" you know? (laughs) that's the problem.

Do you have a medium that helps you cope with these feelings? Like you write down a journal... you share with other people...

Uh, no. usually I'm quite a positive person. (laughs) when I'm down, I try to self internalise, like I try to motivate myself, like uh, you don't feel down, you know, tomorrow will be a better day... that's how I do it. (smiles) Otherwise I will listen to music? Yeah. listen to music.

What kind of music?

The smooth, slow instrumental music. Will calm your mood down. Make you much more happier. (laughs)

Because the purpose of our app is to find out what mediums are most comfortable for sufferers to use so like, to connect the medium to non sufferers you know, so the non-sufferers who understand that pain...

Usually music. Else some people might take exercise. Yeah.that's what I can think of. Cannot be you eat, or drink right? (laughs) music and exercise to release your emotions. Or stress. When you feel down, that's what I can think of. Usually I will use music. Because I seldom do exercise. (laughs)

Because I was thinking, the non sufferers, how do you think they can understand your struggles? If you were to tell someone? What medium do you think is best? Because non sufferers usually don't care, unless it comes to their children or their friends...

I think you have to communicate face to face. Talk to them. Let them know. For example, my previous work, my colleagues doesn't know I have pain. Unless I communicate with them, then the only thing they can do is empathise with you. Because they cannot understand how painful it is, from one to ten, what is your pain? I cannot understand. What they can do is, "oh, if you feel pain, maybe you can sit down for a while. Rest for a while, then you come back and do your work again." (laughs) that's the empathy they can gain. So I think, to me, it's to talk to them. You have to communicate with them to let them know what's happening.

Okay. You mentioned before that you never told them, right?

Yeah. they also didn't ask. They take it that if they see that you're physically good, then you're ok.

Has that opinion really impacted your health?

Because they didn't actually ask during the interview. Some interviews, maybe, some other jobs, big firms right, they might ask you, "Do you have any physical, proper whatever" if you interview for healthcare or age care, they will ask "do you have physical problems?" because they need you to not leave the patient or need you to lift heavy weight. So you have to tell them. But for some of the jobs they don't ask. So if they don't ask, I mean, I wouldn't tell you, what are my problem. Also the fear that if I tell you, you might not employ me. That's the fear, for people with pain. Because they want the job but they fear that "oh, if I tell you I have this pain, I have that pain, I might not want her."

Yeah.

That's the biggest fear for handicapped people too, they also fear that they might not be employed because they're handicapped.

Yeah.

(laughs)

Do you know that there's a recruitment company for those with disabilities?

Yeah. at least there's that.

My husband asked me, "why don't you go there since you've also got a disability?" (laughs)

You can try.

It's whether or not I want to tell them it's my disability or my spinal pain problem. It's up to whether you want to tell them, and they have to source a job for you. But usually I'm able to manage my pain, still physically okay, forget it. (laughs) I'll look for a job on my own.

I think they exist in the first place to give you more inclusive bosses.

Yes, empathy. Empathy is very important.

If you try to find a job there's also all these anxieties.

Yeah, anxieties. You feel that you won't get a job.

Going back to the question of, so it's mainly communication...

Yes. Because there's no way they'll look at a diary. They won't look at your diary, or journal, or whatever. It's just that, face to face will be fast. You get the response immediately. Whether they want to get you in, or they want to employ you, or they want to empathise, "yeah it's no problem! We'll still take you in." you know? Honesty. You got to tell them.

So we had the idea of using lights to communicate like, the person with chronic pain has a flare up. So say, it's a series of dots, sometimes from 1 to 10, there are 10 lights. Say, the lights are around 7. It means that the pain is flaring up. Do you think that will help with letting the non-sufferers understand chronic pain?

Yeah yeah. That's very important. Because usually they'll ask you on the scale of 1 to 10, what is your pain. Yeah... sometimes I tell my patients and my doctor, that yeah, it's 9. (huffs and smiles). They cannot imagine that, I mean to them it's 9 and 10 is really very painful. 5 and 6,

still manageable. 7 and 8, yeah. That means you are tolerant of your pain but it's still painful. That's very important.

How about instead of doctors, people who are your coworkers? Will it help?

Yeah, it will help too. Because usually we will ask on the scale, you know, what is your pain level. It's very important, because if you come up with "yeah, I'm in pain, or slightly painful", they cannot imagine, 1 to 10, which are the areas that you're in pain.

So do you think, if we were to use this device, chronic pain sufferers, we were thinking, sometimes they might be embarrassed about it? Like they might not want others to know of their condition?

In what sense or situation?

Let's say we put the device on a desk, for example. It might also come in an app form but we are not a hundred percent sure yet - it's just a general idea. When they are in pain, the meter goes up. Do you think they still would want to use the device due to that?

For the device, I personally would not use it at work. But how would you go about using it at work?

Like say, an app?

I'm alright with apps. If I were in pain, I could show someone the app discreetly. But I would not exhibit my pain. If I were an office worker, I do not want everyone walking past my desk to see what my pain level is, right? It would be very awkward. (knits brows) Let's say one person walks past and see that my pain is level 3 or another might come later and see that it is at level 4.

So it's a bit embarrassing?

Yeah, unless I am in a lot of pain, in which I will tell the person directly, I do not want people to constantly know my pain level.

But what if a person doesn't believe you are in pain? Will you just show them the app?

Yes, but I would not exhibit it – it is not an exhibition. I don't want people (shakes head and knits brows) walking past my table every hour to check which level I am at.

Yes, I understand. How about a wearable device, then?

I think that is fine because it is very private. Like right now, I am wearing a Fitbit. If it could show me my pain levels, it would still be closer to me unlike if I have a machine that announces how much pain I am in. Apps is fine and so is this, but not a device that does that.

So, if it is a wearable device, what will motivate you to wear it? What if it not only measured your pain levels but also could tell the time?

Oh yes, so this Fitbit tells me things such as the time, how many steps I've walked, my heart rate and how many hours did I sleep. It was many different uses and if could also detect my pain, that would be the best.

Out of curiosity, if we were to create a device like that, would you prefer an app or a wearable?

I think either way is okay. I also have a Fitbit app on my phone so when I go out, I can check it whenever I want. So, maybe both would be good as well. However, I feel like an app will be cheaper to make compared to something like a Fitbit, which cost me around \$150, almost \$200. As for apps, I could download it for maybe \$10?

Actually, we are using Arduino to create the device. We already have some of the parts so the price does not matter that much.

I see. (Laughs) Make it less public and more private. That would be better for the patient as they can keep it to themselves and show others if they want to. At least that is what I think.

So, to sum it up, you prefer the app or wearable form because of privacy, right?

Yeah.

But if this is the case, there is a chance that any conversation you have might not include your chronic pain. The other person might have no knowledge of it at all.

Yes, yes, it's true. Unless they ask me or I tell them. However, when we are looking for a job, some candidates are more open or honest about their pain.

What do you think can motivate them to ask?

You mean the boss? Or the employee?

Some people don't understand that chronic pain sufferers are in pain and might think that they are just given special treatment.

You usually have to make it known to them. You have to tell them, otherwise they would not know.

But like we discussed, some people get embarrassed. For example, I get embarrassed when I need to tell complete strangers that I need the chair that they are sitting on because I have chronic pain.

Actually, I'm not very sure as I don't feel embarrassed when it comes to this. (shakes head) If I am meeting up with anybody and I need to sit, I would just tell them. Something like "I'm so sorry but I have spinal problems" and grab a chair to sit down.

Ah, I see.

That is why I let them know of my condition beforehand. If I am applying for a job, I have to tell my boss about this problem so as in to not let it jeopardize my future work.

But there is the fear of getting fired.

You will have to keep reinforcing that even though you have this pain, you are physically well, unless I am in a level 9 or 10. I am still able to walk and run although I have this pain. If it does not affect your work, then they should definitely employ you. Unless, of course, you are in serious pain. But that is also why I cannot apply for certain jobs, like those in the healthcare industry.

I hope you find a job soon.

(Laughs) I'm still looking!

We are trying to get more chronic pain sufferers to open up to non-sufferers and have a conversation about their condition.

That is the most difficult part because not all sufferers are vocal. Some of them are rather introverted and think it is their personal matter.

Is it also because of pride?

Yup, it is quite tough.

And the non-sufferers might not care?

Yeah, my old Chinese boss used to say “if you got to do the job, you got to do the job”. They don’t bother. You can take a break but you always have to come back and finish your job.

So, it can be quite challenging but we are working to bridge the gap. Make the non-sufferers who don’t care hopefully care about it.

You would have to try to get to those more introverted types. For me, I am okay with telling others about my pain. It is not because I do not have pride, it’s because I have certain needs and I need to prioritize them. Sometimes even when I am in a lot of pain, I am still not allowed to sit.

Maybe for the introverts, what do you feel about a device that helps them put their needs before their pride or embarrassment?

It’s tough as if they don’t want to talk, that is it. If you probe too much, they might not like it. They might have low self-esteem but they still have egos. They might feel inferior but they also know what they want. If they want to tell you, good but if they don’t want to, they will not.

I feel it is possible to convince them to speak up but it is tough.

Yeah, not everyone wants to talk about their pain. You would also have to bridge the gap between sufferers and non-sufferers and how to empathize with them. To me, face-to-face communication is very important. Going through emails, journals or diaries is not as effective.

There’s also this whole question on how to talk to people.

You must think of how to ask the question. Some people don’t like getting asked private questions, they will think you are intruding on their privacy and not tell you.

I understand. This is why the light-up device was proposed. We hope it might help to bridge the gap a little bit. For example, a wearable device might blink a few times to catch their attention.

Yes, because the device idea doesn’t really work on introverts because they do not want to let anybody know. Something like an app or a wearable can let people know as well, but on your own devices. That’s what I think.

Reflection:

Upon reflection, it seems that a device that is put on the table that indicates a level of pain for other people to see might not be a good idea, as sufferers might feel embarrassed about showing their pain so readily to people they don’t know that well. It would be better as an app

and device so that they can show it if needed, especially since the app and device might not intrude on the sufferers' privacy and might open the conversation between sufferers and non-sufferers within their own control.

It also appears to not be a good idea to propose a diary, as non-sufferers who don't care about chronic pain are unlikely to read it.

I've improvised by asking more questions since this is a testing interview session and we wanted to get the initial feelings of interviewees. I feel like we should add more questions as a result.