

I participated at Yale university in New Haven, Connecticut.

I had participated in a different study at Yale University and the researcher who was my contact from that study referred me to you all and peaked my interest. I studied psychology in school, which is not exactly the same as psychiatry, but I had interest in the topic and found it worthwhile participating. So that's kind of how I found out about this study and then gathering more information from the research assistant Lia, I was able to decide whether I wanted to participate or not.

After going over all the information and all the like the procedures and steps from the study I felt pretty comfortable with the surveys and the different types of quizzes that I had to perform and then the MRI I was pretty comfortable with as well. I've never had an MRI before, so that was a new and interesting experience. I'm not afraid of confined spaces in any way so that was pretty straightforward for me. I did have some anxiety over the lumbar puncture procedure just because I never had one I don't think most people have probably and have never known anyone who's had one either so that was new to me and a little anxiety inducing just the unknown of what could happen and just it being a more invasive procedure. But I obviously ended up going through with it and having it performed and it was pretty straightforward. I was ... all of my fears were assuaged by again the research assistant Lia and she really helped me get a better understanding of what the procedure was and what the side effects could be.

Yeah I was aware of it, despite never having an MRI before. I think that's one of those procedures that you kind of just see on television often enough where you can kind of guess what it might be like so that was helpful having that sort of background information in my head. And from what I remember I was given that information before deciding to participate in that procedure and was kind of warned that it was going to be in a confined space which again I feel OK and comfortable with so I ... I proceeded but I was given adequate warning about what that experience might be like.

I think it's like one of those things that's hard to describe unless you actually have done it before because you have to stay perfectly still and then it's very noisy which I don't think translates very well in media so it's certainly one of those things that you can't fully understand unless you've done it but in no way was it uncomfortable or scary but I found it particularly interesting and that just might be my background and my educational background. But I'm glad that I did it. Moving forward if I have to get another MRI performed I'll understand what the expectations of it are and feel more comfortable going forward with it. And that's something that I really appreciate - I've done a few Yale studies now - it's just

being exposed to new experiences in a safe way, you know. I don't have any medical necessity to get an MRI, thank goodness, and so having that experience as part of a study instead of a medical necessity was pretty interesting and getting to experience that in a less stressful way than if I was getting it done as a necessity.

Yeah I think they matched up pretty well. I think similarly it's hard to really describe what it feels like to someone who may have never experienced it before. But I think the description and the preparation for the procedure was pretty thorough. I was given the opportunity to kind of research it myself and look into it more before making that decision which I found helpful and I think something that Lia did when we were discussing the procedure is she gave me statistics on the side effects that were found from people who were doing this exact study at other sites and and at the Yale site as well. So it wasn't some random like ohh this is the percentage of people who have this side effects generally, it was specifically this is the percentage of people who have experienced this in this study which I found reassuring and helpful and I if I remember correctly she was telling me that most participants had no symptoms, no side effects and if they did it was like a minor headache and some body aches, which is what I experienced so that was meeting the expectations that have been set for me. So that was reassuring. I think there's always that fear and anxiety of well what if I'm like that .01% where like something other than the typical side effects happens and I don't think that, like, fear of the unknown will ever really go away until you experience those things. But having done the procedure I can say that I'm glad I did it again similarly to what I said about the MRI just having the experience of doing it and you know not many people can say that they've had a lumbar puncture so it could be a good fun fact, I don't know, but I felt adequately prepared and the description of the procedure was fairly accurate to what I experienced.

Oh, I mean it's like it's pretty hard to have expectations when you've never experienced something before. Going into it with the knowledge that you know a needle is going to be in your spine that's that like hearing that sounds scary and so I was kind of preparing myself to feel the pain and to feel discomfort just as a worst case scenario sort of thing. And it did not meet those expectations in the best way so that was a positive. And then just expect- the expectations I had aside from like understanding like this these are the steps that are going to happen all of the gaps that you just don't know because you've never experienced my brain kind of filled in of like ohh this is probably gonna take a long time because they're extracting fluid and it probably is going for a little bit. So kind of making up these expectations of worst case scenario just to prepare myself but really none of those things happened and it was straightforward and easy and comfortable for the most part as much as like having a needle in your body can be.

I had googled like lumbar puncture and read more like about what the procedure is like and you know the side effects as well but I was curious about what exactly the steps are when the procedure is performed and having that information and knowing that going into it was helpful for me just having a better understanding of OK this is exactly what the doctor's gonna be doing and this is what I should expect and that puts some of my nerves to rest so I'm glad I had the opportunity to look into it on my own and then again going back to the specific data that was provided to me for this particular study.

I think just having honestly several conversations specifically about the lumbar puncture I have been comfortable with the MRI from the beginning, that wasn't a barrier for me. But having conversations with the research assistant that I was working with about it and almost easing into it and not feeling pressured by how to make up my mind right away and being given the time to like I already said do my research on my own and mull it over was really helpful in me being comfortable making a decision and then moving forward with the procedures.

I remember having a conversation with him about again like what the procedures expectations were and he kind of went through with me what he was going to be doing so I was like aware of what was going to happen. We didn't have much more conversation with that it was very business. And yeah overall the procedure was like pretty quick so he was pretty in and out.

Yeah I remember .. it's been over six months now so I have to pull it back up, but the appointment was early in the morning and I remember I had a friend accompanying me to drive me home so that was comforting because I was a little nervous but not overly so. And then I had been taken to one of the procedure rooms and kind of just going over the expectations again with the reach- research assistant and the actual procedure itself was at least from my perspective of you know not being able to see it seems pretty straightforward. I heard the doctor had come in and prepped the the spot on my spine where the needle would be and there was you know a little, like, pinch when the anesthesia went in which was just like a regular sort of blood draw type of pain, it wasn't extremely painful. And after the anesthesia had set in it was when from what I understand about the procedure is the other needle went in to extract the spinal fluid and like I had previously mentioned I didn't really feel it much at all. I felt the initial pressure of the the needle going in and while it was in there, like I said, I didn't feel it at all, I didn't even know it was in there. And the research assistant who was accompanying me, she was, you know, trying to distract me and keep me in conversation so that I wouldn't, you know, feel nervous or panicked or anything and that was helpful. I was pretty interested in what was going on,

more so than nervous or scared and found it all quite interesting. It didn't take very long either, actually it took a lot less time than I expected for the whole like that part of the procedure to be done. And when the needle was removed there was some like pressure again but no pain and and then the area was cleaned and bandaged and that's basically what I remember about the lumbar puncture. I remember having some blood drawn afterwards as well which is a basic procedure. And I was given some snacks, made comfortable and was kept in the procedure room for monitoring for a little while and then got to go home. And after the procedure and especially after the anesthesia had worn off there was some lower back achiness, I wouldn't say pain necessarily but more of a soreness and a very slight headache which I was able to take some Advil and it went away pretty quickly. So that's mostly what I remember from the procedure. I don't remember feeling like overly nervous or scared and the team that worked with me was really great at making me feel comfortable.

So I would feel comfortable recommending another person to have the procedure done knowing that I have been pretty nervous and apprehensive in the beginning about agreeing to participate in that procedure specifically. I would say that it's interesting and not as scary as you might think. So if that's like a barrier to participating I would say that it's really not as bad as your imagination might make it out to be.

I think, you know, immediately following the procedure and having some friends know that I was having it done they were certainly curious about it and I was able to try to describe how it was. Which you're not like viewing the procedure happening since it's behind you so it was more of a describing the sensation of what was happening. But since there's a local anesthesia administered you don't really feel much which is good you know you don't want to be feeling the pain but it was mostly just slight pressure and it was funny at one point I thought that we were finished like I thought that the needle had been removed and I was just kind of waiting for the go ahead that we were done and then turned out like the needle was still in and I completely did not notice or feel it at all which was pretty interesting and shocking to me.

I think it's something I felt comfortable with from the beginning. At least at the site that I've participated in the appointment scheduling aside from like requirements of you know having certain appointments being earlier in the morning they were extremely flexible and it made me feel comfortable with doing a longitudinal study knowing that it wouldn't have to be so strict and like rigid with the scheduling and there was some flexibility there so that kind of assured me that moving forward in the long term that that would remain the same.

I will say I had an overwhelmingly positive experience participating in the study so far. I really couldn't recommend it enough. I've participated in some other Yale studies like I've

mentioned that are a little less convenient not that you know having these procedures is necessarily convenient but as I already mentioned the flexibility and willingness to work with me on scheduling and making sure that I have fully understand the expectations while preparing to go into these different steps of the process was really helpful. And I think overall what I appreciated the most, and this is mostly because I this is just how my brain likes to prepare myself, is having as much information as possible and I feel like there was a lot of information provided up front and I also felt very comfortable asking questions. Never at any point was I hesitant or felt uncomfortable asking the research assistant or you or the psychiatrist anything. So I think with something new and potentially scary having that information and having a team that made me feel extremely comfortable was probably the most helpful thing for me with my willingness to move forward with participation and I think that simple fact made it very very positive and a very good experience for me.

I'll just yeah reiterate I'm very excited and eventually seeing what the findings are and as I already mentioned having studied psychology myself it's something that I have interested in and I think that definitely helped with my interest and willingness to participate in this study as well because I do find it interesting and worthwhile to be studying which wanted me to participate even more. So I think the work you're doing is really interesting and cool and I'm grateful I had the opportunity to assist and like participate and be part of it.