Pinkrat interview

KA: Um (.) So I'm going to start with some um more general uh ice breaker questions (.) um so I'd love for you to tell me a little bit about yourself and this can be anything you know your hobbies uh things like that

Pinkrat: ma((pause)) OK um well my name is [REMOVED] I'm seventeen years old and I have ADHD uh inattentive type and autism (.) I was diagnosed with autism not entirely sure when but I would guess when I was around (.) let's do some maths ((pause)) uh ((pause)) bout ten (.) uh probably about ten yeah makes sense. Um ((pause)) and ADHD when I was (.) fifteen (.) roughly. Um (.) my hobbies are just uh I like to play with lego quite a lot um there's ((pause)) uh video games (.) yeah stuff like that. Oh fencing as well that's-

KA: Oh that's so cool. As in like with the with foils and the?

Pinkrat: That's the one

KA: Oh how did you get introduced to that? Was that like through school or are there clubs in your area?

Pinkrat: I wanted to try it for I wanted to try it for a while but um uh it took a while to convince my parents but got there in the end. Um I've been doing that since I was (.) probably about ten or so as well

KA: Wow yeah you must be so good now I imagine I think with any sport that you do kind of from childhood so much of it goes into your muscle memory and then you're yeah

Pinkrat: That's (.) that's the idea

KA: Yeah ohh that's really really cool I haven't actually met many people who do fencing before so that's super interesting (.) um (.) I do gymnastics or at least I try to but I'm really really rubbish it. But other than that I'm not really doing many sports at the moment ((laughs)) Um ((pause)) cool cool and I know you mentioned a bit about um (.) I guess like your diagnostic journey um with the ADHD and both the autism there I also wanted to chat a bit about your journey with like anxiety and how that relates to um the ADHD and autism as well. So do you want to talk a little bit about that?

Pinkrat: Um (.) Ok yeah (.) yes (.) um ((pause)) sorry ((pause)) do you want me to just talk about how you want me to just talk about um my anxiety and-

KA: Yeah maybe like how it how it manifests for you and um you know maybe specific times that you feel a bit more anxious than other times

Pinkrat: Well (.) I'd say it's mostly uh I s'pose you might call it a social anxiety

KA: Mm

Pinkrat: It's really hard for me to speak to (.) new people. But uh most of all when it's in a large group setting I'm um meeting multiple people at once and that manifests itself mainly as a (.) standing awkwardly and silently in the corner quite a lot

KA: Yeah

Pinkrat: Uh (.) It can also mean that overtime (.) as I interact with people in that environment it's it can build up and become overwhelming (.) which occasionally can lead to a meltdown but (.) but ideally not

KA: Yeah yeah well given that you know it can be quite a nerve wracking experience for you to speak with new people I'm especially grateful that you uh you know are participating in my research. It means a lot you know when all of my participates sorry participants take part but especially those who have you know social anxiety and things like that. So big thank you. Um (.) and yeah (.) I know you you mentioned there that in extreme cases it can kind of result in a bit of a meltdown. Are there steps that you find that you can take that normally help you get out of the meltdown stage?

Pinkrat: You mean like avoiding it?

KA: Um yeah it can be avoiding it. Or I guess when you're when you find yourself in a situation that perhaps you can't avoid are there certain things that you can do that make you feel a little less anxious or not so much?

Pinkrat: Not really (.) um (.) There are plenty of ways of (.) you know trying to (.) bring your bring down your own emotions but I'd say that most of the time it's only ever a very temporary measure. It can delay it but not for long and definitely not inevi- uh definitely not (.) what's the word I'm looking for uh um ((pause))

KA: Oh um (.) indefinitely? Is- ((overlaps))

Pinkrat: That's the one indefinitely

KA: Yeah

Pinkrat: Um yeah so it's ((pause)) the only fool proof way to prevent that situation honest honestly is to just remove yourself from it. Um (.) find somewhere quiet. It can (.) it can it can be hard in certain situations but uh removing to remove yourself. But in those situations just finding somewhere quiet is crucial

KA: Mm yeah ((pause)) And if you were uh to say describe how anxiety feels to you how would you describe it?

Pinkrat: Um ((pause)) just the ((pause)) A persistent (.) it's like a blockage almost that stops me from (.) you know I might be thinking I want to go over there and talk and talk to that person or I want to say this thing and just the words are (.) not coming. It's uh there's no (.) there's no way to make myself speak to people it's just it's just (.) and over time it builds up this feeling of feelings of frustration and apprehension and nervousness. They all just build up and up and up to the point where like I said the best course of action's to just go

KA: Mm that sounds like it must be difficult as well kind of balancing that desire to do certain things but as you say feeling like you're really blocked from doing so. Um (.) and yeah I guess kind of related to that you said that um in these situations if it gets to an extreme you experience a meltdown. What does a meltdown feel like to you?

Pinkrat: ((pause)) I'd say ((pause)) It's um very ((pause)) sort of a pretty much uncontrollable outpouring of anger um in the way that a breakdown is well could be defined as an

uncontrollable outpouring of sadness or (.) um (.) or just overwhelmed it (.) it's (.) perhaps I could describe it best as trying to compress a liquid um sooner or later it's going to burst out

KA: Mm

Pinkrat: Um when it does it has quite a lot of force to it

KA: Yeah yeah that makes a lot of sense. Um now I'm going to talk a bit about something that we a certain model we tend to use a lot in cognitive behavioural therapy and I'm not sure if you've experienced much of that before but I'll just introduce it in case you haven't (.) um (.) so we have this model called the Hot Cross Bun Model which sounds a bit funky but basically what it means is we split it into four parts like the cross on a hot cross bun. Um and with anxiety um sometimes we like to split that into the four separate parts um so that would be like our it includes our bodily sensations um our thoughts so like our cognitions above that um the kind of raw emotions we feel and then our behaviours that we exhibit. So I wondered if you had any particular thoughts about all or any of those sections in terms of how anxiety feels to you?

Pinkrat: Um behaviourally I'd say that ((inaudible)) Now it's ((pause)) it's often manifested as (.) in terms of anxiety it's just quietly (.) quietly sitting in a uh well not sitting but just you know keeping to yourself and looking. I'm not sure how it would look to be honest but um ((pause)) it's (.) just yeah I guess that's the right way of saying just silent and ((overlaps))

KA: Mm

Pinkrat: and avoiding people. Whether it's avoiding their attention or yeah

KA: Mm so like a lot under the surface and kind of on the top not seeing it?

Pinkrat: Yes. Yeah it definitely actually that's a good way of putting it

KA: Mm and yeah what about the emotions maybe?

Pinkrat: The inwardly feeling it can (.) the metapor I've seen used a fair bit that makes sense is almost like a uh like a stormy ocean when it when it's building (.) it depends that's what it (.) Ok let's go with the metaphor of an ocean. You know it ((stutters)) might start with uneasiness and the occasional ripple disturbing otherwise calm waters but over time as I was talking about before as it all just compounds on itself it becomes more like a stormy ocean um uncontrollable. And so it's just yeah

KA: Yeah I really I mean I can relate to that a lot actually I um have anxiety myself and definitely the metaphor of like a stormy ocean is one that resonates with me a bit as well. Um (.) yeah and about now perhaps those physical feelings um I guess like those bodily sensations uh do you have any comments about how anxiety feels to you with regards to that?

Pinkrat: Uh ((pause)) there's a (.) there's an urge to do something particularly with your hands I think when it's when it's you know when it's building just (.) as I you know it's just the urge to do something I suppose um is it is just it just builds and builds (.) um (.) Just doing anything really. So that could be uh (.) just what just whatever picking your hands or fiddling with something it it's uh (.) yeah I'd say like that

KA: Mm yeah that's something actually we hear quite a lot with our different participants it's yeah this idea of (.) I guess almost like quite a primal like in discomfort obviously we always try and like do anything to like get away from the thing that's causing us discomfort right? And we hear a lot of our participants have a similar sense of you know wanting to do something to kind of push the anxiety away like as it were. Um (.) so yeah it's interesting to hear that you experienced similar. Um (.) yeah OK um ((pause)) The next question is a bit about that overlap between your experiences of autism and anxiety. Um so for you do you think those two things are quite separate or do you think they have a lot of overlap for you?

Pinkrat: I'd say it's probably that my autism is what makes the anxiety it almost amplifies it um whereas it might perhaps be manageable without it but fixation on it leads the uncontrollable fixation on it leads to well building the building of it until it just becomes too much

KA: Yeah yeah I imagine as well especially because of the um like the social aspect of it that probably plays a role into the more social anxiety I'm sure (.) um (.) Yeah and perhaps I mean this this might be a bit of a sort of in depth question I guess but can you think of any sort of really specific examples of how you know your autism might um exacerbate your anxiety or make your anxiety worse?

Pinkrat: ((pause)) well (.) say for example (.) um (.) Let's say that you tell a few jokes and (.) nobody laughs and that whereas usually it might be there might be a tiny part of you that says (.) um (.) I'm worried they don't like me (.) um usually the responses is just oh these jokes weren't funny then but with my autism a lot of time I'll just tend to amplify it uh until my thoughts are dominated by these people don't like me

KA: Mm

Pinkrat: Um s'pose that's one example ((pause)) try to think of another one ((pause)) Do you want another example?

KA: Uhm I think that that one's fine that was a good example. Yeah if there's none that's coming to your head quickly. Um OK great we're going to move on a little bit now to talk about something called alexithymia um which is a really really long word that essentially means a difficulty identifying or describing emotions and it's something that we tend to research quite a bit in our lab um and it quite often can co-occur with autism um and we think it as well as autism links to this uh you know ability to detect signals coming from our body that I said we'd be talking about earlier (.) um. So is this something that you have experienced with? Um do you sometimes find it difficult to recognise or understand your emotions?

Pinkrat: Well (.) I wouldn't say that's an issue for me personally I'd say that being aware of what it is that I'm feeling isn't the issue it's more just controlling it

KA: Mmhm ah OK (.) um (.) That's really really interesting um (.) yeah. For some of our participants but very much not all of the participants it seems to be like a around a fifty fifty split some of them say that sometimes um when they're experiencing a certain emotion um that it they can feel that it's very intense and they can feel that it's something um but they don't necessarily know if for example it's positive or negative or say if they're excited for something or if they're scared for something. Um o does that does that resonate at all or still no?

Pinkrat: Um ((pause)) Oh I'd say perhaps not beyond what people usually experience you know

KA: Mm

Pinkrat: if there's a if there's some sort of really exciting event it could be a mixture of excitement and nerves (.) um which can be confused. But I'd say most people probably experience that. So I wouldn't say there's anything for me personally beyond (.) that which might be considered usual

KA: ((pause)) Yeah (.) No that makes that makes a lot of sense. Um (.) and this is a bit of a difficult question to answer. So don't worry if you don't have any initial thoughts about it um (.) But (.) When you are, you know, trying to to recognise an emotion, are there any signals that you look for um that are especially telling for you about what emotion you're feeling um (.) you know is there anything that you're aware of you kind of look out for?

Pinkrat: Breathing I suppose (.) uh (.) whether I'm breathing or quite heavily. That can (.) that can be an indicator at some points. Uh (.) A lot of time it also can feel like a like a weight (.) um (.) you know (.) yeah I'm sure I'm sure you know and then like a weight on your chest and stomach

KA: Yeah yeah I know exactly. For me I think it's sometimes when I'm nervous about things it feels like (.) something's like dropping out the bottom of my stomach a bit like when you're on a roller coaster and you drop down suddenly and yeah that's kind of what I get a bit but yeah I definitely know as well the ((stutters)) weight on the chest is a (.) is a very common one. Um (.) Yeah and let's take maybe like a a slightly different example now but uh if you were (.) really really angry about something would it be those same kind of signals like the breathing and the heaviness on the chest or?

Pinkrat: Um no but yes. That kind of thing that's just you know uh more intense version of the same feeling I suppose

KA: Oh OK yes yeah um (.) um ((pause)) and- sorry I was just making a quick note of that. Um I know yeah so we that's probably a bit like anxiety and and anger and those sort of more negative emotions. Would it again be the same if you were really really happy? Would you also look to your breathing and things like that or would that be a bit a bit different?

Pinkrat: ((pause)) say that again sorry

KA: Ohh yeah sorry um if you were uh like another example now if you were really really happy would it also be the breathing and the uh feeling on your chest that you consider?

Pinkrat: Yeah except almost as an inverse where it might feel easier to breathe and like a lightness in the chest rather than uh beyond uh beyond the usual possible um

KA: Yeah

Pinkrat: Yeah

KA: Yeah that's so interesting. See with me I'm a bit weird in that I can I can tell when I'm feeling angry and I can tell when I'm feeling um really scared but I actually don't really I couldn't really tell you how happiness feels I just know that in certain situations I am happy because of the situation so I think I'm a little bit alexithymic actually but yeah. It's um very interesting that it's kind of all on the same scale for you just varying degrees of that (.) um (.) cool. Um so we're kind of around the halfway mark ish now um so I just wanted to check in

with you um we can either take a break at this point or if you're feeling that you're kind of getting into the flow of answering we can also keep going it's absolutely up to you

Pinkrat: Um let's keep going

KA: Cool cool. So next we'll talk a little bit about interception which I mentioned at the beginning um and interception is our ability to feel signals coming from inside of our body and again some examples of that might be how fast our heart is beating how hungry we are or how badly we need the toilet. Um so right now if someone asked me for example how fast my heart is beating I could like take my pulse and that would be one way to tell and that would be exteroceptive because we're relying on cues outside of our body to feel that. Um some people but not all people can actually feel their heart beating in their chest without the need of you know touching their body with their hands or anything like that they can almost feel it inside of themself um and that's just one way we can be interoceptive it's kind of that ability to sense these things without having to check externally. Um so for me I cannot feel my heart at all if I'm not touching my pulse except if I've been on a run because I'm quite unfit if I've been on a run I tend to feel my heart beating quite a lot afterwards and then I can feel it. Or if I'm really scared about something that I can then I can feel my heart. But just day to day I can't really feel it at all

Pinkrat: Yeah

KA: So yeah how ((stutters)) is that for you? Do you can you tend to feel your heart or?

Pinkrat: I think probably (.) probably something like that after exercising is when it probably feels the most or when you know I'm stressed for whatever reason. But apart from that uh there's nothing (.) hm I don't usually feel it unless for whatever reason it's elevated

KA: Yeah yeah. And just thinking about those times that it might happen to be elevated (.) um (.) do you find it quite unpleasant or stressful when you feel that it is elevated or is it just quite neutral for you?

Pinkrat: ((pause)) Sorry say that again?

KA: So it in those times when you do feel your heart rate and you do feel that it's elevated is that quite unpleasant and stressful or is it just neutral?

Pinkrat: ((pause)) I'd (.) Yeah I'd say it's elevated

KA: Mm yeah yeah. Um ((pause)) and yeah when it that kind of I guess feeling of having a fast heart rate, does that stress you out more or does it kind of depend on what's the cause of it being elevated?

Pinkrat: It definitely doesn't it definitely doesn't help (.) um (.) it's just one more thing to prioritise attention to I suppose um as in just another thing to keep track of when things are getting too much

KA: Yeah yeah that's yeah (.) interesting um because yeah there's a theory that links interception to anxiety and that theory kind of suggests that if say for example you know someone's heartbeat increases and they're really aware of their heartbeat at all times that might make them more anxious because they think that something's wrong with them because their hearts beating fast and then because they're more anxious their heart starts beating even faster which

makes them even more anxious which makes their heart beat faster and we call a negative feedback loop because you know you start from one triggering event and then it keeps making itself worse and worse. Is that something that you feel like you experience or maybe not so much?

Pinkrat: I - yes I'd say that I probably do experience that that's some- I've definitely been aware of it in the past

KA: Yeah yeah. Um and have you ever tried methods or strategies maybe when you're feeling anxious to you know focus on either your breathing or slowing your heart rate down or things like that or not yet?

Pinkrat: Yes but I have reached a point where I have been aware of them for a few years I've tried them it works well when ((inaudible)) I can remove myself from the situation (.) um (.) you know if all that's changed is my breathing it doesn't help

KA: Yeah yeah I can imagine if you're in a very stressful situation actually it's probably quite hard to get enough focus on just your breathing to just control that (.) um (.) cool (.) Um and yeah we've spoken quite a bit there about like heart rate and breathing and that kind of thing um but looking at other signals have you ever had any I guess difficulties with signals such as knowing when you're hungry or knowing when you need to use the bathroom or things like that?

Pinkrat: Not personally I'd say that that's not something that I particularly uh I struggle with particularly

KA: Yeah ok cool yeah. As I say it's such a range of experiences we get reported with these type of things. Um ((pause)) and yeah. I as well as looking at anxiety I also look at eating behaviours and also eating disorders in um adolescents who are autistic. Um and I just wondered if you'd be comfortable talking about that. Um is that something that maybe you've ever had experience with or not personally?

Pinkrat: (.) Sorry could you just say that again? I uh yeah

KA: Um yeah uh I was just asking if you're comfortable speaking about it um if you've ever had any personal experience um with either eating disorders or just more broadly difficulties with your eating

Pinkrat: Uh ((pause)) not (.) not really. I mean there was a time when because I was (.) I was getting used to my ADHD medication my appetite was reduced but not personally in terms of eating disorders uh that's not been an issue

KA: Cool yeah yeah. And sometimes we do see with some of our um adolescent participants especially those who are autistic that there can be certain sensory limitations with food so um for example certain textures of food are really aversive or things like that. Um have you ever noticed anything like that before?

Pinkrat: ((pause)) sorry could you just say it one more time

KA: Ohh yeah yeah no problem. Sorry it's my fault I'm probably giving you really long-winded questions I tend to ramble a lot ((laughs)) Um I was just saying um are there any sensory issues that you have with food?

Pinkrat: Um yeah I'd say some foods in particular can be um unpleasant just because of the texture but um (.) that's easy enough to get around just don't eat them

KA: ((laughs)) yeah yeah. And is it like a lot of different foods um?

Pinkrat: No not (.) not too many. Um I wouldn't say that I wouldn't hat it vastly affects what I personally eat cause there's just a few things that I wont

KA: Mm yeah I have similar and not it doesn't affect me lots but sometimes if there are certain like overlapping textures like if something's really creamy and then there's like I don't know (.) like hard stuff in there or lumps or whatever urgh I hate stuff like that. That's my uh my issue with it. Um cool and just going back to again this like the more general signals in the body (.) um (.) are there any body signals that you're aware of that you find especially unpleasant to feel or no?

Pinkrat: Uh ((pause)) no uh (.) that's not a huge issue uh although am very aware that a lot of other autistic people find it hard. Occasionally I couldn't give you specific I'm afraid but occasionally I will misinterpret something ((pause))

KA: Ok ok. Yeah that makes sense. And yeah although you said you know a lot of autistic individuals feel certain things I think something that hugely characterises autism is that it's so different for you know different people so yeah there really is no you know average or normal in that sense and that's why it's so useful to get a range of um you know ideas and experiences. Um (.) yeah the last thing that I wanted to ask about really was just whether you have ever experienced masking which (.) are you familiar with the term masking?

Pinkrat: There's a lot it's definitely a big issue uh (.) ((inaudible)) just as in purely because it's just (.) there's a societal expectation to conform to a certain way of behaving and if not it can be demoralising to go and try to talk to someone and then (.) um (.) just them lose interest in conversations because you're not hiding who you are so it's (.) it's hard um

KA: Mm

Pinkrat: There's only the very few people (.) that (.) it's almost like a subconscious urge (.) um (.) because if (.) you know autism is a part of who I am it define- like it or not it defines the way I interact with people and so it is demoralising when the way I interact with people because of my autism is not good enough. So it's it there is a huge amount of pressure um to mask you know people can be people can be accepting of the fact that I have autism you know if I say if I say how I have autism they'll say "cool (.) I you know I don't really care" (.) um (.) but some of the traits that come with that are less decisively acceptable so there is an expectation to mask (.) um ((pause)) Uh you know whether people realise it or not um (.) it's very hard to not have to mask um you know situations where you like can just be yourself are few and far between

KA: Yeah and that's really I guess upsetting to hear. I think in a lot of ways we are becoming more accepting as a society but as you said a lot of the time of that acceptingness it's (.) it's people saying "ohh yes I don't mind" but then they continue to judge people for traits that are you know just a manifestation of the same thing that they had said that they didn't mind about. And yeah that's (.) I really really hope that we move forward even further to a degree where it's not even just acceptance but society itself is more accessible for people of a range of different cognitive profiles um (.) because (.) yeah if there's one thing I've learned from

doing all my psychology research is that really there is absolutely no normal so it's weird that as a society we've kind of picked one way of thinking and thought ohh yes this is gonna be the way of thinking that we operate on and we're gonna make it really difficult for anyone who (.) who think slightly differently from this ((pause)) yes it's it must be quite frustrating. Um ((pause)) but yeah when you mask uh does that affect at all um I guess the way you connect and the way you feel about your body or not so much?

Pinkrat: Uh not particularly. Well it doesn't really affect the way I feel about myself but it's (.) uh it's more when I don't mask um and there's judgement associated with that which affects the way I think about myself (.)

KA: Yeah yeah. Certainly that makes sense. That makes a lot of sense. Um yeah it's been really interesting speaking with (.) with people about masking because it does seem like a really like exhausting thing to do but then equally (.) such like an inevitable part of yeah

Pinkrat: It can be tiring (.) to act in a certain way for hours at a time. Uh well it certainly doesn't help in situations where it might become more stressful and just keep (.) keep smiling (.)

KA: Yeah yeah. Um and yeah I guess you know when you're masking does it become more difficult to focus on other things or you know does it feel like a lot of your brain power's focusing on masking?

Pinkrat: Definitely ((pause))

KA: Yeah

Pinkrat: Um it does it does I'm conscious of it (.) to keep it up (.) sorry

KA: Yeah

Pinkrat: Uh situations where I might be already feeling anxious it's just then a complete standstill

KA: Yeah yeah. Um I'm just going to make a note of that ((pause)) great. OK well that's pretty much all of the list of topic questions I had to ask you but before we finish up today I just wanted to give you the chance to ask um (.) you know is there any questions you have or is there anything that you think that I haven't asked about that you would like the chance to talk about?

Pinkrat: I wouldn't say so I think that's pretty much everything

KA: Yeah yeah OK. Well thank you so much once again for you know giving up your time for this. It means a huge amount to us as a research group