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Catatonia and autism: an interview with Dr Amitta Shah

Can you tell us how you first became interested in autism?

So I first became interested a long time ago, when I was an undergraduate at UCL, doing my degree in psychology, and it was in the final year, and we only had one lecture on autism, and it was given by none other than Professor Uta Frith, and I think the way her enthusiasm sparked off something in me and I became interested in autism as I'd never been on any other subject on the course. So I remember very distinctly that after the lecture, I ran up to her and I said, "Could I follow up on this? I want more references," and she invited me to her office in the afternoon, and I haven't looked back since, really.

So that was my first, you know, sort of interest in autism, and then I did my research in autism under Uta Frith, and of course I did all my other research and clinical work under the guidance of Dr Lorna Wing, so I really had two of the best people in the world as my mentors!

Can you tell us about your current work?

AS: Currently, I work as an independent consultant psychologist and I have always been interested in the secondary difficulties of autism, so I've done a lot of work in initial diagnosis; I used to work at the Lorna Wing Centre using the DISCO but my work has been with more complex difficulties, so I've worked with challenging behaviour, with people with autism who have a breakdown, either in behaviour or in mental health, and that's what really got me interested in catatonia. So a lot of my work at the moment is raising awareness of catatonia, doing a lot of training so that people become aware and pick it up early and know what to do when somebody develops catatonia, because it can be such a devastating condition.

And I'm now, as we speak, I am actually looking to see how, where we can link in with the NHS, because it's still not, because the professionals are still not picking it up; in fact, to the point of where families are going with, because they've heard about it or they've seen a review or

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something, and they're saying, you know, "Is this catatonia?" A lot of psychiatrists, psychologists, neurologists who get to see these things, they haven't heard about it or seen how it is manifested in people with autism. So my work at the moment has all become focused on catatonia.

What is catatonia and how is it linked to autism?

Catatonia is a very complex disorder, and basically it affects a person's ability to carry out voluntary actions; it affects speech, movements, volition, you know... it's not volition as in the will to do something; they want to do something, but they can't actually execute that. So at the extreme end, it's very easy to recognise, so the person is actually quite immobile, quite mute, they're not moving, they're not speaking, they're not doing anything, and they're motionless, and that's quite easy to recognise, and that's what a lot of catatonia literature has looked at; the very severe end.

But actually, catatonia, it's a very complex phenomenon and it can occur at very different levels; you can have it very mildly, and then it can increase to being moderate and to the severe levels, so it's a progressive condition, if it's not managed well.

Can you tell us what the early indicators of catatonia are in autistic people?

So, in people with autism, catatonia is a very interesting phenomenon in the sense that a lot of features of catatonia actually are features of autism as well. So there is an overlap between the two conditions. But that's not the catatonia type deterioration and that's not what needs the management, it's when these features become exacerbated and when the catatonia actually increases.

So the first, what you may see, the early signs are that the person becomes, the person with autism will become slow, slow in their movements, they might start hesitating, they might start speaking much slowly, they might not, and gradually, they will not be able to get out of bed, they may not, they may want to but they're not able to actually complete movements, and sometimes if they start a movement, they're not able to stop a movement.

So, the early signs are if you find that somebody's actually showing any deterioration or if they start losing interest in the things that they've been doing before, if they start losing skills, or if they're not able to, if they start losing their independence, particularly, because they become very prompt-dependent, so they can't carry out actions and activities unless somebody gives them a prompt, and this can be a verbal prompt or sometimes a physical prompt, and then they can't carry out the activities and actions and so on.

How does catatonia differ in autistic people - if at all?

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It's a very interesting question because you know historically, catatonia has been associated with schizophrenia, quite wrongly. So it was only, so if anybody showed any catatonia, they would also be given a label of a type of schizophrenia. We started, in people with autism, we don't often see the extreme form of catatonia. So what you actually see is this pattern of deterioration and it can be quite subtle initially as well. So, you know, there may just be an increase in their repetitive movements, they may start showing a lot of complex rituals, those which they hadn't shown before, or an increase in the ones that they had been showing, and then gradually it affects more and more of their movements, and their behaviour.

I think the other thing is that, you know, a lot of people with autism are not able to talk about what is happening to them, so that in itself complicates things, because we relate it to underlying stress, trauma, anxiety, so it's... people are not able to communicate and they'll slowly start shutting down, so there's various... in autism, we see various forms of catatonia, so either you see the catatonic features, which are sometimes part of the autistic features or they're an exacerbation, or you see a shutdown which can be either a temporary shutdown in some situations, which is very anxiety-provoking, or they get shut down for longer and longer periods. Or they may have just transient difficulties on some days, they're not able to function very well, they're not able to do the things without having prompts. And in autism particularly our studies showed that it's related to, it's most frequently seen in people with autism who show a passive, who are more passive anyway. So the people who are passive are actually less active, they're less spontaneous, they have difficulty initiating interaction and communication and so on, and these people seem to be more at risk of developing catatonia.

Are there any treatments for catatonia in autistic people, and are they effective?

In terms of treatment, you know, whenever there is a condition, there's people always trying the medical treatments, and in the past, catatonia, it has been, people have followed the medical model and they have tried, and it's a trial and error, there isn't any tried and tested medication, there are case reports of particular medications that people have tried, but it's usually in, when the catatonia is very severe, because it can become life-threatening at that stage as well and you have to try anything, and the other thing that has been tried is ECT, but we would only recommend medication and ECT as very last resort treatments, but what Dr Lorna Wing and I developed what we call the Shah and Wing approach, which is a very, it's a non-medical approach to looking at catatonia and understanding it. So it's a very individual approach, it's holistic, it's not any particular treatment, but it's actually, it's about becoming aware of catatonia early on, you know, in its early stages, and getting carers, staff, and other people to actually recognise it and do something about it at very early stages.

So we have, so there's various stages, so one of the things is how do you support somebody who has catatonia, so that's part of treatment, you know, because often staff think that they're being lazy, they're not cooperative, they're being wilful and so on, so they don't provide the amount of support that they need, so you know, how do you respond to somebody with catatonia, and then following on from that is we were looking at the cause of catatonia, you know, in a

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particular individual, cause if you look, a lot of our studies showed that there were particular stresses which people, trauma which people had gone through, which were often responsible for triggering off the catatonia, and this stress can be very different for different individuals, so you need a detailed assessment, and look at that, and then try and look at their environment, their program, their lifestyle to see how you can cut down on the stress and how you can also raise their threshold for tolerating stress and anxiety, cause there is always going to be something that triggers off stress and anxiety.

So we work, we look at working at, and this isn't about a particular psychological treatment, it's not that "OK, so we have somebody and we're going to give them six sessions of CBT", it's actually looking at what the person needs and sometimes and, you know, sometimes they may need input from the speech and language therapist, the OTs can devise programs which will be beneficial for them, physiotherapists can help with the movement side of things, and psychologists particularly can look at the, can do a good assessment as to the type of autism, the level of autism, how the autism affects them and what are the likely stresses for this person, and then they will devise an individual plan of management, so that's what, you know, we recommend, this approach, to treat and manage catatonia.