

Parental perception of adolescent and adulthood autism transitional behaviours

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ABSTRACT

In today's current literature, maladaptive pubescent behaviour in adolescent and adulthood autism are not easily identifiable. This has resulted in a lack of awareness in parents, caretakers, special educators and other allied healthcare professionals. The aim of this study was to identify non-maladaptive and maladaptive behaviours which develop during puberty in autistic adolescents and how it affects their overall quality of life. A focus on identifying maladaptive behaviours arising during puberty, relating to hygiene and social behaviours was applied, in addition to methods applied by parents and caretakers in dealing with the aforementioned. A two-part data collection methodology was employed wherein a total of nine participants were recruited. We used the Adult Autism Assessment Survey form that was formatted to be suitable for use in the United Arab Emirates and to fulfil the objectives of this research. Demographic data was collected through this form as well. This was then followed up by interviews with the participants. Collected data was then analysed using the phenomenological method with the process of coding the interviewed data. Findings showed that, individuals with autism have an increased independence with age. It also showed that they developed more adaptive behaviours than maladaptive behaviours. The study identified pubescent developing non-maladaptive and maladaptive behaviours.

Keywords

parental perception, autism spectrum disorder, autism transitional behaviour, adolescent behaviour

Introduction

The history of defining autism was not a linear process. Children and adolescents who presented with signs and symptoms of Autism Spectrum Disorder (ASD) were then labelled as a mere form of childhood schizophrenia due to the similarities in both diagnoses' presentations. ASD and schizophrenia shared deficits with language, social interaction and the occasional catatonia etc. [1].

However, in 1943, Leo Kanner, a psychiatrist at John Hopkins University, put forward the notion that children who had an "innate inability to form relationships with people" have a unique disorder that he coined as infantile autism [2]. Kanner was the foremost academic in history to clearly defined the forming maladaptive behaviours that these individuals with ASD would present with, such as:

1. Delayed echolalia (impairments of social communications)
2. Extreme autistic loneliness (impairments of social relationship)
3. Anxiously obsessive desire for the consistency (behavioural characteristics; impairments of imaginative thought).

However, due to his unchanged perspective, the second edition of the Diagnostic Statistical Manual remained unchanged in the definition of autism that it was still a psychiatric condition; rather than the developmental disorder it is defined as now. Maladaptive pubescent behaviour in adolescent and adulthood autism are not easily identifiable in today's current literature, creating gaps in knowledge for this vital issue at hand. It has resulted in a lack of awareness in parents, caretakers, special educators and other allied healthcare professionals [3]. Allied healthcare professionals in the field of autism is solely focused on the paediatric realms of the spectrum.

Occupational therapists focus on the child's sensory functions, their gross and fine motor functions as well as their activities of daily living and how all the factors come together to make up the individual's quality of life. However due to the gap of knowledge regarding the maladaptive and non-maladaptive behaviours that emerge during puberty and get set in stone with routine, these therapists wouldn't be able to pinpoint what behaviours to intervene [4,5].

Methodology

The data was collected and interpreted using the phenomenological qualitative approach to investigate the parental perceptions of maladaptive behaviours associated with their autistic child/adult. It is a type of qualitative study that has its main focus of a person's lived experiences in the world [6,7].

As United Arab Emirates has recently started its year of tolerance; it has begun its initiative of making the nation inclusive to all individuals who are differently-abled, or as in their notion "people of determination". There are multiple schools who have educated these autistic individuals; however, there are only a few centres one of which; "Special Needs Family Centre" in Dubai that is equipped to be instrumental to autistic individuals over the age of 18years [8].

This study aims to identify the origin of the pathology of maladaptive behaviours in adolescence and adult autism. It would help identify the root cause of these unwanted behaviours in the offspring or students and could lead to better intervention planning.

To prepare for the data collections, in-depth, a semi-structured interview guide with questions was developed based on the concepts of Critical Incident Technique(CIT) focusing on examples of incidence of maladaptive and non- maladaptive behaviours among autistic individuals.

There were two parts to the data collection that was used. The first was a survey shared using google forms. We used the Adult Autism Assessment Survey form that was formatted to be suitable for use in the United Arab Emirates and to fulfil the objectives of this research. All the demographic data was initially collected through this form as well as to be more time-efficient.

It was then followed up by questions on google meet interviews with the participants. This study was conducted in a room with minimal distraction and maximum comfort of the parents in terms of privacy and even ergonomics (each interview was estimated to be approximately 20 minutes).

Inclusion and exclusion criteria

The sample population were approached using convenience and purposeful method based on the inclusion and exclusion criteria. After obtaining the approval from IRB committee, recruitment was done through the following criteria:

Inclusion criteria:

- Parents of individuals who are diagnosed to have autism
- Their individuals should be above the age of 16 years old
- Able to read, understand and converse in English

Exclusion criteria:

- Parents of individuals who are not diagnosed to have autism
- Their individual is below the age of 16 years old
- Cannot read, understand or converse in English

Results and discussion

Demographic data result

The survey had a total of nine participants; however, only 5 of these were available to conduct the interview. The other four participants were not interviewed due to the current situation of COVID-19. The UAE had imposed a very strict law that if a person of disability tested positive, the parents would be faced with heavy penalties. With this in mind, the interview was moved to an online interview using Google Meet. However, some of the parents were not able to connect to the meeting as because of their age and other stresses of having a child, found it difficult to maneuver using Google Hangout.

Out of the nine participants, the age range of the parents was between 64 years to 30 years old, and their children were between the ages of 38 and 16. Majority of the participants (66.7%) of the parents were the mothers and 33.3% were the fathers. The children of the respondents were 88.9% male and 11.1% female.

Some (37.5%) of the participants had an annual income of above USD 51000, 25% had a yearly income between USD 31000 to 50000. A few (25%) of the participants had an annual income between USD 21000 to USD 30000. Finally, 12.5% had an annual income between USD 10000 to 20000.

A majority (77.8%) of the participants had an education level equating to a graduate degree, whereas the other 22.2% of the participants disclosed having been educated at a degree/diploma level.

Independence in activities of daily living (ADL)

All parents reported that their children had an increase in independence level in aspects of body hygiene. One parent said, "the importance of implicating a routine on the child was necessary. Such practices influenced performance and the child can act independently after sometime". Individuals with autism thrive from a routine. Therefore, if the parents had a selected performance for their children from a young age, there would be a potential increase in their activity of daily living independence. The majority of the parents reported that the primary caretaker was responsible for maintaining hygiene importance such as the mother, father, both or the nanny.

Future expectations of ADLs

Most (40%) of the participants reported that they would like their children to be more independent in shaving the beard and underarms. One parent expressed "I do desire that my child was more independent in grooming. For instance, if only my child could apply moisturizer or aftershave, without being told". Two parents expressed the wish that they would like to see their child more independent in toileting, such as washing their backside more efficiently as one mother said that their child still had stains on their underwear from the less efficient wash. Only one parent was delighted with her child's body hygiene.

Self-awareness

Autistic individual awareness about the changes in their body

Four out of the five parents reported that their child did not inquire about their body self-awareness. The high functioning autistic parent (parent two) shared "As my son transitioned into adulthood, he started asking about his physical changes. For instance, he started to ask about his facial hair". The mother said that she tended to these questions with visual images and then he proceeded to do his research over the internet.

Communication about body changes

Some (20%) of respondents reported that the school would educate them on the importance of their body changes. Most (80%) of the parents said that both mother and the father would attend to communication around physical changes.

Parent three noted, "Social stories are used." She continued sharing "However, around my friends, all their sons find out about their needs and satisfy by himself. They hide it so he does the same. They don't like to be talked to about it. He tries to hide that kind of fact from me even though I don't talk to him about it". However, she also said that he occasionally walks out of the shower naked around his female sibling; this behaviour would be corrected immediately.

Other parents expressed the importance of these body changes and the impact of fitness on their high functioning autistic child. Parent two reported, "I noticed that a fitness routine enabled him to acquire the confidence to deal with everyday life". She stated that his behaviours needed to be corrected at the age of 13 to 14 concerning changing their clothes; however, once the routine was kept consistent, he manages to maintain an excellent habit

to date.

Another parent (parent five), shared “my child is nonverbal, we don’t need to talk to him about his body changes”. Further prompted with the safety of the issue, they said: “We are always supervising our child, so there was no need to communicate. Parents find ways to have adequate functional communication; they do this by using social stories and verbal instructions. Some parents will argue that communications are not needed as the child doesn't have many social interactions. Hence, only communications that occur always is pertaining to day to day activities that are required.

Physical changes

Two parents (parent one and parent three) reported that their child was overweight. One explained that this was because their child wasn't compliant with physical exercise. An example by a parent (parent three) is noted in a quote “My son doesn’t do any physical activity; he is always sitting on his bed or the couch where he feels comfortable”. In conjunction with this, another parent also reported that her child's posture is affected because the time spent on his phone where he is mostly slouching.

Parental perception of child's awareness of the opposite gender

Two respondents reported that their child did not display any physical attraction to the opposite sex. They both echoed that their child behaved appropriately when interacting with the female gender. One of these parents (parent three) shared “my son has a good sense of humour even though he is non-verbal when he interacts with others”. One parent shared “my son has sexual desires when he sees a woman's video in provocative clothing”. When such behaviour is observed, they will respect the child's privacy if the child is expressing it in a socially acceptable manner.

However, they will only correct him if he crossed the line. The socially accepted behaviours may differ at time. For instance, a parent shared her views; “I think it's ok for my son to kiss me on the checks because I am his mother, but he shouldn't do this with other women. We live in the UAE and this form of public display of affection is not only looked down, and it is also illegal”. So, when her son behaviours in such a manner, she will apply physical cues, and she believes this is a method of educating him.

The parent (parent two) with the high functioning adult shared “My son is undoubtedly aware of an attractive female and he does smile when he is attracted to them or recalls their name”. Another parent shared “My son has no interaction with the opposite gender, but if he had sexual urges, he would masturbate in the privacy of his room”.

Hormonal changes

Sleep

A significant number parents (60%) reported that their child had evidence of poor sleep hygiene. One of the parents (parent three) shared that if their child were anxious, it would result in a poor sleep night and cause stimming behaviour. This stimming behaviour consisted of walking around the table or a room. The parent allows the child to continue this behaviour as it is habitual and helps regulate his sensory modulation. The action presents when he has an anomaly in his routine. For instance, when the COVID situation arose, he had to stay at home for a few months, which hindered his daily routine. Another parent reported that sleep disturbance occurred on and off, and when it did happen, it would result in the son having anger and irritation issues. He would also stim by trying to hug a family member tightly (deep compression). It occurs if he is amid loud noises such as the television or crying of babies.

One parent had a significant concern about his son's sleeping patterns. He stated the child's sleeping pattern was "Terrible." He also spoke about how the full moon affects the autistic individual's sleep even though he has blackout curtains. He suggested that it was something in the atmosphere. In conjunction, another mother reported that her son also had sleep deficits during the full moon as well. One of the respondents said her son's sleep hygiene was no longer an issue since she started giving his risperidone. However, he does wake up to use the washroom multiple times in the middle of the night, affecting his sleep quality.

Diet

All the respondents reported that their child's diet was intact and did not have deficits in their diet and appetite. The majority of the parents said that their sons had quite an appetite resulting in two parents reporting that their children were obese. Some parents reported that they would have informed their children when to stop eating. It

could be a lack of executive functioning as to when to terminate eating a meal. Some parents reported that the son did not like vegetables and preferred to eat fast food. Another parent suggested that the child does not like the sensation of noodles as he began the transition from childhood to adulthood.

Mood

The majority of the parents reported that if the individuals don't get adequate sleep, it will result in high aggression and irritation levels. One parent said that if her son did not stick to his daily routine and is left idle, it would result in a regression of behaviour and sensory modulation deficits. Another parent reported that her son's mood has improved. His emotion regulation matured with age and that he would get angry often. However, he would get irritated if his daily routine and sensory diet changed. He also gets agitated if he gets corrected for a behaviour.

Hormonal change communication

The majority of the parents reported that they wouldn't modify the behaviour if the child is aggressive or irritated. Instead of doing that, they would provide a sensory input such as massage him or tickle his back to distract him from the other irritative external stimulant as stated by parent one.

One parent (parent three) reported that they physically restrain the son because he engages in harmful behaviours like banging his head on the walls. Occasionally they would use verbal communication to inhibit this behaviour.

All the participants were well involved in the hormonal change communication in aspects if the behaviour arose. One of the parents (parent four) involved an external help from an applied behavioural therapist as her son started dressing in the mother's nightgowns, and ever since the behaviour has been resolved.

Habitual changes effect on the family

When sensory triggers affect the autistic individual's sensory diet, it will hinder the families. For example, one of the autistic individual's brother (participant five) would use a mosquito bat. The sound would trigger an unwanted sensory input, causing the individual to get agitated and make him attack the brother. However, over time, the parent reported that he has gained more control of his sensory regulation and can control his response to sensory hindrances.

The majority of the parents reported that their children got more independent and started helping around the familial tasks. For example, one child got into the behaviour of filling empty bottles. He also has an obsessive need for sheets to be folded and organized and he does it himself. She mentioned that the behaviours were there before, but it has increased during this pubescent transition and has become very beneficial towards the family. The other parent has it worse. However, he says that they just accept it the way it is and get on with it. He mentioned that he and his wife get woken up several times in the night. It doesn't affect his day, but he reported that his wife gets stressed out and moody for the rest of the day due to sleep deprivation. They try and combat this with sensory modulation as the nanny "rough and tumbles" with him, which allows a sensory input as well as tires him out during the day.

Only one parent with the eldest child said that her son's behaviour does affect the rest of the family. In fact, over time, his emotion quotient has increased in ways that he would call his grandmother and grandfather in a very needful way. Two of the respondents reported that their sleep gets hindered if their son's sleep is disturbed. One of them said the sons come into their room in the middle of the night to hold the mother tight. However, she did say it wasn't problematic, so they did not find the need to correct this behaviour.

Conclusion

The maladaptive behaviours were less prevalent than the non-maladaptive behaviours, therefore this proved the null hypothesis. Despite the cognitive deficits, individuals with autism thrive on routine and structured schedules. This enabled them to increase in their independence level through the adolescence and adulthood transition, thereby proving the alternate hypothesis wrong and supporting the null hypothesis again. The alternate hypothesis that was proved correct was that due to individuals with autism having presentations of poor functional communication which lead to them having a deficit in information regarding these behaviours on whether it is inappropriate or not.

In short, the paper presents pubescent developing behaviours of individuals on the spectrum, whether they are non-maladaptive and maladaptive behaviours. Nevertheless, in the majority of the cases, due to the autistic individual's tendencies to adapt to a structured routine, the behaviours are mostly non-maladaptive behaviours or behaviours that don't cause a hindrance to the daily living, their families or the environment around them.

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