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Transitioning into adulthood with autism: Insights from parental narratives

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Abstract
Autism is a life-long condition that has an unpredictable prognosis. Studies have shown that transitioning into adolescence causes a lot of difficulties in the individual as they encounter physical and psychological changes in their body. Hence, the curiosities, frustrations, identity formation that comes along with it cannot be resolved due to the lack of expressive language in these autistic individuals. As the individual reaches adulthood, the problems with adaptive functioning, independent living and social communication add on to the cascade of event. Thus, the transitioning causes a lot of distress and anxiety in the parents. Although a few studies have been conducted on autistic adults, very few studies have talked about how adults with autism have journeyed through their life. Hence, this study intends to explore the transition from infancy to adulthood and what were the major challenges they experienced during the transition. This study used a qualitative research design, and narrative inquire was used for data collection. The study consists of five participants, who are the primary care givers of an autistic adult. The age range for the autistic adult was considered between 18 to 35 years. The participants were selected through snowball sampling, and only those who met the inclusion and exclusion criteria were selected. The data was analyzed using William Labov's narrative analysis. The findings indicate that transition is multifaceted, and involves struggles throughout various aspects. The participants had retrospectively looked back at their child's life with regret about the things that they could have done. The participants worry about the time after them and who will look after their child when they are gone.

Keywords: Adult autistic, transition

Introduction
Autism can be defined as "A lifelong neurodevelopmental disorder characterized by persistent deficits in social communication and social interaction across multiple contexts, as well as restricted, repetitive patterns of behavior" (American Psychiatric Association, 2022) [3]. When looking at the prevalence of autism worldwide, recent studies show that ethnic groups and low and middle income countries are 95% more affected by neurodevelopmental disorders. Further, prevalence of autism in India show that 1 in 68 children are affected with autism (Panda, 2019) [29]. The *developmental theories of autism* suggest that, all the minute differences in the child's relationship with the environment causes them to have a divergence from a normal developmental pathway (Happé, 2015) [13]. Among which the 'hypo-connectivity hypothesis' states that the fronto-posterior connectivity deficits are fairly responsible for the cognitive deficits in autism (Just *et al*., 2012) [17].
Navigating the transition from adolescence to adulthood undergoes drastic changes, and often not smooth. Studies have shown that when looking at the trajectory of autism, IQ (Intelligence Quotient) had increased significantly by a mean of 7.48 points from 12 to 23 years, while autism symptoms remained unchanged. Whereas, in another study conducted by Bal *et al*. 2018 a group of verbal adults showed significant reductions in the prevalence of several symptoms exhibited during childhood, thus the improvements suggest that symptoms indicative of ASD (Autism Spectrum Disorder) in young children may no longer be diagnostic markers in adolescents and adults. Autistic teenagers lack the skills necessary to cope with such sudden changes, as they are internally void of cognitive, social, and communicative skills that would help ease out this situation. Further, they are not provided with interventions to help deal with these situations (Kuo *et al*., 2018) [19].

This educational void after highschool is often referred by parent's as the 'service cliff' (Laxman *et al*., 2019) [22]. As a result, studies have shown that the parental expectations for transition outcomes are lower for parents of children with ASD than for parents of children with intellectual disability or multiple disabilities. Further, studies have suggested how health outcomes have declined as the autistic individual ages in socio-communication-interactive-cognitive domains (Dempsey *et al*., 2017; Kumar *et al*., 2021) [7, 18].

Discovering autism and its spectrum in India has paved through quiet a journey. From being looked upon synonymously to Mental Retardation (MR) to being recognized as its own spectrum of disorder. It was not until 2016 that the bill for Rights of Persons with Disability (PwD) act was passed and autistic individuals were given an official diagnosis. Although India has the most literature on Autism among all the Low and Middle Income Countries (LAMIC), the availability of interventions according to different transitioning ages is still limited (Singhai *et al*., 2022) [35]. The financial burden of taking care of an autistic adult is much more than an autistic child, moreover even though a few service providers are available, the wages are low but their cost of living is high (Wolpe *et al*., 2023; Lee *et al*., 2019) [37, 23]. In India, there are health insurance schemes such as Niramaya, The Indra Gandhi National Disabled Pension Scheme etc. A commonly given state pension for all people with developmental disability amounts to about 5,600 Rs./month. This 5,600 Rs. Amount is given to all people with developmental disability from infancy to adulthood. In practicality though, it is not near to enough for an adult with disability to sustain in this rising economy. Studies found that parents found it exhausting to engage their adult child in some sort of activity just for the sake of doing something. Further, the reduced communication, insistence for sameness, fixated routines, unresponsiveness to change etc. cause an evident boredom and distress in the families of the adult autistic (Daley *et al*., 2014) [6]. With all the transition obstacles, financial burdens, legal hindrances and so on, it is only obvious that the caregivers of the autistic individual go through a lot of stress and all of these take a mental toll on them.

Hence, when we review the literature on autism and adulthood, there seems to be an insufficient amount of studies focusing on the actual livelihood difficulties of an adult with autism. Many of the studies either focus on how autism is diagnosed during adulthood causes difficult, but the literature in lacking in terms of how the prognosis of autism is into adolescence and adulthood, when the child is diagnosed in childhood. The literature in the LAMIC is already lacking, and adulthood has been least explored content in autism research in India. Hence, this study attempts to address this gap in literature through the following objectives

- To explore the transition from infancy to adulthood and what were the major challenges the parents faced during the transition
- To explore the journey of adults with autism in terms of experience with puberty, livelihood situation, support and services etc.

Method

A Qualitative research design was used, since the focus of the study was two look at the parents journey, which involves a lot of investigation into the verbal content. A narrative enquiry was used for the data collection, to aid in understanding the content of the story as it unfolds over time, the structure, the way in which it is performed, or how it is received. There are 5 participants, who are the primary care givers of an autistic adult. The researcher used snowball sampling technique. The sample was selected after consulting with various clinicians and parents of adults with autism. Since the target population that the researcher intends to study is scares and mostly confined within the boundaries of their home, the researcher felt that escalating the referred contacts from known people would be a better sampling technique. The participants were from various parts of Kerala,

The inclusion criteria for the sample involves,

a) A mild to moderate level of autism diagnosis for the autistic adult.
b) The age range of the adults with autism should be from 19 to 35 years as per Havighurst, (1952) [14] developmental task theory.
c) The autistic adult has to be diagnosed at an early age, preferably early childhood and needs to have started therapy early on.

The exclusion criteria for the sample involves,

a) Any autistic adult that is completely bed ridden and needs constant support for activities of daily living.
b) The autistic adults that have medical comorbid conditions like Fragile X syndrome, Cerebral Palsy, Duchenne muscular dystrophy etc.
c) Adults with autism whose primary care givers are not their parents.

Procedure

The researcher conducted a narrative interview on the sample of 5 parents of autistic adults. These parents who have met the inclusion and exclusion criteria were selected, only after asking for their informed consent and willingness to participate. The researcher collected the data in person, at the participant's home, to assure that they were at their at most comfort. Being present at the participant's house also allowed the researcher to get a firsthand look into the environment of the autistic child and the researcher most importantly got to interact and observe the autistic adult at his comfort. Each interview took about 60 to 90 minutes, and before the narrative interview began, the researcher briefed the selected parents about the intention and goal of the study, and only after they proceeded to give their written consent was the data collection process started. The narration was audio recorded by the researcher after asking for the participant's permission. The audio recording was transcribed.

Further, narrative analysis was used to code and consolidate the data. William Labov's (1972) [20] concept of socio-cultural narrative was used in this study. Labov's analysis involved asking one broad question on a specific topic of interest, encircling the timelines, orientations and context of the narrative. Labov's model of narrative analysis is divided into six sections: Abstract, orientation, complicating action, resolution, evaluation, and coda.

Ethical Considerations

According to the APA guidelines, the parents of the autistic adult was asked for consent regarding their participation in the research, Further consent was asked regarding their comfort and convenience while recording their voices. The participant was informed that the recorded voice will be kept confidential and will only be used for the purpose of data interpretation. It was also informed that there will be no particular benefit in participating in the research, however

there was no sort of physical, emotionally or verbal harm suffered by the participants. The participant was informed about their right to withdraw from the study within a time duration of 42 hours. The personal details of the participant such as the parent's and their child's name were kept as confidential and the data received was anonymously mentioned in the appendix. The results obtained from the interpretation was used as it is and it was not fabricated so that a desirable result can be obtained.

Results

Table 1: Six elements of Labov's narrative analysis of each participant

Participants	Elements	
	Abstract	**Not reported**
	Orientation	It has been 60 days, and he is not looking at my face… Then when he was 8 months old, from NIMHANS they told us he has brain related problem. Then we started therapy in Kozhikode. At 4 years old, we went to stay at ICONS Shornur…. Then at 6 years old, we sent him to a boarding school, and he stayed there until the Covid lock down came.
	Complicating factor	When I was 4 months pregnant with him, I had a vaginal bleeding that was black in color. When my son was born, everyone in the house was telling how his body was blueish in color, and that caused concern in them. However, I did not make it an issue. But after a while, he was just staring at the light…… When Covid started, it felt like many problems came. His aggressions increased, because we were stuck at home all day long and he show cased his frustrations by breaking the glass, hitting his head on the wall. After a certain age, he wants to sit alone in his room and does not like it when we disturb his privacy. I understood that when I saw his semen on his pants when I was going to wash it. All of this might be because, he is at the adolescence age, as his sound has changed, and his aggressive tendencies have increased
P1	Resolution	During Covid, after joining a few WhatsApp groups with experienced mothers of autistic children, I learned through them how to control his anger bursts. A lot of his temper and aggression has reduced now, because during his aggressive episodes, he was trying to convey his need, which I was not able to understand then.
	Evaluation	People usually have the mindset that no change is going to come about if we do anything for these type of children, and this mindset has to be changed because if trained, these children can do anything. I now feel that, if I had sent him to a normal school, he might have improved a lot. Now, his daily routine is a mess, because he does not have anything to do. I think regarding the pension for these children, government might have given order for a certain amount, but as it keeps coming down, it gets reduced due to many demands and taxes.
	Coda	Through him, Allah has shown me a lot of new paths, and a lot of changes have occurred in me. However, I still sit uncertain because despite this pension that he gets, I want some sort of legitimate work to be provided to him. Because after my time, who will look after him?

Similarily, All six elements of Labov's narrative analysis was recorded for the remaining participants.

Abstract provides a summary of what the narrative is going to be about, allowing the readers to identify the general outline of the story, hence keeping them engaged. Here, out of the five narratives, only P3 reported an abstract.

Orientation describes the entire contextual setting of where, what, and when, the narrative is taking place. This provides us with information about all the characters involved in the narrative. All the participants have noticed delays in their child's development during infancy.

The complicating factor describes the actual events of the narrative. The core happenings of how the story flourished by. Among the major events that happened in these participant's lives, it seems to revolve around the time when their son hit puberty or was transitioning to adolescence. It can be seen in the narratives of P1, P4 and P5 that a lot of them showed a spike in hyperactivity and aggressive tendencies during the age of 12 to 15.

Resolution gives the final events of the narrative and encapsulates the main essence of the complicating actions. When looking at the resolutions of the participants, we can see that all the participants come to terms with the reality of this disability, how it progresses in various situations and what can be done about it. The coming to terms with this fact either was through the help of support groups (P1, P2, and P4) or self-initiated changes (P3 and P5).

Evaluation reveals the narrator's attitude towards the narrative by emphasizing the relative importance of some narrative units compared to others. A common aspect about the evaluations of the participant was that, they retrospectively looked back at how their son has transitioned and changed throughout. Along with their reflection, they express feelings of guilt (P1, P2 and P3), feelings of gratification (P4 and P5) and wisdoms that they have gathered throughout their journey with their autistic son.

Coda provides the ending credits, by trying to rephrase the participant's experience in a clause or two. All the participants have positively phrased their journey with autism. Thus, even though a lot of sadness and remorse was experienced by the participants, they have evaluated their journey in a positive outlook.

Table 2: Comparison of themes of the participants

P1	P2	P3	P4	P5
Alleged signs of atypical pregnancy Battling frustrations about uncertainty Unrealistic expectations Out-of-reach provisions Therapy-Hopping Separation-Individuation struggles Counter factual thinking-untaken steps Meaning making-a route to acceptance Covid-a complicator in transition Support groups-a learning platform Service cliff What after their time?	Alleged signs of atypical pregnancy Initial unawareness Out-of-reach Provisions Battling frustrations about uncertainty Unrealistic expectations Unresolved guilt Maladaptive coping Meaning making-a route to acceptance Adulthood onset epilepsy Support groups-a learning platform Service cliff What after their time?	Positive outlook on trajectory Rationalizing upon retrospection Covid-a complicator in transition Unrealistic expectations Parental burden Service cliff Out-of-reach provisions Therapy-HoppingMeaning making-a route to acceptance Support groups-a learning platform What after their time?	Initial unawareness Battling frustrations about uncertainty Out-of-reach provisions Unrealistic expectations Separation-Individuation struggles Covid-a complicator in transition Meaning making-a route to acceptance Lack of family support Counter factual thinking-untaken steps Financial hardships Support groups-a learning platform Service cliff What after their time?	Alleged signs of atypical pregnancy Unrealistic expectations Comorbid issues Misfortunate experience with practitioners Out-of-reach provisions Parental burden Financial hardships Meaning making-a route to acceptance Adulthood onset epilepsy Lack of family support Support groups-a learning platform Service cliff What after their time?

Table 2 shows the themes of all the five participants. Upon comparing the themes, we find some themes that are common in most or all the participants. Hence the major themes of the five participants are; Service cliff, Covid-A complicator in transition, Support groups-a learning opportunity, Alleged signs of atypical pregnancy, Out-of-reach provisions, Unrealistic Expectations, Apprehensions about future, and Meaning making-a route to acceptance.

Discussion

Service cliff

Once an autistic child has finished with high school, or an equivalent education till adolescence, the autistic person and their caregivers are confronted with the devastating truth that there are little to none opportunities available for them now, and this cessation of services after school age is what is called 'service cliff'. It is essentially, what the term indicates, the parents and the autistic adult themselves feel like they are standing at a cliff, with no further route to go. A study by Schiltz *et al*. (2023) [33] examined the trajectory of the formal and informal help in adult autistics, and they found that other support declined significantly from adolescence to young adulthood, while the helpfulness of informal family support did not change significantly across time. Further, occupational therapy, which is necessary for autistic adults to deal with daily living tasks have shown to be 20 percent unmet for most older autistic adults, and more than 45 percent of young adults have unmet social skill training needs (McCarty, 2022) [27].

It has come to the point where many parents report that they have to self-advocate for their child's services, or that they had to leave their full-time jobs to concentrate on improving the adaptive skills of their child (Lappé *et al*., 2018) [21]. Hence, vocational training if given, can help young autistic adults to deal with the demands of adulthood. In India, currently very few centers are providing vocational training for young adults, further they are not accessible to a lot of the adult autistic families and their criterias for selection are also not met by many.

Covid-A complicator in transitioning

The autistic youth all around the world have experienced the lockdown differently. For some, learning at home likely reduced the sensory stress commonly experienced by autistic pupils in school environments (Heyworth *et al*., 2021 [15], as cited in Hamilton *et al*., 2023) [12]. While for others, the inability to have a daily activity, who are resistant to change caused their routines to be altered, which inversely caused temper tantrums and hyperactivity (Akcay *et al*., 2020) [1]. Studies have also shown how the caregivers stress and anxiety increased during this period, and how it negatively affected their family dynamics (Asbury *et al*., 2020) [4]. Similar findings can be seen in this study as well, as reported by P1:

"It was during the COVID pandemic that we really struggled with him, as we were not able to take his anywhere outside, but his aggression kept increasing. It was so hard for us to contain his behavioral issues, that I would call other relatives for help. It all took a mental toll on me, I don't even want to think about that time period"

Irregularities in sleep and lack of a daily routine has been another factor that increased among autistic youth during COVID. As it can be seen from the narratives of the participants, COVID was a time period that had some or the other significant role in the transition of the young autistic adult. All the five had reported how COVID had initially been a struggle for them, especially in controlling their growing teenager's hyper and aggressive actions. Another common thing among all the participants was how the incoming of the lockdown period caused a halt in the educational pursuits of their autistic adults. It was challenging to in coorperate remote learning for people with autism, due to the complex curriculum and the uniqueness of the disorder inherently, where instead of mass learning, personalized learning is much beneficial.

Support groups-a learning platform

Support from loved ones, or in this case, from other families who are going through a similar situation like ours will help ease our difficulties. Studies have shown that parents of children of disabilities often have low self-esteem, low self-efficacy, poor life satisfaction, and even resultant marital discord (Zablotsky *et al*., 2014) [38]. Hence having a support group of other parents, families, people working in this field etc. have shown to induce feelings of being understood, creating a lasting connection with other parents of disabled children, in turn helping others as well, and as a whole, having a positive experience (Jackson *et al*., 2018) [16].

During the pandemic era, there was a rise in WhatsApp groups for various need. Such training for autistic people was also given through WhatsApp groups by expert practitioners sharing their opinions, mothers sharing their experiences, and in turn making, not only a learning platform for all, but also a support system during those times of difficulty. In a study, it was reported that, during the pandemic, among the usage of social media apps, the participants were asked to choose one app only for all their use. It was found that 93% of the respondents preferred WhatsApp, when compared to other apps, and this was because, WhatsApp acted as an all-in-one app that yielded to both professional tasks, as well as entertainment (Moawad, 2022) [28].

Out-of-reach provisions

Lack of accessibility to education systems, therapy, pensions, scholarships have all been a common theme among all 5 participants. As it was reported by P4:

"We had joined him in a special school near Kuwait hospital, and I felt that, that school gave good training and even he was happy to go there. But the fees over there was too expensive, and it was very far away from our house, so we had to search for a more efficient option"

Typically, the services provided to people with disabilities are more intricate, which causes them to be expensive. Hence, financial accessability is also a major issue. Studies have reported how parents of autistic children had only heard of the term autism itself after their child got diagnosed, and so navigating through this unknown condition along with far out-of-reach provisions was even more difficult. Moreover, parents consulted multiple professionals or traveled long distances to confirm the diagnosis (Mahapatra *et al*., 2019) [26].

Since the autistic people represented in this study are adults, it is to be noted that 15-20 years back, diagnosis and screening of autism was not accessible easily, and especially in Kerala. Many of the participants in this study have reported how they were referred from a medical college to go to NIMHANS in Bangalore for diagnosis. Accessibility was an issue in the case of their pension and scholarship requirements. Most of the participants (P1, P2, and P3) reported that they are getting some amount of pension for their child, but it is not regular. Learning centers are usually inclusive for autistic children, but once the child reaches adulthood interventions are scares, which leads to most adult autistics staying at home, dependent on family. Among the participants in this study, only P5 has provided vocational training for their autistic adult. But it was not a feasible option for them in the long term.

Alleged signs of atypical pregnancy

All the participants in the study have reported some form of abnormality during the prenatal and perinatal periods. It is interesting to note that three of the participants in this study have had cesearian delivary (P1, P2, & P5). As it was reported by P1;

"When I was 4 months pregnant with him, I had a vaginal bleeding that was black in color. When my son was born, everyone in the house was telling how his body was blueish in color"

Many family studies, pedigree analysis, and twin studies have suggested that autism has a strong genetic basis, with genetic factors accounting for 30-40% of autism cases (Ramaswami & Geschwind, 2018, as cited in Lu *et al*., 2022) [32, 24]. Many other factors are known to contribute to the prevalence of autism, such as neurotoxicity increase through environment chemicals, Maternal diabetes, Hypertension, Substance abuse etc. however none of these have been conclusive enough to yield as the leading cause of autism. In a case control study conducted in Saudi Arabia, it was found that Approximately 39% (n=34) of the 87 children with ASD were delivered by cesarean section (Al-Zalabani, Al-Jabree, & Zeidan, 2019) [2]. Moreover, another meta-analysis found that cesarean section increased the prevalence of ASD by 33% and ADHD by 17% (Zhang *et al*., 2019) [39]. Hence, although studies link caesarian delivery to the prevalence of autism, It can be said that, the factors that lead up to having a caesarian delivery is what might be a risk factor to having neurodevelopmental disorders. However, we cannot be conclusive about it, as a lot of unfound factors are yet to be uncovered.

Unrealistic expectations

When reading the narratives of the participants, we notice how in the initial phase of diagnosis the parent consults many doctors and therapists in order to get some sort of reasonable explanation that their child is going to be okay, or that this is going to be a temporary issue which can be resolved by pharmacological treatment. This extends to the parental attitude of attempting to fix the child, instead of adopting an approach of embracing their neurodiversity (Narayan & Srikanth, 2020) [9]. In a study conducted on the parental attitudes and expectations of ASD in India, the results found that 71% of the participants would do anything to make their child 'normal' and 85% believed that their child would benefit from being in an environment with neuro-typical children (Narayan & Srikanth, 2020) [9]. This finding is seen consistent with this study as well, as P1, P2 and P3 had reported how they had sent their child to normal school and they felt that it was beneficial for them.

The unrealistic expectation of the participants can be seen in the initial phases of when their child was diagnosed, eventually as the reality of the situation dawned upon them, their expectations seemed to have become realistic. Now, most of the participants have either compensated by making do with daily living activities (P2, P3, P5) or some have developed learned helplessness (P1 and P4). Hence there can be seen a transition of the parental expectations as their child journeyed through each phase of life.

Apprehensions about future

Participants in this study have come to terms with the fact that, they will have to be there with their autistic child till death. Hence, the concern that these parents have is after their death, who is going to look after my son. As it was reported by P1:

"However, I still sit uncertain because despite this pension that he gets, I want some sort of legitimate work to be provided to him. Because after my time, who will look after him?"

In a study conducted in Iran about the parental future concerns with autistic children, results showed that ambiguity of the child's future, the ability to live in society in the absence of parents and future occupation were the main concerns of the parents (Ganjeh *et al*., 2020) [8]. If we are to take a look at the participants in this study, P2 and P5 have gone through a sudden unexpected situation, that is,

upon reaching adulthood their son had an episode of seizure. Such unforeseen situations add onto the apprehension they experience for their child's future.

Meaning making-a route to acceptance

The acceptance of the situation is all about how the parents perceive the situation and what meaning they make out of it. Some might perceive the situation as positive to overcome the stress, some might incorporate various coping strategies, or some might turn to spirituality of religion for solace (Pargament, 1997) [30]. As it was reported by P3;

"All the things that I learned through having journeyed with him, I share all the knowledge with other mothers I meet. Autism is never a curse, but a blessing in disguise."

The participants in this study indulge in counterfactual thinking, which means that they long for what has not happened but, could have happened. They mourn the idea of normalcy in their child and live adjusting to the life that they have. As it was reported by P5;

"Honestly speaking as a mother I do wish deep inside that he gains independence and live his life on his own, but I know that it is not possible as of now."

When looking back at their life with their autistic child, in a study, the parents have described a sense of developing personal competence, pride in their autistic adult relation's progression, and an increased appreciation of others (Marsack-Topolewski *et al*., 2020) [25]. This finding is also seen in our study, where some of the participants look back at their journey with their son and feel a satisfaction about the turn of events.

Conclusion

Transitioning to adolescence and adulthood is 'multifaceted' with many challenges in terms of social, psychological, economical, and educational aspects. These challenges can be navigated if specifically catered interventions, or vocational trainings are provided for the adult autistic. However, there exist a 'service cliff', which means that there are no educational pursuits available for the autistic individuals. This eventually leads to stress, anxiety, financial burden, familial conflicts etc. in the parents of these children which makes then 'Regretful upon retrospection'. Nevertheless, despite these challenges, the participants have journeyed to acceptance of the situation through spiritual and religious means. But, the question of 'what after us?' still remains uncertain.

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