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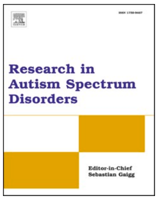

“We are mama and papa bears”: A qualitative study of parents’ adaptation process during transition to adulthood

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ABSTRACT

This qualitative study aimed to understand the stressors, external and internal support, coping strategies, and family adaptation outcomes during transition, from a parent’s perspective, using the ABCX model (McCubbin & McCubbin, 1993). Thirteen parents of adolescents and young adults with ASD were interviewed. These parents reported a continually high level of stress due to normative strains and ASD-related demands. They described the tangible, emotional, informational, and internal resources received and needed. Parents, as active agents in their children’s lives, have their own views towards transition, philosophy, and ways of coping. Even though many of them reported negative experiences, these parents also found new meanings and happiness in their lives. This study detailed the adaptation process during transition.

1. Introduction

For most adolescents and young adults with autism spectrum disorder (ASD), transitioning to adulthood is particularly challenging and often results in less than desirable outcomes. Data from national surveys indicate that young adult outcomes — such as employment, independent living, and community participation — are limited for individuals with ASD when compared to peers with other disabilities (Newman et al., 2011)

It has long been known that the stress levels observed in the parents of children with ASD are higher than the stress levels observed in parents of typically developing children or of children with other disabilities (Abbeduto et al., 2004; Hayes & Watson, 2013). Yet, less is known about the stress levels, trajectories of stress, or coping mechanisms among older parents with adolescents or young adults with ASD. On the one hand, early evidence on older parents of adolescents or adults with developmental disorders or other conditions has suggested that parents are better able cope with their stress as they age (Ha, Hong, Seltzer, & Greenberg, 2008; Magaña & Smith, 2006). On the other hand, it is generally believed that the negative transition outcomes experienced by individuals with ASD may extend to their parents as many parents continue to provide extensive support for their adolescents and adult children with ASD (Smith et al., 2010; Ankeny, Wilkins, & Spain, 2009). As the child reaches adulthood, the realization of the continuity of the adult child’s disabilities and uncertainties about the future may increase family stress (Bristol & Schopler, 1983). Please refer to Barker, Mailick, and Smith (2014) for a precise and comprehensive summary on the chronic stress in mothers of adolescents and adults with ASD.

Fortunately, transition is not all negative. Parents also express positive emotions during the transition to adulthood such as new

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opportunities for personal growth (Lutz, Patterson, & Klein, 2012). Such examples of positive reframing are critical, and particular types of coping mechanisms produce better outcomes. For instance, parents who use problem-focused coping (e.g., obtaining services; Abbeduto et al., 2004) and/or emotion-focused coping, (e.g., positive reframing) report less psychological and parenting distress (Benson, 2010; Manning, Wainwright, & Bennett, 2011), more positive interactions with their child, and a higher desire to contribute to their community (Smith et al., 2010).

With parents as the constant in a child's life, the study of successful transition should include family wellbeing and parental perceptions (Neece, Kraemer, & Blacher, 2009).While there are some examples of research efforts to foster a greater understanding of parenting adolescents and young adults with ASD during transition at the individual level, there is a dearth of research on parent-level outcomes (Davies & Beamish, 2009; Henninger & Taylor, 2014). To date, only two qualitative studies on parent perceptions of transition are available. Kucharczyk et al. (2015) and Snell-Rood et al. (2020) interviewed stakeholders, including parents of individuals with ASD, to understand the transition experience and needs. The results identified several gaps between best practice and actual transition planning including the insufficiency of schools to meet the specialized needs of students with ASD and adequate parent support for obtaining a seamless transition with successful planning for positive postsecondary outcomes for adult services, postsecondary education, and employment. Yet, these two studies did not necessarily have a focus on parents.

The lack of research on parent perceptions and experiences during transition of youth and young adults with ASD limits understanding of the context of normative changes related to aging (Seltzer, Krauss, Orsmond, & Vestal, 2001). As more children with ASD are identified, more families of adults with ASD will be experiencing the transition process and the risks described earlier. More research on parent perspectives of transition is necessary as a first step for ensuring the development of effective, family-centered interventions (Yoder-Wise & Kowalski, 2003) that can support transition so that families and youth achieve their most optimal and desired outcomes (Gerhardt & Lanier, 2011; Kucharczyk et al., 2015).

Table 1
Demographic Information.

Parent variables	*M (SD)*	Range
Age	56.0(8.4)	39−66
No. of children per family	2.2(.8)	1−4
No. of children with ASD per family	1.3(.5)	1−2
Therapies currently receiving (no. of different types)	.3(.7)	0−2
	N	%
Race (Non-Caucasian)	2	16.7
Gender (Male)	3	25
Marital status (Married)	10	83.3
Employment status (primary caregiver)		
Employed (full-time)	6	50
Employed (part-time)	4	33.3
Retired	1	8.3
Student	1	8.3
Employment status (second caregiver)		
Employed (full-time)	9	81.8
Employed (part-time)	1	9.1
Retired	1	9.1
Education		
High school	2	16.7
Some college	2	16.7
Technical school	1	8.3
College	3	25
Advanced/ professional degree	4	33.3
Annual household income ($)		
20,001–40,000	1	8.3
40,001–60,000	2	16.7
60,001–80,000	5	41.7
More than 80,000	4	33.3
Child variables	*M (SD)*	Range
Age	21.2(3.82)	15−27
No. of diagnoses other than ASD	1.21(1.12)	0−3
Therapies currently receiving (no. of different types)	1.92 (1.24)	0−4
	N	%
Gender (female)	5	33.3
Race (white)	9	64.3
Reported cognitive ability score		
<75	7	46.7
75−115	8	53.5

*Reported values are based on available data.

1.1. Guiding framework

The ABCX Model (McCubbin & McCubbin, 1993) was used to conceptualize and analyze family adaptation and adjustment experiences during the transition process (Lustig, 1999). The model consists of three main predictive components of (a) stressors, (b) resources, and (c) family coping and perception and one outcome component of parent/caregiver adaptation. *Stressors (A)* are defined as life events or transitions that have an impact on the family system (e.g., the severity of autism; McCubbin & Patterson, 1983) and the cumulative effects of daily stressors over time (Lavee, McCubbin, & Patterson, 1985). *Resources (B)* are defined as the family's abilities to counteract the negative effects implicated by the stressors (e.g., family's social network), the existing resources, and newly developed resources following the crisis experienced by the family (McCubbin & Patterson, 1983). *Family coping and perception (C)* are defined as the family's views on the crisis (e.g., perceived impacts; McCubbin & Patterson, 1983) and the family's general orientation to their situations (e.g., overall appraisal, coping strategies; Florian & Dangoor & Florian, 1994). *Family adaptation (X)* is the outcomes of the adaptation and adjustment process and is a product of the "A", "B", and "C' components (Lavee et al., 1985).

A recent quantitative study has shown that the ABCX model was useful to understand and evaluate the complex relationships between predictors and outcomes among parents of transition-age youths or adult children (Wong, McGrew, & Ruble, 2020). While this quantitative study provided a useful snapshot of the impact of commonly experienced stressors (e.g. filial obligation), resources (e.g. parent-teacher alliance), and coping (e.g. optimism) on parent outcomes, it lacked the breath and depth of the parent adaptation process during transition. To further understand parent experiences and perspectives during transition in detail, a qualitative approach was applied in this study using the ABCX model as a guide.

2. Methods

2.1. Participants

2.1.1. Recruitment and sample selection

Twenty-eight parent support groups and professional agencies for ASD in a Midwest state were contacted. Thirteen parents of adolescents or young adults, aged from 15 to 27, with a clinical diagnosis of ASD, who currently or previously had an Individualized Education Program (IEP) were recruited. The sample was systematically recruited based on geographic locations (e.g., suburban, and rural), SES, race, and gender, with at least 20 % of the participants representing minority groups. The average age of the parents was 56 years. More than half of them (58.3 %) had a college or higher degree, and approximately one-fourth of them were fathers. Reportedly, approximately half of their children represented had a cognitive ability lower than 2 standard deviations below the mean ($IQ < 70$). See Table 1.

2.2. Measures

2.2.1. Background

To understand and describe the sample of the parent participants, a 26-item questionnaire was administered. The questionnaire included demographic information such as age and gender of the parent and of the children.

2.2.2. Open-ended questions

Participants answered semi-structured, open-ended questions. Interviews were approximately 40–60 min in length. See Appendix A for the interview guide, which was developed based on the ABCX model (Crabtree & Miller, 1999). The first author conducted the semi-structured interviews with the parents at locations convenient to them. All interviews were audio-recorded.

2.3. Analyses

A hybrid thematic approach (Fereday & Muir-Cochrane, 2006) was used by employing a combination of a deductive and inductive methods in which we aimed to capture the essential components of a phenomenon, in our case the positive and negative transition experiences of parents by searching for emerging themes (Braun & Clarke, 2006) as well as those already described in the research. That is, before extensive data analysis occurred, a codebook was developed based on major constructs of the ABCX model for deductive analysis (Crabtree & Miller, 1999).

2.3.1. Creating codes and saturation

Initially, four deductive codes related to resources (B) were developed as guided by the widely reported sources of support in the literature. Based on Schaefer, Coyne, and Lazarus (1981) and Thoits (2010), three main sources of social support (B) were identified – emotional, instrumental, and informational. Other than external resources, internal resources are also found to be important for parents who rebound in face of adversity (Bayat, 2007), therefore one additional code – personal resources (B) – was developed to capture parents' internal strengths.

After applying these four codes to all transcripts, an inductive coding method was employed to generate sub-codes for the four predetermined codes and to further categorize other emerging ideas. During the inductive coding phase, descriptive coding (i.e., a brief descriptive code assigned to a passage that contains a prominent idea) and emotion coding (i.e., a code assigned to the types of the emotions described or recalled by parents) were used. At this stage, 95 codes were identified from and applied to the four transcripts for the first round.

After testing the codes, the codes were further applied to five more transcripts for the second round. As new themes appeared and new codes developed, the new codebook was reapplied to the coded transcripts. At this stage, 117 codes and sub-codes were identified. The new codebook was then applied to the four remaining transcripts. The iterative process was terminated when the data were saturated (i.e., with no new themes emerging for three consecutive transcripts). Finally, the relationships among the codes, such as causes/explanations, relationships among people, and theoretical construct, were examined repeatedly, and the codes were further clustered deductively into the ABCX model.

2.3.2. Data triangulation and reliability

In order to ensure the reliability and validity of the results, the analyses followed the recommendations of Fusch and Ness (2015) and Guest, Bunce, and Johnson (2006). For instance, data triangulation was implemented by collecting data from sample variability (e.g., parents of children with different ages/ genders, and of different race/SES). The data collection was ceased when no new themes emerged. Inter rater consistency was also tested. Transcripts were selected and coded by an independent coder (i.e., a doctoral student) using the following procedure: (a) 20 % of the transcripts were randomly selected for the secondary coder to review, and the secondary coder came up with her own themes; and (b) the two coders cross-checked their themes to see whether there were any new or divergent themes. No divergent themes were identified; thus, the second coder independently applied the codebook developed by the primary coder to 20 % of the transcripts. Reliability was calculated based on the appearance and absence of the themes (i.e., whether a particular code appeared in a transcript). The reliability between two coders was 88.5 %. The two coders discussed any disagreements and reached a 100 % agreement.

3. Results

3.1. A- Parents' stressors and demands

"A" includes the stressors, hardships, and demands parents experience during the stressor, i.e., the transition process (McCubbin & Patterson, 1983). Four themes were reported below.

3.1.1. Parent's deteriorating health

During the transition period, parents are stepping into their middle or old age. Not surprisingly, more than half of parents experienced deteriorating health. Several of them had significant health issues (e.g., cancer). One mother expressed, "*I have actually been diagnosed four times with cancer and I have multiple sclerosis, and I have a rare joint disease. I actually had surgery last Thursday and I came back to work Friday. I'm worn out.*"

Other than physical health, three parents mentioned mental health conditions (e.g., depression). Rearing a child with ASD may exacerbate the symptoms, while having a past or current mental health diagnosis may make parents prone to negative experiences. A father who has a diagnosis of Attention Deficit Disorder said, "*Oh gosh. My mental health, it's gone, I don't have any. I'm serious.*"

3.1.2. Demands of the child

All parents noticed some sort of change in the demands associated with and driven by their child's development. The demands mainly fell within five areas: (a) daily activity, education, or employment; (b) social intimacy and friendships; (c) physical or mental health; (c) living situation; and (d) daily living skills.

One significant event that marks adulthood is employment or post-secondary education. Parents reported seeing excitement in soon-to-be adult children with ASD to work or further their education. One parent observed that her child "*was really looking forward to [the job] and he was reading up on things and he wants to know.*" The parents of children with more limited IQ also mentioned the need for their children to continue to be challenged in some structured activities after school.

More than half of the parents observed changes in the social or community participation needs of their children. Adolescence and young adulthood are the prime times for developing romantic relationships. The parents reported seeing the demands of developing intimate relationships in their children and the resulting tension and discomfort. For instance, a parent regretted allowing her daughter with ASD to be alone with her boyfriend, which resulted in a sexual assault. Adult children also show the desire to have friends. However, their friends do not always have the best interests of the individuals with ASD at heart, with several parents reporting that they felt the need to monitor their children's social life. In the new technological era, meeting a new friend is different from the parents' generation. With several parents reporting how their children made friends online, parents stated that they need to adjust to the new ways their children with ASD were making friends. As one said, "*I had to adjust my understanding of how people are making friends now*."

As the children grow, parents also see changes in the demands associated with their children's physical development and mental health status. For instance, many children become stronger as they age, which pose challenges for parents who reported a need to control them physically. One father noted, "*As I'm getting older I'm fearful he can be dangerous to me. Even though he is my son, he has strength that's beyond belief so I can get hurt.*"

As children grow and parents age, concerns were raised about the children's daily living skills and future living situation. All of the parents in the current study reported that they continued to see the impact of ASD on daily life, in spite of improvement. At times, the demands on daily life could be tremendous. One father shared, "*I have an 8-h job. Sometimes [my children] have sleeping difficulties, I am up at 2.00, 3.00 in the morning… When I'm sleeping sometimes they are doing things like raiding the refrigerator or doing things that could be* *dangerous, but I have to get my sleep because I'm about to pass out.*" Similarly, almost all parents reported that there was a demand to plan for their children's future living situation. In order to successfully transition out of the family, daily living skills was an area that should be prioritized.

3.1.3. Having multiple children with a developmental disorder/ mental health condition

Five parents reported having more than one child with a developmental disorder or mental health condition. Of these, three have at least two youths or young adults with ASD of transition age. The multiplied quantity of demands was best summarized by a single father who commented, "*I'm not a typical person with one autistic child, I have two…I can't be in two places or three places at the same time.*"

3.1.4. Normative changes and strains

As time passes, parents experience normative transitions and stressful events, which produce tension and role strain. Normative transitions can be broadly defined as expected family events, such as a child leaving home; family events can be defined as less expected stressors, such as a family member's illness (Aldous, 1990). Almost all parents reported they went through some normative family strains throughout the transition process. As parents age, their own parents age too. Several parents reported that they took on great responsibility taking care of their parents and children simultaneously. One mother whose mother was diagnosed with Alzheimer's said "*I'm like so overwhelmed with my mom but [child] is getting the shaft.*" A few parents also reported on the loss of parents or spouses who were actively involved in their lives. Additionally, more than half of the parents reported that they experienced job changes, retirement, or having a child without disability moving out of the household.

3.2. B- support needs and resources available

"B" includes resources that help families meet the demands of the stressors and hardships (McCubbin & Patterson, 1983). In this section, parents' experience of receiving insufficient support and resources available is also described. Six themes were identified.

3.2.1. Dealing with a broken system

3.2.1.1. Negative experience with schools. Students with ASD and their parents are entitled to educational services based on U.S. law; however, nearly all parents reported significantly negative experiences with their schools. Approximately half of the parents observed a lack of quality teaching during high school; a mother noted, "*The school was an embarrassment as far as I was concerned because some of the stuff that they would send home was so watered down…they weren't trying so hard to adapt the materials the way they needed to.*" In addition to academic skills, half of the parents also reported that their schools did not provide adequate social skills support. The teaching at school is inflexible or lacks individualization to meet the child's needs. A father reported that his son had to choose between a class he liked and transition services because of time conflicts and said "*[Child] literally had to sign a form which says I'm declining this job hunting service.*"

Aside from quality instruction, parent-school collaboration is also critical to the success of students (Martinez, Conroy, J& Cerreto, 2012). However, more than half of the parents expressed that they were not fully included in the decision-making process for their child's educational program. A father with a non-verbal child recalled that *"The IEPs were made ahead of time."* and that he was not consulted about his daughter's needs for her educational plan. Almost all parents reported that tensions developed between them and their schools. One parent even *"started recording all of our meetings because of what they were doing."*

3.2.1.2. Parents' reasoning behind the insufficient support. A few parents with children with ASD and intellectual disability reported that the insufficient support was related to a lack of appropriate assessment. A parent said, *"By the time she became a freshman, they gave her a picture vocational assessment…the assessment they gave her was from 1982. One of the jobs was bathroom attendant, you know the person who hands you a towel? Oh, wait no place even has that…that job doesn't exist… what are you people doing?*" Other observations from the majority of the parents was that the system had no accountability, was all about paper pushing, and had low expectations of their children.

Overall, parents reported the quantity and quality of transition services were lacking. Students with ASD often need a long period of time to adjust to a new environment or to learn new skills. However, the lack of transition services limits the length and breadth of support a student with ASD can receive. A mother said that her district only had twenty slots for vocational school, "*The school said it [vocational school] was very competitive and he had to have certain scores. They basically told me that was out, like he was not smart enough to go to vocational school believe it or not.*" Even if a student with ASD receives transition support, the services were not perceived by parents as sufficient or sustainable. As one parent said, "*But the job coach just taught [child] one task and that was it."* Other than school- or job-related support, a few parents mentioned that they did not have access to autism-specialized medical professionals and that they could not recruit community-based workers for their waiver program.

3.2.1.3. Negative experience with VR. The Office of Vocational Rehabilitation (VR) and job agencies play an important role. However, more than half of the parents expressed that VR services do not always meet expectations. A mother reported that, "*One guy [job coach] came here and sat here two hours and talked to me about why he didn't like his job. And I kept trying to bring the conversation back to [child]… at one point he turns to me and he goes, 'You know it's really hard to get a job for a person with a disability.'*" At times, parents are also unsure about the status or progress of VR services. Negative experiences seemed to circulate in the ASD community. A mother said, "*I probably* *have 100 people in town who have had kids who have gone through voc rehab; I don't have one positive experience.*"

3.2.1.4. Fighting the gigantic system. Despite all the reported unfair treatment or insufficient support, it appears that the system is too big to change or fight. A mother felt like she was "*spending all this time trying to get the school to do their jobs correctly, but they are not going to do it.*" Even though parents may seek due process, most parents could not "*just sue them*" because they "*don't have $20000 to sue them.*"

Although insufficient support from schools and VR was widely discussed, all parents were able to identify the support that helped them buffer the stressors during the transition process. The roles of family members and other parents of children with ASD were identified across several domains and, therefore, will be discussed separately.

3.2.1.5. Tangible support. Tangible support refers to instrumental aids or services (Friedman & King, 1994). Parents identified six sources of tangible support from family members, quality professionals, community participation opportunities, job/salary, waiver services, and insurance. Half of the parents were able to recruit quality professionals for help and were able to identify some helpful school professionals/paraprofessionals they encountered. A few parents also reported that having recreational programs for older individuals with disabilities (e.g., swimming class) was important to them. In order to afford services, almost all of the parents reported that their job or salary was crucial because they often needed to pay out-of-pocket for services (all parents, except one, held a job at the time of the interview). The other financial support was from waiver services and insurance coverage. Overall, parents' social-economic status played an important role in access to tangible support, such as setting up a trust and paying out-of-pocket expenses for services and professional support.

3.2.1.6. Emotional support. Emotional support includes expressions of care and love received from other people that help alleviate negative emotions (Friedman & King, 1994). The parents reported six sources of emotional support: religion, family members, spouses, other parents of children with disabilities, and professional counseling. More than half of the parents reported that their spiritual life or people associated with their religious practice help them cope; while a number of parents reported that their spouses were a major source of emotional support. A father expressed, "*Probably the best support I have was from my wife and she'd probably say the same with me.*" Almost half of the parents reported receiving counseling, but only a small number of them found it useful.

3.2.1.7. Informational support. Almost half of the parents reported that information about transition is overwhelming. As one parent said, "*There's just so many materials that are on there and you can just be inundated.*" Four main sources of information, including websites, conferences and training, other professionals, and other parents of children with ASD were reported. Most parents mentioned that they seek information online regularly. Several of them also mentioned that they went to seminars, talks, training, or conferences to get more advanced information and highlighted the importance of being in the same social network with "*a bunch of people [resourceful professionals.*]".

3.2.1.8. Internal support. In face of the hardships involved with taking care of a child with disabilities, parents' internal resources also played a critical role for support. Parents identified eight useful personal characteristics or practices: (a) "me time"; (b) imagination; (c) sense of justice; (d) perseverance; (e) optimism and a sense of humor; (f) care and love; (g) research, analytical and execution skills; and (h) health and exercise. Several parents reported that preserving time for oneself was the key to function effectively as a parent with a full load of responsibility because "*if you are a total giver you will break down.*" Several parents also mentioned that imagination or creativity is needed in order to create learning opportunities for their children. Almost all of the parents reported that their perseverance is an invaluable character. Parents indicated that they do not give up easily until their goals are met. Oftentimes, optimism or a sense of humor is needed when encountering chronic or acute stress. A mother highlighted that "*there are situations where you either laugh or cry, and I would rather laugh than cry … there is something positive in every situation.*" Parents' genuine care and love for their children are the driving force behind all their actions. The powerful love can be illustrated in a father's statement, "*I care in my heart about my daughter…I will do everything I can for her to be successful.*"

3.2.1.9. Other parents and their own family members as support. Taking care of a child with ASD can be a lonely journey because "*a lot of people they want to distant themselves, they don't know what to say, they don't know how to react to you*". Most of the parents mentioned that other parents of children with ASD provided tremendous emotional and informational support during transition. A mother explained "*And the only reason we've come together is we all have kids that are similar…We laugh and complain about things but it's kind of a camaraderie that comes because of shared experience.*" Several parents reported that their own family members provided tangible and emotional support. However, the unreplaceable support from families is especially notable, yet temporary. A mother recalled, "*my mom died in 2009 and she was a huge help to me…And now I don't have anybody else like that in town.*"

3.3. C- coping strategies and perception

"C" refers to parent coping strategies, perceptions, and meanings of the stressors and hardships (McCubbin & Patterson, 1983), in other words, how parents perceive the transition process, solve problems, and make meaning of the experience. Five themes were identified.

3.3.1. Death and planning

Most parents have planned for their children surrounding their own death. A mother said, "*You start thinking of kind of your own personal mortality… You become very calculating about it…*" Parents need to plan further than their own longevity for their children's lives, many of them have already set up a trust or had a detailed plan for their children with ASD after they themselves are gone.

3.3.2. Meaning of transition

In general, all parents agreed that transition is a change and is a phase which prepares their child for "*the next step*" – adulthood. Such a process is an "*ongoing*" and "*forever*" process. Transition also has another layer of meaning for half of the parents. They stated that "*when the children transitioned, it became our responsibilities*", highlighting that transition is a shift of responsibility from a shared one between the school and the parents to the parents alone.

However, adults or soon-to-be adults with ASD may have a different or a simpler understanding of transition. All parents of children with ASD and intellectual disability perceived their children having a limited understanding of transition. For instance, a father described that his daughter would think of transition as, "*it's going to mean she's going to be home a lot more.*" Several parents of transition-age individuals without ID thought that their children's understanding of transition was consistent with their own.

3.3.3. Responsibilities

Most of the parents reported that the preparation of their youths/young adults for transition to adulthood was their responsibility. One parent commented, "*[I] had to own it and to do it.*" Another parent stated, "*Unless [parents] do this, it's not going to happen.*" Even though several mothers reported that they are united as a team with their husbands, half of them indicated that they take on more responsibilities than their spouses in their child's lives. They often referred to themselves as "*mama bears*" protecting their vulnerable children.

Most parents indicated no expectation for the siblings of their children with ASD to take on the responsibility as caretaker; however, they did report that siblings have a responsibility to look out for their brother or sister. A mother shared her expectation with her child without a disability that "*It's your job to take care of your brother. But it doesn't mean you do everything for him. It means you keep an eye on him, which siblings do anyway.*"

3.3.4. Guiding philosophy

Almost all the parents reported that they have a life philosophy that guides their decisions, that provides a reason for their experiences, or that supports them to move on. For instance, one mother's philosophy was "*there's a saying that I love. In 100 years from now, doesn't matter how much money you make, or what kind of car you drove, or what kind of house you lived in, but it's the fact that you made a difference in a child's life.*"

3.3.5. Coping

Parents reported using avoidance, emotion-focused, and problem-focused coping. For instance, one mother still avoids talking about her worries for her son with ASD. Another parent said that she recently felt overwhelmed, but decided to hang out with her friends and have a nice dinner. However, among all the coping strategies, problem-focused coping was mentioned most frequently. All the parents gave at least one example of how they solved a problem in their child's or their own lives. One mother said, "*Because we finally got to the point where I just realized I wasn't going to get anything from any of those people. So that's when I got interested and I got my supported employment training and I said basically, 'Hell with you and I'll take this over.'*" Throughout the course of problem solving, parents have to stay "*open-minded*" because it is a "*trial-and-error*" process to find the "*kryptonite*."

Parents oversee and manage almost every aspect of their children's lives, and this is especially true for parents of children with more severe limitations. They reported seeking out support and monitoring progress. Almost all of the parents considered themselves as their child's "*unpaid*" case manager and advocate.

3.4. X- adaptation outcomes

"X" includes family adaptation and outcomes as a result of the interaction among the A, B, and C factors (McCubbin & Patterson, 1983). Four themes were identified.

3.4.1. Restricted life

Due to the deficits and availability of resources, almost all the parents of adolescents or adults with ASD were living a relatively restricted life. For instance, many parents could not move to another place, retire, or even freely engage in their own preferred activities. One father reported that he felt "*like a prisoner*."

3.4.2. Family adjustment

Across time, families find their own ways to adapt and adjust to the stressors. Half of the parents reported that they learned how to "*let go*", allowing their children to grow as adults and reassessing their roles in their children's lives. One mother shared that after a family discussion, the parents decided to let their son help with his sister's medications, and they "*have never had a problem.*"

3.4.3. Spousal adjustment

Parents reported that raising a child with disabilities causes strain between spouses. One mother complained, "[My husband] works

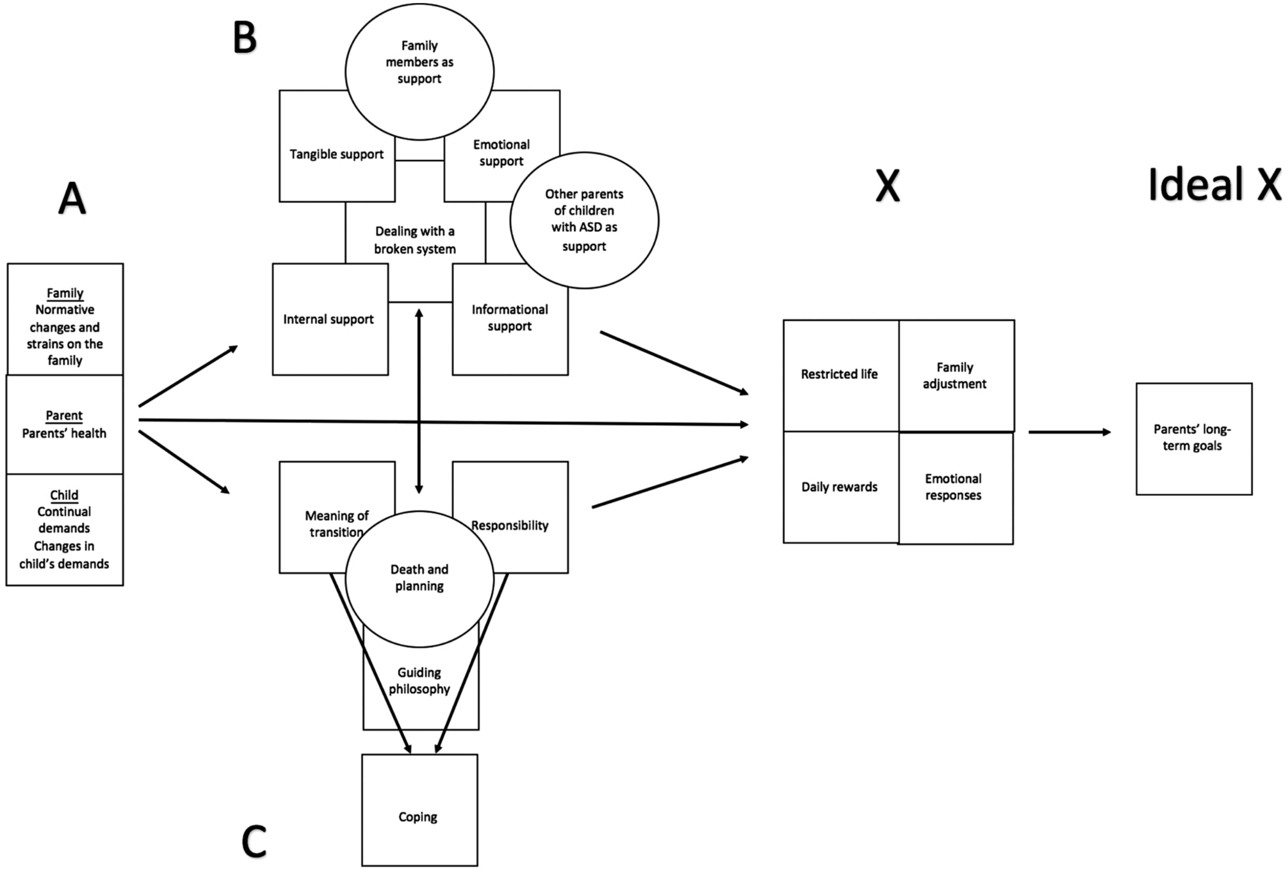

Fig. 1. The stressors, resources, and coping during transition.

evenings, and I'm busy with the family and kids during the day. And then I work on the weekends, and so we are not even in the same place a lot of the time." Despite all the tension, parents reported that they usually find a way to balance the needs of the children and with their spouses. The key was that "There has to be love, understanding, and patience" in the relationship reported by one parent. However, a few parents also mentioned that unsolvable tension led to divorce.

3.4.4. Sibling adjustment

Many parents reported that when the siblings were young, many developed resentment or misunderstanding toward their siblings with ASD. As siblings matured, however, the majority of the parents reported siblings developed more understanding and a sense of responsibility. Some siblings even told their parents that they will take care of the brother or sister with ASD. A parent commented that it made her "*feel really good* "when she heard her daughter express this sentiment.

3.4.5. Daily rewards

Raising a child with disability is not all about negative experiences. More than half of the parents reported that they experienced small, yet, exciting successes, such as having a dinner outside without disruptive behavior. These successes were accomplishments that parents "*would never have dreamed of.*" Many parents were also able to see the positive influences that being a parent of a child with ASD had on themselves. A mother concluded that "*Anything good that's made me able to do what I have done, I learned from being his mother.*"

3.4.6. Uncertainty

Many parents expressed that there were still several uncertainties during the transition process, and that they were unsure of the exact next step. They "*see little kind of successes, but on the flipside of it, there was [sic] so many unknowns altogether in the transition.*"

3.4.7. Emotional responses

Parents experienced a combination of several types of emotions or feelings during transition: Stress, worry/ anxiety, frustration, sadness, guilt, peace/satisfaction, and hope. More than half of the parents reported that they were extremely stressed. One mother said, "*'I'm telling you it's a high stress life, a very high stress life…sometimes I do have moments where I am going home and I wish I could just keep on driving, to nowhere just run away sometimes.*" Almost all parents worried about their children's future. A lack of support and understanding during transition was also frustrating and sad. In face of the excessive demands, several parents felt guilty towards their children because they felt like they could have done better. However, several parents were also *satisfied or hopeful*. A mother whose son finally got a job noted, "*And it seems like things have kind of calmed somewhat since we now have the experience. So, it's just living alive kind of thing. And so that's been just lovely.*"

3.5. Ideal X – ideal adaptation outcomes for parents

Clearly, being the parent of an adult with ASD impacts the ageing experience. Parents have their own dreams and ideas for a positive experience growing older. Several parents said that they wanted to spend more time with their significant others (e.g., spouses, other adult children). Knowing their families are safe and sound was important to all parents. Many parents looked forward to being able to travel, engage in enjoyable activities, and find have time to "unwind." One mother shared that she "*would like to travel; to visit Disney world!*" A father also said he just wanted to "*go to a beach and read a book*." Feeling comfortable and happy was the ultimate goal for the parents.

The majority of the parents also reported that they developed a sense of purpose in their lives – they wanted to contribute back to the community. For instance, two parents wanted to become ASD specialists. Four parents wanted to extend service support through their non-profit organizations, volunteer work, or professional networks. A parent noted, "*So that's why I developed this nonprofit, because I have a different idea of what transition should be*." See Fig. 1 for a visual representation of the results.

4. Discussion

The current findings contribute to the literature by detailing the parent adaptation process during transition using the ABCX model. Similar to previous studies, adults with ASD often have impairments that are continual stressors in older parents' lives (Orsmond, Krauss, & Seltzer, 2004). Changes in the child's demands (e.g., different symptoms representations and needs) add to the parent's stress. Such stressors are within the context of age-related normative changes (e.g., taking care of both the previous and the next generation of family, Grundy & Henretta, 2006) and deteriorating health exacerbated by chronic stress and aging (Quittner, Glueckauf, & Jackson, 1990; Thoits, 2010). Grønborg, Schendel, and Parner (2013) found that the sibling recurrence risk for ASDs was 6.9, meaning that many parents are rearing more than one child with ASD; thus, the burden of transition is multiplied for some families (Orsmond, Lin, & Seltzer, 2007). The results suggest that interventions targeting transition support need to be cognizant of the fact that many aging parents are also experiencing normative stressful events, which may limit their ability to cope with youth-related stressors.

Consistent with previous studies, these parents were navigating through the lack of an effective, coordinated system with an overwhelmingly large amount of information during the transition (Kucharczyk et al., 2015; Ruble, McGrew, Wong, Adams, & Yu, 2019; Snell-Rood et al., 2020). However, parents were able to identify four types of support—tangible, emotional, informational, and internal—that help them through the challenges associated with transition. The results showed that parents relied heavily on their family members, on other parents of youth and adults with ASD, and on themselves for support. Unfortunately, family members, especially the parents of adults with ASD, leave the support system as they age. The death of a significant other results in a loss of support that can be especially difficult for parents. Also, the nearly absent nomination of professionals as important sources of support poses questions for training and service delivery at the system- and individual-levels and challenges the expert model during transition (Brookman-Frazee & Koegel, 2004; Dunst & Paget, 1991). Instead, parents view other parents who have experienced transition as a resource. It highlights the value of parent-to-parent interventions (Ruffolo, Kuhn, & Evans, 2006; Singer et al., 1999) and parent support groups (Boyd, 2002).

The results also provided unique information about the reasoning behind parents' choice of coping strategies and actions. Parents managed stressors according to their philosophy, perceived meaning of transition, and perceived responsibility. Echoing a previous study with parents of individuals with ASD (Sanders & Morgan, 1997), mortality is salient for older-age parents. To them, planning during transition is urgent and paramount for their child's well-being after their death. As a result, they often expressed frustration and anger when advocating or interacting with professionals (Seligman, 2000). The current results provide a deeper look into the reasoning behind their actions and emotions and will hopefully facilitate more understanding (Stoner et al., 2005).

As a result of both tremendous demands and limited support, many parents reported that they are living a restricted life (Traustadottir, 1991). Having a child with disability and insufficient support adds stressors to a normative aging process, such as retirement and engaging in social activity. Even though maternal well-being was reported to improve across time (Lounds, Seltzer, Greenberg, & Shattuck, 2007), the results showed that many parents continue to experience high-level negative emotions or feelings during transition, such as sadness and anxiety. The prevalent negative emotions and reported unhelpfulness of counseling confirm the need for more research on effective intervention to support this particular group of parents (Langley, Totsika, & Hastings, 2017; Ziolko, 1991).

Over time, many families experience a positive adjustment. Although previous studies suggested that non-disabled siblings might develop resentment toward their sibling with disabilities (Barr & McLeod, 2010), the results showed that non-disabled siblings gained more understanding and took on more responsibility over time. Similarly, parents of adults with ASD expressed positivity (Hastings et al., 2005) and a desire to help others. Such positive perceptions may be the result of coping with stress (Hastings & Taunt, 2002). Lynch and Morley (1995, p. 212) noted, "It is not uncommon for parents to move into leadership roles in groups or support relationships with other parents of newly diagnosed children with disabilities." Aging parents went through difficult moments during transition, gained resiliency, and wanted to contribute back to society. Such help-giving behaviors may contribute to family empowerment (Dempsey & Dunst, 2004) and is aligned with Erickson's theory about the importance of generativity for this age-group (Slater, 2003). This result highlights the need to explore the positive experiences of rearing children with ASD and their roles as outcomes or mediators (Hastings et al., 2005).

4.1. Limitations

There were several limitations of the study to consider. First, despite some diversity with geographical location, ethnicity, and SES, the majority of the participants were white and English-speaking. Also, the rate (38 %) of having more than one child, youth, or young adult with developmental or mental health conditions as reported by parents was higher than those reported in the literature (Green, 2013). Our preliminary results might vary if we could have recruited more parents with diverse backgrounds. Second, information was only collected through interviews but no other sources (e.g., document, siblings; Lincoln & Guba, 1985). Assessment from multiple sources such as written IEPs, other school records, parent dairies, and documents from VR can further our understanding of the transition process experienced by parents. Third, the current data are cross-sectional. It is unclear whether the constructs of A, B, C, and X are stable across time. Longitudinal studies would be more potent to describe the changes in the A, B, C, and X factors across time. Fourth, our study did not fully capture the family experience during transition as only parents, not other family members, participated in this study. While we truly believe that parents are critical voices, they only represent part of the family. Siblings, spouses, and adults with ASD may have different perspectives on their stressors, resources, coping strategies, and idea outcomes across time.

Ethical approval

All procedures performed involving human participants were in accordance with the ethical standards of the institutional research committees where the data was collected and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in this study.

Informed consent

Informed consent was collected from all the participants included in the study.

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CRediT authorship contribution statement

Venus Wong: Conceptualization, Data curation, Formal analysis, Investigation, Resources, Writing - original draft, Writing - review & editing, Project administration. **Lisa Ruble:** Resources, Writing - review & editing. **Laura Brown:** Formal analysis, Writing - review & editing.

Declaration of Competing Interest

Venus Wong declares that she has no conflict of interest. Lisa Ruble declares that she has no conflict of interest. Laura Brown declares that she has no conflict of interest.

Appendix A

1. What does transition mean to you?
2. Can you tell me what you and your child have experienced during the transition process?
    - a What has happened to your child (e.g. academic, psychological, behavioral, job-wise, social)?
    - b What has happened to your family (e.g. financial, marital, family relationship, mental and physical health)?
    - c How does the school help your child through the transition process? (e.g. IEP meeting, learning support)?
3. When you hear the words family transition outcomes, what first comes to your mind? When I said family transition outcomes that mean the results of the transition process from the family perspective.
    - a [If parents only talk about the transition outcomes of their child, clarify the concept that family transition outcomes include their outcomes as parents too] Usually, when people talk about transition outcomes, they focus on the students. However, parents or caregivers are often the ones who go through the process with their child. Sometimes, parents and siblings may have their own needs during the child with disabilities' transition. With that in mind, what areas should mental health or school professionals pay attention to at the family level?
    - b What are good family transition outcomes for your family?
4. What types of support have you already had that have helped you and your child through the transition process? What types of support do you wish you had for you and your child during the transition process that you don't have now?
    - a Internal (e.g. coping style, personality), tangible (e.g. money), emotional, informational (e.g. information regarding services)?
5. Please use three words or sentences to conclude your experience with regard to the transition process so far.
6. Is there anything else you would like to tell me in order to help me understand the transition process?

Appendix B. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.rasd.2020.101650.

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