Meaningful outcomes for enhancing quality of life for individuals with autism spectrum disorder

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ABSTRACT

Background Autism spectrum disorder (ASD) is a developmental disorder that continues across the lifespan, but little research exists to examine interventions from both child and adult perspectives. The researchers in this study considered the perspectives of individuals with ASD and caregivers of children with ASD to determine interventions and outcomes perceived as meaningful for both children and adults.

Methods Grounded theory methodology was used to guide data collection and analysis. Participants included 5 parents of children with ASD and 5 adults with ASD. Data were collected through interviews.

Results A central theme of intervention priorities for quality of life was supported. Individual themes identified from parents focused on future planning, community involvement, and scheduling and planning. Individual themes identified from the adults focused on misconceptions. Both groups shared the themes of acceptance; financial challenges; support, resources, and advocacy; skills learned; and socially and functionally based interventions.

Conclusion Results support interventions and resources for individuals with ASD focused on meaningful outcomes, including acceptance, community involvement, social success, independent living, and vocational/financial stability.

KEYWORDS autism spectrum disorder; meaningful outcomes; quality of life

Introduction

Autism spectrum disorder (ASD) is a complex developmental disability that results in challenges with social participation, daily living skills, communication, financial independence, and education attainment (Robertson, 2010). Onset of ASD occurs in childhood and delays development of motor, social, and language skills (Filipek et al., 1999; Ikeda, Hinckson, & Krägeloh, 2014). Impairments in social capabilities affect overall functional abilities across all domains of life (Ikeda et al., 2014). These impairments in function continue into adulthood, although there is limited research that specifically studies the ongoing impact on the adult with ASD. It is essential to understand factors that influence quality of life (QOL) from the perspective of the adult with ASD. An intervention process that incorporates such factors will translate into meaningful outcomes. Additionally, it is also important to understand the experiences of adults with ASD to target support structures and interventions during earlier phases in development. This serves as a foundation for social participation and QOL as a person transitions into adult roles. The perspectives of both adults with ASD and the caregivers of children with ASD provide information necessary to enhance QOL across the lifespan.

QOL includes dimensions of physical and psychological health, personal beliefs, level of independence, and the individual's environment (The WHOQOL Group, 1995). Challenges in areas such as social participation, daily living skills, and communication negatively affect QOL (Karande, Bhosrekar, Kulkarni, & Thakker, 2009; Law et al., 2014). QOL is important to consider when examining interventions for children and adults with ASD.

Children and adults with ASD participate in a variety of interventions throughout the lifespan (Ikeda et al., 2014). However, interventions for ASD are not always congruent with the goals and outcomes of the clients and families (Kohler, 1999). Further, outcomes of these interventions are rarely related to QOL. It is important to develop an understanding of the outcomes of intervention perceived as meaningful and important to individuals with ASD and their families. The identification of meaningful outcomes and factors that improve QOL from the perspectives of key stakeholders allows interventionists, funding bodies, and policymakers to make
client-centred decisions. It is essential to understand the perspectives of both parents of children with ASD and adults with ASD in order to form a complete picture of the most meaningful interventions across the lifespan.

**Quality of life**

QOL extends beyond basic physical conditions such as food and shelter to include more complex factors such as values, interests, social participation (Schalock, 2000), emotional wellbeing, interpersonal relations, personal development, and self-determination (Schalock, 2004). Both adults and children with disability demonstrate lower QOL, making QOL an important area of consideration to guide interventions. Children with physical disability demonstrate significantly lower scores in physical and psychosocial areas (Law et al., 2014). In addition, children recently diagnosed with a learning disability identify several aspects of QOL that were lower than children without disability (Karande et al., 2009). Factors such as environmental barriers, behavioural difficulties, family functioning, general health, and the physical function of the child negatively impacts on QOL. In addition, limitations in family activities, emotional impact on parents, social limitations due to behavioural problems and physical health, time factors, and mental health are aspects that affect QOL in children (Karande et al., 2009). Individuals with ASD exhibit significantly diminished QOL as compared to those with other disability, including Down syndrome, attention-deficit/hyperactivity disorder, and chronic medical conditions, and typically developing peers (Donovan, 1988; Kuhlthau et al., 2010; Lee, Harrington, Louie, & Newschaffer, 2008). Social participation and social supports contribute to QOL (Tobin, Drager, & Richardson, 2014). The perception of having adequate social supports is associated with better overall QOL for the adults with ASD (Khanna, Jariwala-Parikh, West-Strum, & Mahabaleshwar, 2014). Difficulties in social skills, relationships with peers, and emotional empathy extend into adulthood for people with ASD (Ikeda et al., 2014). Adults with ASD have significantly lower physical and psychosocial QOL than their counterparts (Khanna et al., 2014).

Measurements of QOL include both objective and subjective measures. Subjective components of QOL are often more challenging to measure than the objective components (Saldana et al., 2009). Objective quantitative results provide only a small portion of useful information into the reasons why individuals with ASD tend to have less satisfaction with QOL. More objective measures, such as the amount of support received, IQ, and severity of ASD, are not necessarily correlated with QOL for people with ASD (Renty & Roeyers, 2006). Instead the subjective measures of QOL are more comparable to the defined concept of QOL (Renty & Roeyers, 2006). Qualitative information provides insight into why individuals with ASD tend to have less satisfaction in their QOL (Jennes-Coussens, Magill-Evans, & Koning, 2006). Subjective information gathered from the perspective of the individual provides essential information to determine meaningful and impactful interventions to enhance QOL.

**Interventions**

A variety of interventions are used to treat individuals with ASD. Interventions include behavioural, relationship-based approaches, and medication. Additionally, speech and occupational therapy are two of the most common interventions for children with ASD (McLennan, Huculak, & Sheehan, 2008). However, service delivery and outcomes of intervention are rarely considered from the family’s or individual’s perspective. Parents of children with ASD identified common problems in service delivery for interventions for their children. Interventions did not always meet the desired outcomes or address skills valued by parents (Kohler, 1999). The effectiveness of interventions is well documented. However, little information exists on the subjective reasons why certain interventions are considered effective (Ruble & McGrew, 2007).

The concept of QOL is conceptualised from the perspective of the individual. Therefore, consideration of QOL in the intervention process results in interventions that are inherently client centred. Client-centred care involves developing partnerships and supporting informed decisions made by the stakeholders (Restall, Ripat, & Stern, 2003). It requires a shift from the client as a passive recipient to one of an active participant in the intervention process (Chewning & Sleath, 1996). Client-centred interventions are associated with better outcomes and overall satisfaction (Chewning & Sleath, 1996; Restall et al., 2003). Families are viewed as primary stakeholders, as they are often pivotal in the intervention process for their child. Families often continue to serve as a voice and advocate for the child as they age into adulthood. Along with this, families provide the contextual framework for the child’s QOL (Lindström & Eriksson, 1993). It is important to consider families and individuals as important contributors to the development of knowledge to guide decision-making processes for intervention (Renty & Roeyers, 2006; Ruble & McGrew, 2007).
**Statement of the problem**

In order to provide effective interventions across the lifespan, intervention outcomes must be explored from the perspective of individuals with ASD. There is little evidence outlining the intervention effectiveness or outcomes across the lifespan from childhood to adulthood. In addition, the relationship between QOL and interventions for children and adults with ASD is not well understood. It is difficult to implement client-centred approaches without information from the individuals affected the most by the intervention. The perspectives of individuals with ASD and parents of children with ASD provide key information with regard to interventions that are meaningful and impactful. Subjective information with regard to interventions and QOL provides unique insight into how interventions impact QOL. Perspectives from key stakeholders are essential in identifying and implementing meaningful client-centred interventions. The researchers in this study sought to examine the interventions related to QOL for both children and adults with ASD. They looked at the outcomes of interventions from the perspectives of parents of children with ASD and adults with ASD. Unifying themes regarding the relationship of interventions to meaningful outcomes and QOL were identified to provide information that encompasses the lifespan of people with ASD.

**Methods**

Grounded theory methodology was used to guide data collection and analysis. Grounded theory is a qualitative research method that allows the development of a theory to explain a process or phenomenon and provide a collective concept of an experience (Creswell, 2007). Throughout the process of grounded theory research, the hypothesis is continually developed and refined to fit the data that is uncovered. Data are collected, analysed, coded, and categorised until no new categories or relationships emerge from the data (Portney & Watkins, 2009).

**Participants**

Participants included five parents of children with ASD and five adults with ASD. The children of the parents and the adults met the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (American Psychiatric Association, 2000) criteria for pervasive developmental disorder not otherwise specified, autism, or Asperger’s syndrome as identified by a psychologist, psychiatrist, or physician. Maximum variation sampling was implemented during recruitment to obtain representation of the various levels of functioning and symptomology across the ASD spectrum. This was more limited for adult participants because they needed to have the social and communication skills to participate in an interview process. The parent participants had children ranging in age from 4 to 8 years old and the adults varied in age from 28 to 60. All the children of the parent participants had a diagnosis of an ASD, participated in applied behavioural analysis (ABA) ASD classrooms, and received interventions outside of the school setting such as occupational therapy and speech therapy. There were three females and two male adults with ASD who participated in the study. Two of the adults had full-time employment (one male and one female), one part-time (one male), and two were unemployed (two female). Three of them reported receiving some type of current intervention, which included psychological services and social skills groups.

**Procedures**

The primary investigator obtained ethics approval through Temple University’s institutional review board (approval number 12938) prior to the start of the study. Written informed consent and consent to audio-tape was attained from each participant prior to interviews. Parent participants were recruited through schools programs for children with ASD and through private therapy practices. Adult participants were recruited through adult ASD support groups and an ASD organisation providing resources and support for adults diagnosed with ASD. Individual interviews with each participant were completed over a 1–2 hour period in a convenient location for participants. The setting varied but included participants’ homes and the office of the primary researcher. All interviews were completed by one of three researchers who had graduate degrees or were in the process of completing graduate degrees and had formal training in qualitative research methods and interviewing techniques. The following guiding questions were developed and used to facilitate the interview process:

1. What are those things that most impact your (your child’s) quality of life?
2. What are those things that most impact your (your child’s) social participation?
3. What interventions were most important to you (for your child) and why?
4. What interventions were most helpful/effective for you (for your child) and why?
Interviews were transcribed and then analysed by the three researchers for triangulation.

**Data analysis**

Data were initially analysed separately for the adult and parent interviews, and then cross-analysed to identify overlapping themes and develop a central theme. The transcribed data were first microanalysed, which allowed open coding of the data. Open coding was completed separately for each of the adult and parent interviews resulting in the development of numerous nodes. The data analysis strategy of making comparisons (Corbin & Strauss, 2008) was used throughout the process of generating nodes. The technique of constant comparisons allowed data that seemed to be similar and was initially coded in one category to be more accurately coded in multiple categories. After the third interview for the parents and the fourth interview for the adults were microanalysed, no new nodes emerged. It is possible that the data were saturated or that the participants in the fourth and fifth interviews simply shared similar experiences with the first three. Axial coding followed in which categories were identified and linked to subcategories for both sets of participants, and subsequently analysed for overlapping categories identified from the adults with ASD and parents of children with ASD. The process of “theoretical integration” allowed concepts to be joined to one another for the development of the central category.

**Data trustworthiness**

There were a number of methodological actions implemented to strengthen the data collection process and trustworthiness. These included interview training, reflexivity, triangulation, and stakeholder checks (Lysack, Luborsky, & Dillaway, 2006). All researchers completing interviews with the participants underwent training focused on interview techniques prior to the start of the study. Along with this, guiding questions were developed to ensure consistency in data collection across interviewers, but also to allow for flexibility to expand and adapt questions as needed to obtain detailed information.

Triangulation during data analysis was implemented in order to ensure validity of the results. Three different researchers initially completed the open and axial coding process independently based on the transcripts for each participant. A validation process in which researchers compared their analyses to determine similar and dissimilar results followed this procedure. Dissimilar results, although infrequent, were discussed and at times validated through stakeholder checks. Stakeholder checks were completed with three out of the 10 participants, all of which were adult participants. Information gathered during data analysis and the triangulation process helped guide the decision-making process and the development of a central theme.

Reflexivity, a critical and honest reflection on the research process (Lysack et al., 2006) was attempted during data analysis through bracketing. Although the definition of bracketing is inconsistent within the qualitative literature (Tufford & Newman, 2012), for the purpose of this study, bracketing refers to the researcher acknowledging beliefs and biases and then bracketing those biases during the analysis process (Creswell & Miller, 2000). The researchers acknowledged biases related to their professional training as occupational therapists and in public health in relationship to the interventions identified and discussed by the participants. A bias to those interventions more commonly used in occupational therapy was acknowledged, as well as beliefs related to past research experiences, including the assumption of intelligence across the ASD spectrum and the importance of strength-based interventions. During the process of analysis, there was a point where researchers needed to acknowledge the bias towards identifying actual types of interventions versus the outcomes of interventions, which were the evolving themes emerging from the data.

In addition to the methodological actions to ensure trustworthiness, credibility and quality of this research is supported by what seemed to be data saturation after the third interview with the parents of caregivers and the fourth interview with the individuals with ASD. Although five interviews were completed with each stakeholder group, additional interviews are necessary to truly ensure data saturation.

**Results**

Analysis of the data from adults with ASD and parents of children with ASD revealed individual themes that were unique to each group and overlapping themes that the groups shared with each other. These themes supported a central theme of Intervention priorities for quality of life. Both adult and parent participants focused on the outcomes of interventions and prioritised interventions according to how they would lead to improved QOL. Many of the parents specified the desire for their children...
to be happy as one of the primary outcomes for interventions targeting QOL. Neither of the stakeholder groups identified an overarching focus on specific interventions, but rather on the outcomes of interventions that were meaningful. Participants identified outcomes of interventions as the most important impact on QOL.

**Individual parent themes**

Much like other studies (Goin-Kochel, Myers, & Mackintosh, 2007; Kuhlthau et al., 2010), parents served as proxy reporters due to the unique social and communication characteristics of ASD. The parents identified individual themes of future independence, community participation, and scheduling/planning as areas of consideration to improve QOL and social participation in the intervention process. This concept of anticipatory planning was identified as a key feature of promoting social participation in research completed with children having other disabilities (Bedell, Cohn, & Dumas, 2005). All of the parents in the study expressed concerns regarding the future of their children, including that their children would eventually not have parent support and would need to perform adult roles or live independently. Participant 3 explained:

The challenge is just hoping that he’ll fit in to a typical lifestyle. I just feel like as a parent I don’t care really how he is because I’m always with him. It’s when I’m gone and who’s going to take care of him afterwards and how is he going to be treated.

Most of the parent participants discussed the impact of the sibling’s relationship with the child with ASD. This was related to the child with ASD’s QOL for two main reasons. First, many of the parents reported that the sibling would be essential as an advocate and caretaker in the future, directly impacting the QOL of the child with ASD. Second, research has identified that families provide the contextual framework for a child’s QOL (Lindström & Erikkson, 1993). In considering the future impact of the sibling on the child with ASD, Participant 4 stated:

I’ve told his siblings that they have to always look out for their brother. If they had a serious boyfriend or girlfriend, I would let that person know that he is part of … that person’s life. But at the same time I don’t want this to be something that they have to deal with all of the time.

Additionally, parents identified they felt that their children without ASD received less attention:

… it’s affecting my other children. I can’t give them the attention that I would, that I feel they really need. (Participant 5)

Parents identified community participation as another individual theme and area of focus that improves QOL and social participation. They discussed the need for their children with ASD to be involved in the community and have appropriate resources or adaptations to participate in the community. Participant 3 talked about how one of her most rewarding experiences was watching her son learn to play in the playground: “When he looked like a typical kid on the playground and he wasn’t pacing back and forth and he wasn’t going up the sliding board the same way 50 times. He wasn’t all over the place.” The parents identified that acceptance and support by individuals and organisations supported community participation that was necessary to enhance the child’s QOL and social participation. One example was a movie night for individuals with ASD and their families where the environment was adapted to support participation in this typical community activity.

All of the parents reported that they need to maintain strict schedules, resulting in significant planning and challenges in keeping up with the interventions needed to enhance QOL. They explained that children with ASD have many additional activities and therapies that require time and energy for navigation and implementation of recommendations. When asked about some of the challenges of parenting a child with ASD, Participant 1 identified the challenge of keeping up with therapy schedules and the overwhelming feeling that came from the multiple suggestions that each professional provided to the parent. Participant 2 explained, “Now we have to actually schedule … the babysitter maybe 2, 3 months in advance. And that’s everything that you schedule … even meals and different things like that … you can’t fall off the strict schedule.”

Along with this need for significant scheduling, parents reported the need to plan out almost all of their activities due to the unique nature of their child and characteristics associated with ASD. For example, Participant 2 described the significant planning when visiting other’s homes and unfamiliar places with her child: “They want to touch things they’re not supposed to be touching … you can’t have them jumping in someone’s house where there’s glass objects, so you have to plan ahead of time.”

In summary, parent participants described wide-reaching implications of providing care for their children with ASD and improve QOL. This involved reflecting on the entire lifespan and the family unit as a whole. Parents discussed community and social participation as highly valuable. They also described the struggles of thorough planning of daily routines required that allow for community and social participation. Additionally, parent
participants discussed the importance of long-term planning for their children’s future living situations with potential implications for siblings.

**Individual adult themes**

We analysed the data from adult participants with ASD and found that two individual themes, *misconceptions* and *specific interventions*, emerged. With regard to the first theme of misconceptions, adult participants described that their emotional needs and expression of emotions tended to be misunderstood, which impacted QOL. In discussion of the theme specific interventions, participants identified interventions that they found to be helpful as a child, interventions that they were receiving at the time of the interview, and interventions that they thought would have been helpful had they been available when the participants were children.

Adults with ASD identified misconceptions and misunderstandings from the neurotypical population regarding their interests and need for social interactions and relationships. They reported an interest in having a variety of relationships with others, including romantic relationships, friendships, and familiar relationships. In discussing misconceptions about the desire for individuals with ASD to engage in social interactions, Participant 10 explained:

> Well, I think the vast majority of any adult with autism will tell you that that’s a very big misconception. That we are often very misunderstood about that. So, there are times obviously that we need to be alone and we kind of have to isolate ourselves, but there are some people that do genuinely say that they don’t care if they have friends or not, good friends or whatever, but the vast majority of people that I know or my personal thought is that we all really do. We all really do.

Many of the adults reported that others misunderstood their behaviours and feelings: “A big misconception, I think, is, we don’t have emotions, we don’t have feelings, and we don’t have compassion. And that isn’t it. I think, I process emotion differently from most people” (Participant 7). Another participant explained additional misconceptions that he/she experienced. “And people with autism are able to develop strong friends, and we even have relationships with the opposite sex, get married and a lot of people will tell you people with autism can’t do those things but they can” (Participant 9).

The adults discussed a wide variety of types of specific helpful interventions that they received as a child, including occupational therapy, speech therapy, ABA, discrete trial training, psychological therapy, and special educational supports, although many of the participants reported that they did not remember interventions very well from childhood and had difficulty identifying which ones they found to be helpful. These interventions are identified as some of the most common interventions provided by schools and funded by insurance companies for children with ASD (Goin-Kochel et al., 2007). Half of the participants were not diagnosed with ASD until they were adults and some did not have any interventions as a child. At the time of the interview participants identified that they were receiving specific interventions including psychological counselling, support groups, and interventions targeted at learning social skills. This was also identified in a recent systematic review of the literature focused on adults with ASD. Results of the systematic review identified that social participation and QOL is facilitated through membership in support groups and social skills groups, which is consistent with the interventions chosen by adults in the current study (Tobin et al., 2014).

**Overlapping themes**

We compared the data from interviews with adult participants and parents of children with ASD and found the following six overlapping themes affecting QOL: (a) acceptance, (b) financial/vocational, (c) support, (d) resources and advocacy, (e) skills learned, and (f) socially and functionally based interventions.

Both parents and adults with ASD identified acceptance as it related to the diagnosis of ASD and their relationships with others as important for social participation and QOL. Although some parents reported that they needed to grieve as a part of the process of acceptance of the unique aspects of their child with ASD, more often parents reported that they needed to get acceptance from other family members and the community regarding their child with ASD. This was necessary for their child to have opportunities for social participation. Participant 1 explained, “We kind of got out of the grieving process and moved forward into acceptance finally, which takes a long time to get to.” Another parent discussed the value of a community organisation that provides a place of acceptance for children and support. The parent identified the importance of inclusive activities for all siblings in the family. Meanwhile, adults discussed social networks and social participation, which encompassed this concept of acceptance. Participant 6 explained, “I think, it’s even more important that you form that social network and that you work on what you have to work on to survive socially.” According to Participant 7, “So socialising, as long as I’m in this environment, and I’m with other people who accept me as I am, it’s a good thing.”
All of the adults discussed the need for some type of acceptance of having ASD and the unique characteristics of ASD either by the community, family members, or people with whom they work. Many of the adults reported a sense of relief when they received the diagnosis of ASD, especially those diagnosed as adults. For example, Participant 7 said,

But it was such a relief, it’s relief once you find out you’re not alone and there are other people who are the same way, their brain is the same – different in the same way yours is, that they’ve got this name and there’s a whole community. It’s like a different culture.

Along with this, all of the adults reported that social participation with those who understand them and who are similar to them, including people with ASD, as significantly impacting their QOL. Many of the adults reported that they would have benefitted from this type of social participation as a child and adolescent. Both parents and adults identified support groups and social skills groups as interventions that allowed opportunities for social participation and forming social networks.

Financial/vocational was an overlapping theme that either enhanced QOL or limited it. Many parents discussed that their household income was reduced or limited because they were unable to work or they had to decrease the amount of time that they worked to care for their child with ASD. Additionally, all parents reported significant additional expenses for therapies and other items when caring for a child with ASD, which were necessary for improving the child’s QOL. Participant 2 described the challenges associated with having less money available because of working fewer hours:

The disadvantage is that you don’t have money accessible as you would if you had a typical child. Cause you pick and choose but in his case, a lot of it is need or necessity. So you know you could say with my first child, ok, we’re not going to do basketball this year but we’re going to do soccer, um, so you actually, you know, cut something out and it won’t affect the child, but in his case if he needs 2 more hours of speech a week, it it’s a necessity for him to survive.

Adult participants identified financial strains associated with unemployment or underemployment as a primary challenge:

There’s no point in even applying because I’ve worked at places like that before, and I’ve always had such problems. I would end up not working out or I would get transferred and I would be in jobs that were inappropriate for me. (Participant 7)

The adults who were unemployed or underemployed discussed the need for interventions to help find appropriate employment and skills needed for employment: “So, if there are more resources out there for employment services and helping those of us on the spectrum find jobs, because that’s a hard thing for us, finding and keeping employment and meaningful employment” (Participant 10). These adults reported financial strains of being independent or having a decreased quality life due to financial limitations. In contrast, adults who were successfully employed reported that having meaningful employment and the security of having financial stability added to their QOL. Participant 8 described her work: “Being fortunate with my profession and the rate at which one gets paid for that profession. It has helped improve my QOL, in that I have money to pay … for the cable TV and to get the DVR.” Later in the interview, she further described her work: “to me, it’s not really work. It’s fun.”

The parents and adults with ASD shared one another’s perspective that the concepts of supports, resources, and advocacy were important in improving QOL. Most of the parents reported that getting the appropriate and necessary services, resources, and supports was a battle, whereas the adults viewed lack of supports as an ongoing issue. One parent stated,

I don’t know anyone who gets what their child needs from the district. It’s the ones who fight the hardest who get more services. So if you’re not convincing as a parent or don’t hire someone convincing, your son will or daughter will get less services and not do as well. (Participant 5)

Adults reported that there were few available services and resources. Support groups and social groups were viewed as very important by both the parents and individuals with ASD. Additionally, they reported that having someone understand them or having similar experiences was important:

I joined an Asperger’s support group a few months back. I can be myself. We’ve got some things in common, and even in places where we’re different, we can accept each other for the way we are and it’s safe to be yourself. (Participant 7)

These concepts overlap with the theme of acceptance. The concept of advocacy was identified by both groups as important for getting services or needs met.

Both adult and parent participants discussed the value of learning skills, including social skills, and they expressed that they valued socially and functionally based interventions. All of the adults with ASD identified that social skills influence many areas of life such as work, dating, making friends, and participating in social engagements that require small talk. All parent and adult participants identified social skills as a predominant
theme and a primary need for targeted intervention. Adult participants identified the need to learn social skills by observing others or media and being provided with scenarios in which they could practise their social skills with feedback from others.

The concept of having to learn skills versus naturally developing skills was an overlapping theme between both parents and adults. Adults focused on the need to learn social skills. Conversely, parents reported that their child needed to be taught how to do each new developmental skill versus being able to learn skills on their own. Participant 1 explained:

I may go to the playground once, but then I’m thinking of it as, well how many times am I going to go to the playground before he’s this age so he’s gonna get this many interactions to realise I go on the swing, I can get on and off myself, I can get up and down a slide myself. I can say hi to my friend, you know, just normal routines that kids go through.

Adults identified the importance of learning instrumental activities of daily living, such as managing households and finances, as major areas of need. These skills were identified as important for both social participation and overall QOL.

Discussion

Parents and adults with ASD included a range of themes for recommended outcomes of interventions versus specific interventions that impact the quality of daily living. Individual parental themes identified a need for interventions that target the child’s future independence, participation in the community, and anticipatory planning as important to improve QOL. Individual adult themes included overcoming barriers such as misconceptions by others and specific social interventions. There were the overlapping themes of acceptance, financial factors, resources/advocacy, and socially and functionally based interventions as essential outcomes of intervention. Important previous quantitative research has identified the subjective viewpoint of specific types of interventions on predetermined outcomes (Ruble & McGrew, 2007). The results of this study suggest that the subjective viewpoint of key stakeholders is also necessary to understand valued outcomes that affect QOL in order to then identify client-centred interventions. The meaningful outcomes reported by both the parents of children with ASD and adults with ASD were consistent with previous research that identified factors impacting QOL. Research with other developmental disabilities strongly supports that social participation, social supports, resources (financial, time), and anticipatory planning as areas impacting QOL (Karande et al., 2009; Law et al., 2014). This is especially apparent in the area of social participation and its connection to QOL (Tobin et al., 2014).

In general, most of the literature related to social participation and QOL for individuals with ASD relies on an observer rating the interactions of the individual with ASD. This method focuses on these concepts in an objectively measurable construct (Bellini & Hopf, 2007; Jahr, Eikeseth, Eldevik, & Aase, 2007; Lee, Odom, & Loftin, 2007; Macintosh & Dissanayake, 2006; Pierce-Jordan & Lifter, 2005; Tsao & Odom, 2006). Psychometrically sound instruments, such as the Autism Social Skills Profile (Bellini & Hopf, 2007), allow parents, teachers, and other professionals to rate the social skills of individuals with ASD. However, it does not consider whether the perspective of the rater is actually valid. Neither does it consider the perspectives of the person with ASD, which may be different from the perspectives of the raters (Bauminger, Shulman, & Agam, 2003).

Qualitative factors of QOL often provide more valuable information than easily measurable objective factors. For example, Renty and Roeyers (2006) found that the more objective factors such as amount of support received, IQ, and severity of ASD were not correlated with QOL. On the other hand, the subjective factor of perceived availability of support was correlated with QOL. Research validating meaningful outcomes to improve QOL and social participation from the perspective of the individual with ASD and their families is essential in intervention planning. From a clinical and research perspective, it was anticipated that results would identify which specific interventions would improve QOL and social participation, although parents and adults with ASD reported a different perspective. Although they reported participation in a variety of specific interventions such as special education, ABA, occupational therapy, speech therapy, and psychological interventions, they did not specify one or several specific interventions to be the most critical for QOL and social participation. Instead of specific interventions, they identified outcomes of interventions that they found to be most valuable. These included both formal and informal interventions that encouraged community-based involvement of individuals with ASD and functional-based interventions that focused on future independence as most important for QOL. Along with this, both groups valued a social support system and emphasised the importance of having resources and advocacy. Parents also specified the importance of sibling support for the future QOL of their children with ASD.

This research identifies the importance of client-centred interventions that involve developing
partnerships and supporting informed decisions regarding both outcomes and interventions that are meaningful and valued by the individual. Results of the study also suggest that a broader focus on all types of intervention including consultation, advocacy, and education may help improve QOL for individuals with ASD. Results lend themselves to provide discipline-focused direct interventions that are meaningful to individuals with ASD. Further, funding agendas could focus efforts on the education of the neurotypical population to reduce misconceptions and foster increased inclusion in community settings.

**Limitations**

As with any qualitative study, research biases are expected to influence the results. Two of the researchers are occupational therapists and one of the researchers is in the field of public health. This undoubtedly creates biases in the perspectives of the researchers. One of the researchers was, at some point in time, the occupational therapist for children of all of the parents interviewed. Parents may have considered this when they discussed their opinions about interventions they found meaningful. Additionally, the parents who chose to participate in this study may have been a self-selected group of parents that share some of the values and opinions of the researcher. Because this is a qualitative study, however, these biases are valuable to the research process. It is important to consider that opinions about interventions do not occur in isolation of the clinicians providing the interventions; instead, they are influenced by these relationships. The results of this research reflect the interactive process. The parents who were interviewed for this study had children ranging in age from 4 to 8 years old. It is possible that parents of younger children and parents of older children would describe their experiences differently.

Adults with ASD in this study were participants in ASD support groups. Because of their involvement in the ASD community, they may value community-based interventions more than other adults with ASD. All of the adults in the study communicated through verbal speech. There are many adults with ASD who use other forms of communication, such as communication devices or typing. Adults who communicate differently may also have different opinions about types of interventions.

**Conclusion**

In this study, parents of children with ASD and adults with ASD shared the perspective of prioritising interventions for QOL. Both groups focused on the outcomes of interventions, and did not highly value specific interventions over other interventions. Individual themes that arose for parents focused on planning for the future, community involvement, and scheduling and planning, whereas individual themes that arose from interviews with adults focused on specific interventions and misconceptions. Both groups shared the following perspectives: (a) acceptance is important; (b) there are financial challenges; (c) supports, resources, and advocacy are valuable; (d) skills learned; and (e) socially and functionally based interventions are necessary for QOL. Identifying the importance of interventions to both children and adults with ASD is an important first step for future research. Further research is needed to identify how current interventions meet the identified needs of individuals with ASD across the lifespan. Additional research is needed to explore how individual interventions impact QOL in individuals with ASD as they age into adulthood. Research focused on the identification of meaningful interventions to the person and QOL provides direction to guide intervention methods. This research, paired with effectiveness studies, will provide a clearer picture for the focus of interventions in the future. Additional research is also necessary to expand the findings to a broader and more diverse group of individuals with ASD and to determine how meaningful interventions impact QOL in the long term.

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