

Lived Experiences From the Perspective of Individuals With Autism Spectrum Disorder: A Qualitative Meta-Synthesis

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Abstract

Autism spectrum disorder (ASD) includes deficits in social communication and repetitive behavior. Secondhand accounts from parents suggest that ASD affects many aspects of life. However, little is known about this disorder from first-person perspective. This meta-synthesis examines children, adolescents, and adults with ASD to understand their experiences across multiple areas of life and how these experiences vary according to their developmental stage. A thematic synthesis integrating qualitative evidence was undertaken where 10 electronic databases were searched. Thirty-three articles met the inclusion criteria ($n = 318$ individuals) and were examined by two reviewers using a constant comparative approach. Four themes emerged: perception of self, interactions with others, experiences at school, and factors related to employment. Our findings can inform client-centered policies and practices involving individuals with ASD. Our findings can also help to identify gaps in research with first-person narratives from children and adolescents with ASD under-represented in the current literature.

Keywords

autism spectrum disorder, meta-synthesis, qualitative research, lived experiences

Introduction

Autism spectrum disorder (ASD) is characterized by deficits in social communication and social interaction and by repetitive patterns displayed in behavior or interests (American Psychiatric Association, 2013). Most research on ASD focuses on parents', siblings', or health care providers' accounts of this disorder, with less attention paid to those who live with the condition. Increasingly, however, research shows the importance of understanding ASD from firsthand accounts (e.g., Hurlbutt & Chalmers, 2002; Jones, Quigney, & Huws, 2003). This information can further our understanding of ASD and help to identify gaps in programs and services for individuals with this disorder.

Most research on the life experience of having ASD has involved adults (e.g., Hurlbutt & Chalmers, 2002; Müller, Schuler, Burton, & Yates, 2003; Punshon, Skirrow, & Murphy, 2009) instead of children or adolescents with this disorder (e.g., Sagers, Hwang, & Mercer, 2011). However, children with ASD experience many challenges including making friends and being bullied by peers (Calzada, Pistrang, & Mandy, 2011; Connor, 2000). Adolescents with ASD are likely to struggle with forming their identity and making the transition from high school (Browning, Osborne, & Reed, 2009; Humphrey & Lewis, 2008). Critically, these experiences at different developmental

stages must be understood so that younger individuals with ASD can successfully transition into adulthood.

Qualitative research allows “participants to speak in their own voices” and thereby present their experiences from their perspective (O’Day & Killeen, 2002, p. 10). Importantly, this type of research can inform evidence-based practice (Grypdonck, 2006), which might be useful to a wide audience of readers. With respect to meta-syntheses, they promote understanding of multiple studies on a topic and help to identify gaps in research (Major & Savin-Baden, 2010). Meta-syntheses also help to identify patterns on a topic (Erwin, Brotherson, & Summers, 2011), which might be useful for program and policy development.

The purpose of our article is to synthesize and integrate the qualitative research about the lived experiences of individuals with ASD. Our synthesis will address, “What are the experiences of individuals with ASD across major areas of

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life, including successes and challenges?” “How are these experiences affected by their developmental stage, such as childhood, adolescence, and adulthood?” To our knowledge, there are no previous syntheses on this topic. However, a synthesis will help to consolidate the information about lived experiences among individuals with ASD, which is important given the growing literature on this topic. This synthesis will be valuable for health care professionals who can use the findings to inform client-centered policies and practices. This synthesis will also help professionals to understand gaps in programs and services for people with ASD. Finally, this synthesis will increase our understanding of the challenges at key stages of life and prepare individuals with ASD and their families accordingly. One such challenge involves the transition into adulthood with research showing the need for specialized supports for those with ASD (Howlin, 2000).

Method

Search Strategy

The following databases were searched: CINAHL, MEDLINE (OVID), Healthstar, PubMed, EMBASE, Web of Science, PsychInfo, social science citation index, Scopus, and Google Scholar. The search strategy involved the following terms: autism spectrum disorder, pervasive developmental disorder, Asperger syndrome, autistic disorder, qualitative, lived experience, ethnography, phenomenology, biography, interview, personal narratives, autobiography, grounded theory, focus group, and diaries. Reference lists of included articles were also searched.

The inclusion criteria involved peer-reviewed published research between 1980 and 2014 focusing on the experiences of individuals with ASD; individuals had a primary diagnosis of ASD; diagnosis could include comorbid symptoms (e.g., cognitive impairment); individuals could be children, adolescents, or adults; article focused on the experiences of individuals with ASD across multiple areas of life; and qualitative design for the data collection and analysis. Articles containing only quantitative data, opinions, editorials, content analysis, secondhand perspectives, or unpublished work were excluded.

The second author and a research assistant conducted the literature search where 2,892 articles were identified. Next, two researchers reviewed the titles and abstracts of these articles. After removing the duplicates and applying the inclusion criteria, 76 articles were read in full by the first author in discussion with the second author. When selecting the final articles, any discrepancies that arose were resolved with both authors reviewing the inclusion/exclusion criteria together before making a final decision about each article. The articles that were typically excluded from this synthesis did not take a first-person perspective or were from a non-peer-reviewed source. Both authors agreed that 33 articles met the inclusion criteria.

Analytical Approach for Review and Synthesis

The first author read each article before summarizing key attributes. Data were abstracted and compiled by the first author and independently verified by the second author using a structured abstraction form (Tong, Morton, Howard, & Craig, 2009). This form recorded author information, sample characteristics, purpose and objectives, research methods, major findings, and research limitations. The findings were then synthesized in three stages using narrative synthesis guidelines (Petticrew & Roberts, 2005; Saini & Shlonsky, 2012). In the first stage, studies were organized into categories (Petticrew & Roberts, 2005) that represented major areas of life experience (e.g., school and work). In the second stage, findings within each category were analyzed (Petticrew & Roberts, 2005) with sub-categories created (e.g., challenges with curriculum at school). Finally, the last stage involved synthesizing findings across all included studies (Petticrew & Roberts, 2005) with focus placed on lived experiences across different developmental stages (e.g., childhood, adolescence, and adulthood). Four themes emerged: perception of self, interactions with others, experiences at school, and factors related to employment. Representative quotations from each theme were recorded.

Quality Appraisal

The quality of included studies was appraised using the Critical Appraisal Skills Programme, which involves 10 checklist items (Critical Appraisal Skills Programme International, 2010). Both authors independently appraised each article. The first author made notes about each item, which were verified by the second author. The overall methodological quality of the studies was good such that none of the articles had methodological problems that could affect the interpretation of our findings. No articles therefore had to be excluded from our synthesis, which is consistent with narrative synthesis guidelines (Petticrew & Roberts, 2005).

Results

Characteristics of Included Studies

Thirty-three articles were identified in our search. Table 1 provides an overview of the characteristics of each study. The included studies involved 318 individuals with ASD (77% males and 23% females) ranging from 7 to 62 years old. Most studies focused on adults with ASD ($n = 15$), followed by adolescents ($n = 10$) and children ($n = 4$). Some studies had samples with participants representing multiple developmental stages ($n = 2$), whereas the remaining studies could not be classified because no ages were provided ($n = 2$).

Four themes emerged: perception of self (identity, interests/talents, and stress/coping), interaction with others (family, friends, and experts), experiences at school (curriculum

Table 1. Summary of Qualitative Studies.

Author, year (country)	Sample characteristics	Objective	Method	Analysis	Main findings	Themes
1. Browning, Osborne, and Reed, 2009 (Wales)	10 adolescents with autism or Asperger syndrome, 8 males and 2 females, <i>M</i> age = 15 years	Examined issues of stress and coping among individuals with ASD who were transitioning from school	Data collected via structured interviews	Content analysis	Responses from interview questions covered topics including causes of stress, feelings about stress, and ability to solve problems	Self, others
2. Calzada, Pistrang, and Mandy, 2011 (England)	10 children with autism or Asperger syndrome, 9 males and 1 female, age = 9–16 years	Examined the utility of receiving a diagnosis of pervasive developmental disorder	Data collected via semistructured interviews	Thematic analysis	Themes identified included bringing understanding, practical support empowerment, and stigma	Self, others
3. Carrington and Graham, 2001 (Australia)	2 adolescents with Asperger syndrome, both males, age = 13 years	Examined the experiences at school among individuals with Asperger syndrome	Data collected via semistructured interviews	Thematic analysis	Themes identified: Developmental differences, problems associated with disorder, stress, and masquerading	Self, others, school
4. Carrington, Templeton, and Papinczak, 2003 (Australia)	5 adolescents with Asperger syndrome, 4 males and 1 female, age = 14–18 years	Examined the perceptions about friendship among individuals with Asperger syndrome	Data collected via interviews	Thematic analysis	Themes identified: Language about friendships, description of non-friend, description of friend, description of acquaintance, and masquerading	Others
5. Cesaroni and Garber, 1991 (Canada)	2 individuals with high-functioning autism, all males, age = 13 and 27 years	Examined the experiences of two individuals with autism	Data collected via interviews	Categorical analysis	Responses involved: Sensory processing, memory, stereotypical behaviors, and social interaction	Self, others, employment
6. Connor, 2000 (England)	16 children with Asperger syndrome, 15 males and 1 female	Examined the experiences of students with Asperger syndrome	Data collected via interviews	Thematic analysis	Responses involved: Preferred activities at school, likes and dislikes, problems at school, activities at break or lunchtime, friendship, and post-school activities	Others, school
7. Daniel and Billingsley, 2010 (United States)	7 children with autism or Asperger syndrome, all males, age = 10–14 years	Examined the perceptions about friendship among individuals with ASD	Data collected via semistructured interviews, field notes, and document reviews	Thematic analysis	Themes identified: Having friends, challenges with friendships, sharing interests, and transitions and friendship stability	Others
8. Griffith, Totsika, Nash, and Hastings, 2011 (Wales)	11 adults with Asperger syndrome, 8 males and 3 females, age = 37–57 years	Examined service and support needs of individuals with Asperger syndrome	Data collected via semistructured interviews	Interpretive phenomenological analysis	Themes identified: Living with Asperger, employment, mainstream support, and future steps for support	Self, others, employment
9. Gulec-Aslan, Ozbey, and Yassibas, 2013 (Turkey)	1 adult male with ASD, age = 25 years	Examined the experiences of a man with ASD	Data collected via interviews, meetings, reflections, and document reviews	Thematic analysis	Themes identified: Identity, autism story, social experiences, school experiences, and future plans	Self, others, school
10. Haertl, Callahan, Markovics, and Sheppard, 2013 (United States)	6 adults with ASD, 3 males and 3 females, age = 27–55 years	Examined the experiences of individuals with ASD	Data collected via interviews	Thematic analysis	Themes included paradoxical themes and occupational participation	Self, others, school, employment
11. Hughes, 2012 (England)	1 male with Asperger syndrome, multiple developmental stages	Examined personal awareness of Asperger syndrome	Data collected based on personal journal narratives	Autoethno-graphic approach	Narratives included self, communication, and outside world	Self, others, school, employment
12. Humphrey and Lewis, 2008 (England)	20 adolescents with high-functioning autism or Asperger syndrome, age = 11–17 years	Examined the experiences of individuals with ASD in mainstream high school	Data collected via semistructured interviews, diaries, and drawings	Thematic analysis	Themes identified: Constructing an understanding, school life, peer relationships, anxiety and stress, working with teachers, and negotiating difference	Self, others, school
13. Humphrey and Symes, 2010 (England)	36 adolescents with ASD, age = 11–16 years	Examined the responses to bullying at school among individuals with ASD	Data collected via semistructured interviews	Thematic analysis	Themes identified included responses to bullying, support from friends, role of parents, and desire for solitude	Self, school
14. Hurlbutt and Chalmers, 2004 (United States)	6 adults with Asperger syndrome, 3 males and 3 females, age = 25–56 years	Examined the experiences of adults with ASD in employment	Data collected via interviews	Thematic analysis	Themes identified: Unemployment and under-employment, factors affecting employment, and recommendations for workplace success	Employment

(continued)

Table I. (continued)

Author, year (country)	Sample characteristics	Objective	Method	Analysis	Main findings	Themes
15. Hurlbutt and Chalmers, 2002 (United States)	3 adults with high-functioning autism, 2 males and 1 female, age = 31–61 years	Examined the experiences of individuals with ASD	Data collected via meetings and interviews	Thematic analysis	Themes identified: ASD identity, support systems, and strong opinions	Self, others, employment
16. Huws and Jones, 2008 (Wales)	9 adolescents with autism, 6 males and 3 females, age = 16–21 years	Examined experiences related to diagnosis and disclosure	Data collected via interviews	Phenomenological analysis	Themes identified: Disclosure delay, explanations, labeling, disruptions and opportunities, and acceptance and avoidance	Self, others
17. Jones, Quigney, and Huws, 2003 (England)	5 individuals with autism, 3 males and 2 females, no ages provided	Examined the sensory experiences of individuals with ASD	Data collected via websites	Categorical analysis	Categories identified: Negative sensory experiences, coping, positive sensory experiences, and awareness of being different	Self, others, school
18. Jones, Zahl, and Huws, 2001 (England)	5 individuals with autism, 4 males and 1 female, no ages provided	Examined the emotional experiences of individuals with ASD	Data collected via websites	Categorical analysis	Categories identified: Alienation, frustration, depression, and fear or apprehension	Self, others
19. Krieger, Kinebanian, Prodingier, and Heigl, 2012 (Switzerland)	6 adults with Asperger syndrome, 4 males and 2 females, age = 30–45 years	Examined the experiences of individuals with Asperger syndrome in the competitive workforce	Data collected via interviews	Thematic analysis	Themes identified: Socially secure, social environments, cultural competence, feeling protected or offended, and receiving and disclosing diagnosis	Others, school, employment
20. MacLeod, Lewis, and Robertson, 2013 (England)	6 adults with autism or Asperger syndrome, involved in higher education	Examined how individuals with ASD made meaning of their diagnostic label	Data collected via interviews	Thematic analysis	Themes identified: Perception of others, acquired knowledge of ASD, and personal identification with ASD	Self, others
21. Marks, Scharader, Longaker, and Levine, 2000 (United States)	3 adolescents with Asperger syndrome, age = 13–15 years	Examined the experiences of individuals with Asperger syndrome	Data collected via interviews	Thematic analysis	Themes identified: Interests, school life, and social life	Self, others, school
22. Müller, Schuler, and Yates, 2008 (United States)	18 adults with ASD, 13 males and 5 females, age = 18–62 years	Examined social challenges and supports among individuals with ASD	Data collected via interviews	Thematic analysis	Major themes identified included intense social isolation, communication difficulties, and desire to contribute to community	Self, others, employment
23. Müller, Schuler, Burton, and Yates, 2003 (United States)	18 adults with ASD, 13 males and 5 females, age = 18–62 years	Examined the experiences of individuals with ASD in the workplace	Data collected via interviews	Thematic analysis	Major themes identified: Diverse vocational interests, patterns of unemployment and under-employment, negative work experiences, and exceptions to the rule	Employment
24. Penney, 2013 (Canada)	9 adolescents with ASD, 8 males and 1 female, age = 16–21 years	Examined the experiences of individuals with ASD who had a co-occurring depressive and/or anxiety disorder	Data collected via semistructured interviews	Thematic analysis	Themes identified: Behavior intervention, early identification of learning and sensory issues, prevention of victimization, and mental health	Others, school
25. Portway and Johnson, 2005 (England)	25 adults with Asperger syndrome, 21 males and 4 females, age = 18–35 years	Examined the experiences of a "non-obvious disability"	Data collected via interviews	Thematic analysis	Themes identified: Everyday risks and longer term risks	Self, others, school, employment
26. Preece and Jordan, 2010 (England)	14 children with ASD, 10 males and 4 females, <i>M</i> age = 13 years	Examined the experiences of individuals with ASD in respect to daily life and social support	Data collected via interviews	Thematic analysis	Themes identified: Positive attitude to family life, lack of awareness of impact on family, isolation, and problems at school	Self, others, school
27. Punshon, Skirrow, and Murphy, 2009 (England)	10 adults with Asperger syndrome, 7 males and 3 females, age = 21–44 years	Examined the psychological reactions to a diagnosis of Asperger syndrome	Data collected via interviews	Thematic analysis	Themes identified: Negative life experiences, experiences of services, beliefs about symptoms, identity formation, effects of diagnosis on beliefs, and societal views	Self, others
28. Rosqvist, 2012 (Sweden)	12 adults with Asperger syndrome, 3 males and 9 females, age = 18 years and older	Examined how adults with Asperger syndrome viewed their diagnostic label	Data collected via ethnographic fieldwork	Thematic analysis	Themes identified: Receiving the diagnosis, ambivalent ideal of openness, contesting holders of knowledge, and contesting diagnostic criteria	Self, others

(continued)

Table 1. (continued)

Author, year (country)	Sample characteristics	Objective	Method	Analysis	Main findings	Themes
29. Rossetti, Ashby, Arndt, Chadwick, and Kasahara, 2008 (United States)	8 adults with ASD, 6 males and 2 females, all participants typed on a computer to communicate	Examined the experiences of individuals with ASD who were developing independent typing skills	Data collected via open-ended interviews and participant observation	Phenomenological analysis	Findings identified: Troubling independence, recognizing agency, and expressing agency	Self, others, school
30. Sagers, Hwang, and Mercer, 2011 (Australia)	9 adolescents with ASD, 7 males and 2 females, age = 13–16 years	Examined the experiences of individuals with ASD at school	Data collected via interviews	Categorical analysis	Categories identified: Teacher characteristics, curriculum issues, support mechanisms, friendships, environmental considerations, and teasing and bullying	Self, others, school
31. Smith and Sharp, 2012 (England)	9 adults with Asperger syndrome, 6 males and 3 females, age = 25–49 years	Examined sensory processing among individuals with Asperger syndrome	Data collected via interviews	Categorical analysis	Categories identified including heightened senses, sensory stress, and fascination for stimuli	Self, others, school, employment
32. Volkmar and Cohen, 1985 (United States)	1 adult male with ASD, age = 22 years	Examined the experiences of an individual with ASD	Data collected via narrative	Narrative Analysis	Narratives examined areas including family, school, work, and friendships	Self, employment
33. Zukauskas, Silton, and Baptista, 2009 (Brazil)	15 adolescents with Asperger syndrome, 14 males and 1 female, age = 13–20 years	Examined temporality among individuals with Asperger syndrome	Data collected via interviews	Thematic analysis	Themes identified: Factual experience of present and future dimensions, chronological time, and past experience	Self, others, school

Note. ASD = Autism spectrum disorder.

and challenging situations), and factors related to employment (benefits and drawbacks). Representative quotations from each theme are provided in Table 2.

Theme 1: Perception of Self

Twenty-six studies involved themes related to self where individuals with ASD discussed issues related to their identity, interests, and coping skills (see Studies 1–3, 5, 8–13, 15–18, 20–22, 25–33 in Table 1).

Identity. Individuals with ASD described a range of effects associated with their disorder and their sense of self (Calzada et al., 2011; Humphrey & Lewis, 2008; Portway & Johnson, 2005). Some felt indifferent, such that they did not want to understand the meaning of ASD (Calzada et al., 2011) or be associated with others who shared their disorder (MacLeod, Lewis, & Robertson, 2013). Others felt a sense of pride as their condition became an integral part of their identity (Hughes, 2012; MacLeod et al., 2013; Rosqvist, 2012). One individual with ASD explained, “autism is much more a part of someone’s identity in the same way that someone’s gender is or someone’s sexuality” (MacLeod et al., 2013, p. 43).

Particularly, the adults with ASD spoke about acceptance, such that they could not imagine their life without this disorder (Humphrey & Lewis, 2008; Hurlbutt & Chalmers, 2002). Others expressed relief because being diagnosed with ASD provided answers to questions they had about themselves (Haertl, Callahan, Markovics, &

Sheppard, 2013; Huws & Jones, 2008; Punshon et al., 2009; Rosqvist, 2012). Still yet, some described the negative effects on their sense of self (Portway & Johnson, 2005).

Some individuals with ASD felt devastated and helpless because they perceived their disorder as lifelong (Haertl et al., 2013), whereas others wanted to be made normal (Humphrey & Lewis, 2008). Many reported feeling different from others (Calzada et al., 2011; Griffith, Totsika, Nash, & Hastings, 2011; Jones, Zahl, & Huws, 2001; Müller, Schuler, & Yates, 2008) and this led to an internal conflict (Griffith et al., 2011). One person explained, “I can wear this mask that I used to wear when I used to have to deal with people . . . and it’s exhausting” (Griffith et al., 2011, p. 538). In a study of individuals with ASD who communicated via computer, they described the importance of establishing independence from others by typing with fewer physical supports, such as supporting their wrists when typing (Rossetti, Ashby, Arndt, Chadwick, & Kasahara, 2008).

Interests and talents. People with ASD said they thought and behaved in ways that were different from others (MacLeod et al., 2013; Marks, Scharader, Longaker, & Levine, 2000; Zukauskas, Silton, & Baptista, 2009). These peculiarities were sometimes based on repetitive and restrictive interests that ultimately shaped their personality. For example, “I like to take apart stuff . . . VCRs, TVs, stereos, tape recorders, anything that has to do with electricity” (Marks et al., 2000, p. 6). Sometimes these interests developed into talents or aspects of themselves they were proud of including music and attention to detail (Cesaroni &

Table 2. Representative Quotations From Themes.

Theme	Quotation
Perception of self	<p>“I’m not that interested [in the meaning of the diagnosis]” (Calzada, Pistrang, & Mandy, 2011, p. 235).</p> <p>“I lack self confidence, I don’t like myself, I always look in the mirror and think I’m not good looking enough or too short . . . I’m always looking at other people wishing I was them . . . I feel different” (Portway & Johnson, 2005, p. 80).</p> <p>“I know that I can do things they [neuro-typical people] can’t . . . I could actually read the building spec, go through the plans, and then put it together in my head, and I’d find faults and problem” (Griffith, Totsika, Nash, & Hastings, 2011, p. 538).</p>
Interaction with others	<p>“I started using alcohol to mask the illness” (Punshon, Skirrow, & Murphy, 2009, p. 275).</p> <p>“I remember feeling quite uncomfortable around people, straight away. I realised I was not right. It was just a sort of vague uncomfortable feeling that grew and grew” (Portway & Johnson, 2005, p. 80).</p> <p>“One thing that I like is that if we have the same interests” (Daniel & Billingsley, 2010, p. 226).</p> <p>“at the bottom of a remote abyss, removed from everything, and not developing the normal peer relationships I perceived everybody else as experiencing” (Müller, Schuler, & Yates, 2008, p. 179).</p> <p>“I think if you’re going to get support . . . unless you’re talking to somebody who is a real expert with Asperger’s, you’re going to end up doing more damage than not speaking to somebody” (Griffith et al., 2011, p. 541).</p>
Experiences at school	<p>“I get on with the majority of my teachers” (Humphrey & Symes, 2010, p. 87).</p> <p>“It’s hell. It would help if teachers realize a lot of sensory and social aspects of high school can directly impact the work in school. Very negatively in some cases, at least mine” (Penney, 2013, p. 86).</p> <p>“If they were following me then the other students know that there’s something different about me and I don’t like it at all” (Humphrey & Lewis, 2008, p. 38).</p> <p>“Everything was so busy at school, everyone else seemed to know what they were doing, but not me. I was always out of sync, always in the wrong place, late for lessons” (Portway & Johnson, 2005, p. 77).</p>
Factors related to employment	<p>“The years roll by, and I stumble from one job situation to another, and nothing consummated into a promotion or career type move” (Müller, Schuler, Burton, & Yates, 2003, p. 166).</p> <p>“I worked for 13 years at the post office. The relationships with people are straightforward and the tasks are well defined. . . . Everything followed a routine, and the expectations of everyone were clear” (Krieger, Kinebanian, Prodinger, & Heigl, 2012, p. 150).</p> <p>“It’s interacting . . . they come up to you and start asking you questions about your problems . . . I may make a comment, I may do something inappropriate and it builds up and then the employer . . . usually it leads to a reason for dismissal” (Griffith et al., 2011, p. 539).</p> <p>“I am not ashamed to talk about being an Asperger. But as long as the word ‘autistic’ is used as an insult, I don’t believe in progress after disclosure” (Krieger et al., 2012, p. 151).</p>

Garber, 1991; Gulec-Aslan, Ozbey, & Yassibas, 2013; Jones et al., 2003). For some, these talents led others to form stereotypes about what it meant to have ASD and, in turn, who they should be (MacLeod et al., 2013). These interests also led to a strong need for routine in their daily lives (Carrington & Graham, 2001).

Coping skills. Individuals with ASD spoke about having to deal with ongoing anxiety (Griffith et al., 2011; Portway & Johnson, 2005). For instance, “It varies from day to day, in all honesty . . . Some days I’m very much more anxious than on other days . . . anxiety is more or less permanent anyway” (Griffith et al., 2011, p. 537). Some coped with their stress by increasing their self-awareness (Müller et al., 2008), whereas others relied on alcohol (Müller et al., 2008; Punshon et al., 2009; Smith & Sharp, 2012). Some individuals withdrew socially and preferred to spend their time alone (Humphrey & Symes, 2010; Jones et al., 2003; Preece & Jordan, 2010; Punshon et al., 2009; Saggars et al., 2011;

Smith & Sharp, 2012; Volkmar & Cohen, 1985). One individual with ASD explained, “I think that being with other people is the biggest cause of stress. I can enjoy their company to an extent but I like to be able to leave, and I do live alone” (Smith & Sharp, 2012, p. 900).

Compared with typically developing individuals, those with ASD were more likely to report “actual harm” as a source of stress, such as being hit by a classmate (Browning et al., 2009, p. 39). They were also more likely than typically developing individuals to solve problems on their own (instead of seeking outside help) and perceived themselves as being less capable of managing their problems (Browning et al., 2009).

Theme 2: Interaction With Others

Twenty-nine studies involved themes related to interaction with others, which involved the way family, friends, and experts in the field were perceived as viewing those with ASD (see Studies 1–12, 15–22, 24–31, 33 in Table 1).

Family. Individuals with ASD said their family was a main source of social support (Gulec-Aslan et al., 2013; Hurlbutt & Chalmers, 2002; Krieger, Kinebanian, Proding, & Heigl, 2012). This support came in the form of family providing individuals with ASD with the opportunity to socialize (Gulec-Aslan et al., 2013; Zukauskas et al., 2009). For example, “It’s a big trouble that you cannot be a social person . . . I can’t come together with anyone. The people you mostly come together are your family” (Gulec-Aslan et al., 2013, p. 80). Other support from family involved parents accepting their children with ASD as being different (Krieger et al., 2012) and providing affection (Preece & Jordan, 2010). Others spoke about the negative effect their disorder had on their family, including parents and siblings (Penney, 2013). Some found they could not talk to some family members about their condition (Punshon et al., 2009). Those who relied on a computer to communicate also experienced misunderstandings with family members (Rossetti et al., 2008).

Friends. Individuals with ASD had mixed experiences with friends, such that some had positive experiences (Daniel & Billingsley, 2010) and some had negative experiences (Calzada et al., 2011; Carrington & Graham, 2001; Connor, 2000; Hughes, 2012; Marks et al., 2000). One aspect that was very important to friendship was sharing interests, such as playing video games (Daniel & Billingsley, 2010). Particularly, the children with ASD spoke about their teachers also being their friends (Calzada et al., 2011). For those who found making friends difficult, they spoke about issues with understanding social cues (Carrington & Graham, 2001; Cesaroni & Garber, 1991) and processing sensory information including sensitivity to touch (Jones et al., 2003; Smith & Sharp, 2012). Many individuals with ASD reported being bullied or teased by their classmates (Connor, 2000; Gulec-Aslan et al., 2013; Haertl et al., 2013; Humphrey & Lewis, 2008; Huws & Jones, 2008; Penney, 2013; Portway & Johnson, 2005; Preece & Jordan, 2010; Punshon et al., 2009; Saggars et al., 2011) and felt socially isolated (Cesaroni & Garber, 1991; Müller et al., 2008). For instance, “I almost feel like I’m on a different planet” (Müller et al., 2008, p. 179).

Some individuals with ASD reported that the bullying from peers was worse for males than females (Punshon et al., 2009). Some found comfort in those who shared their diagnosis (Jones et al., 2001; Punshon et al., 2009), whereas others found support from church or community groups (Müller et al., 2008). Interestingly, many individuals with ASD could not define friendship or distinguish between friends and acquaintances (Carrington, Templeton, & Papinczak, 2003). Particularly, the adolescents with ASD were concerned about transitioning from school, such that they worried about losing friendships after they graduated, whereas typically developing adolescents worried about their education (Browning et al., 2009). Some adolescents

with ASD also expressed an interest in dating (Marks et al., 2000; Zukauskas et al., 2009).

Experts in the field. Some individuals with ASD had positive experiences with health care workers and believed they were receiving appropriate treatment for their disorder (Griffith et al., 2011). Others expressed a lack of trust for these workers because they believed they did not understand their disorder (Griffith et al., 2011). Particularly, the adults with ASD expressed dissatisfaction over doctors and researchers being seen as the only experts (MacLeod et al., 2013; Rosqvist, 2012). To illustrate, “There’s still a certain kind of mentality that ‘this is something for the experts to take care of’” (Rosqvist, 2012, p. 124).

Theme 3: Experiences at School

Seventeen studies involved themes related to school where individuals with ASD outlined their experiences with the curriculum and challenging situations in this setting (see Studies 3, 6, 9–13, 17, 19, 21, 24–26, 29–31, 33 in Table 1).

Curriculum. Some people with ASD had difficulties with the curriculum, including tight deadlines for assignments and managing a heavy workload (Carrington & Graham, 2001; Saggars et al., 2011). Other issues involved handwriting, such that they had difficulty taking notes or writing tests (Krieger et al., 2012; Penney, 2013; Saggars et al., 2011). Some said they were bored or disinterested in the subject and this affected their attitude about school (Connor, 2000; Marks et al., 2000). Others said they learned best when they had a choice of activity (Connor, 2000) or the activity was hands-on, such as experiments (Marks et al., 2000). Those who communicated using their computer were concerned about keeping up with classmates, particularly to show their knowledge to others (Rossetti et al., 2008). Some individuals with ASD spoke about the critical role of having understanding teachers (Connor, 2000; Gulec-Aslan et al., 2013; Humphrey & Symes, 2010) and receiving adequate support in the classroom (Hughes, 2012; Humphrey & Lewis, 2008; Saggars et al., 2011).

Other students felt they were not receiving enough specialized services, such as to facilitate school to work transition (Haertl et al., 2013) and struggled to understand the information provided by teachers (Jones et al., 2003; Penney, 2013; Preece & Jordan, 2010). For instance, “There is a teacher who talks really quickly, and I find it hard to understand” (Preece & Jordan, 2010, p. 14). Particularly, the adolescents with ASD spoke about how they would prefer if the help provided by teachers was done discreetly to not attract attention from their classmates (Saggars et al., 2011). Others looked forward to graduating from high school and continuing their schooling at the post-secondary level (Zukauskas et al., 2009).

Challenging situations. Some individuals with ASD spoke about the hallway at school as presenting challenging situations (Humphrey & Lewis, 2008). For example, “Sometimes it does bother me because sometimes there can be a lot of pushing and shoving including the corridors because they are small” (Humphrey & Lewis, 2008, p. 37). Others experienced sensory processing issues, such as not being able to work in the classroom because of the noise level (Humphrey & Lewis, 2008; Penney, 2013; Portway & Johnson, 2005; Preece & Jordan, 2010; Smith & Sharp, 2012). Changes to routines at school also caused anxiety among those with ASD, such as when a taxi driver took a different route and was late to pick up a student with ASD (Humphrey & Lewis, 2008). Free time at break or lunch was particularly challenging for some individuals with ASD. One individual with ASD explained, “It’s worse than in class because in class you are busy—I try to stay away from other people” (Connor, 2000, p. 290). Not surprisingly, those with ASD struggled to assimilate themselves to their school environment (Humphrey & Lewis, 2008).

Theme 4: Factors Related to Employment

Twelve studies involved themes related to employment where individuals with ASD identified benefits and drawbacks to work (see Studies 5, 8, 10–11, 14–15, 19, 22–23, 25, 31–32 in Table 1).

Benefits. Some people with ASD succeeded in the workplace because they had found a career that matched their interests (Krieger et al., 2012; Müller et al., 2003). For example, “My professional success can be explained in the choice of an introverted profession in a technical field and a knowledge-intensive environment” (Krieger et al., 2012, p. 149). Others found a career where their sensory problems enhanced their work performance, such as an individual with ASD becoming a great chef because of his taste sensitivities (Smith & Sharp, 2012). Some spoke about the larger meaning of work, such that it provided an opportunity to give back to society (Müller et al., 2008). Others were dissatisfied with their work environment but had learned to accept it for now (Krieger et al., 2012). Some individuals spoke about the importance of a tolerant workplace, such that their coworkers did not condemn them for their behavior (Krieger et al., 2012; Müller et al., 2003). Other individuals stressed the importance of having job mentors to help them to connect to positions where they would be successful (Hurlbutt & Chalmers, 2002, 2004; Müller et al., 2003).

Drawbacks. Some drawbacks identified by individuals with ASD involved the job application process, such as creating a resume or contacting potential employers (Müller et al., 2003). Other issues involved being unemployed, underemployed, and lacking opportunities for training and career

advancement (Griffith et al., 2011; Haertl et al., 2013; Hurlbutt & Chalmers, 2004; Müller et al., 2003; Portway & Johnson, 2005; Volkmar & Cohen, 1985). Problems also occurred in social communication, such as with supervisors and customers (Cesaroni & Garber, 1991; Griffith et al., 2011; Haertl et al., 2013; Hughes, 2012; Hurlbutt & Chalmers, 2004; Müller et al., 2003), which led some to be fired from their position (Griffith et al., 2011). One individual with ASD explained, “It is not that we do not work hard, or have problems with being prompt, not being on time, or unwilling . . . It is that we are not very good at dealing with people in social situations” (Hurlbutt & Chalmers, 2004, p. 218). Some chose to disclose their disorder to people at work, whereas others did not for fear of being stigmatized (Krieger et al., 2012). Some reportedly needed hours to unwind when they got home because of the stress they experienced at work (Griffith et al., 2011; Hughes, 2012; Hurlbutt & Chalmers, 2004).

Discussion

This article synthesized the qualitative research about the lived experiences of individuals with ASD. We identified four themes: perception of self, interaction with others, experiences at school, and factors related to employment. In the first theme, we found individuals with ASD experienced a range of effects associated with their disorder and their identity. Some did not want to understand the implications of their disorder, whereas others struggled with it, especially in adolescence. Interestingly, many adults reported accepting their disorder, such that they could not imagine their life without ASD. The mixed responses related to identity formation in ASD are consistent with research about other disability groups, including those with a visible disability (e.g., Bellin, Sawin, Roux, Buran, & Brei, 2007; Kinavey, 2007). These findings are also consistent with reports from parents of children with ASD who described a grieving process after their child was diagnosed, which for some ended with acceptance of their child’s disorder (DePape & Lindsay, 2014). The repetitive and restrictive interests displayed by those with ASD also shaped their identity. Critically, making use of these interests in the workplace was identified as a success factor for adults with ASD who were involved in employment (Krieger et al., 2012). These special interests should be communicated to high school guidance counselors so that students with ASD can begin early on to explore career paths they might enjoy. Finally, we found the anxiety experienced by those with ASD was related to feeling different from others and this led to some potentially maladaptive coping, such as withdrawing socially or relying on alcohol. These findings are consistent with research involving other disability groups (e.g., Hartley & MacLean, 2008; Lindsay, 2014) and show the importance of developing good coping skills to manage stress.

In the second theme, we found that individuals with ASD had mixed experiences in their relationship with others. Starting with family, individuals with ASD reported they were an important source of social support, but acknowledged that their disorder affected family dynamics. These findings are consistent with previous research on parents' experiences of raising a child with ASD showing that this disorder affects the entire family, including the relationship between spouses and between siblings (e.g., Gray, 2003; Hutton & Caron, 2005). Friends were another important component of the lived experience of individuals with ASD. Some had friends at school while others reported being teased or bullied by their classmates. Interestingly, some males with ASD reported that the bullying was worse for boys, which may point to a gender difference in the lived experiences of individuals with ASD. This result is consistent with other research showing that girls still engage in aggression; however, it is typically more relational than physical in nature (Crick & Grotpeter, 1995). Not surprisingly, many individuals with ASD felt different compared with their classmates, with this feeling heightened when teachers provided extra help to them in the classroom. This was particularly true for adolescents with ASD and so it is important for teachers to be aware that the self-consciousness associated with adolescence may be stronger than normal among those with a disability. With respect to experts in the field, some individuals with ASD were dissatisfied over being seen as secondary to their own disorder. Particularly, in the case of adults with ASD, they spoke about wanting to be seen as experts. This experience is consistent with the traditional medical model where doctors are gatekeepers of knowledge and patients are passive to the care they receive (Weinstein, 2001). With patients now exposed to medical information from multiple sources, including their own experiences, individuals with ASD need to be included in the planning and implementation of their care.

In the third theme, school was an important element in the lived experience of individuals with ASD. Some teachers played a critical role to individuals with ASD by providing them with much needed support in the classroom. However, some teachers were perceived as lacking an understanding of ASD, which is consistent with other research on this topic (Lindsay, Proulx, Scott, & Thomson, 2014). Some individuals with ASD had issues related to the curriculum, such as problems with time management or feeling bored with the material. These problems are consistent with research about giftedness, such that students may feel disinterested in their learning because they are not intellectually stimulated (Diezmann & Watters, 1997). Critically, in the case of those with ASD, some may have exceptional talents, such as in music or math that may be classified at the savant level (Heaton & Wallace, 2004). It is important that educators are aware of this potential when working with individuals with ASD so they may maintain

interest levels in school. Besides the curriculum, individuals with ASD described challenging situations at school, such as crowded hallways and noisy classrooms. These problems are documented in other research reporting sensory and perceptual problems among those with ASD (DePape, Hall, Tillmann, & Trainor, 2012; Kern et al., 2006). Educators need to be aware of these processing issues, especially because students with these problems may be perceived as misbehaving when in fact they cannot process sensory information.

Work was an important factor in the lived experience of ASD, particularly finding a job that matched their interests and skill sets. In this last theme, we found that individuals with ASD were particularly well suited for some jobs and it is in these jobs that they had the most success. In a book by Temple Grandin who herself has ASD, she lists the jobs that some individuals with ASD might enjoy based on how this disorder affects thinking (Grandin & Duffy, 2008). That is, visual thinkers with ASD may be well suited for being a photographer, web designer, or auto mechanic, whereas non-visual thinkers with this disorder may be well suited for being a researcher, engineer, or electrician (Grandin & Duffy, 2008). Although remediation is critical, this approach to employment shows the importance of tapping into existing interests and skill sets among individuals with ASD. With respect to the drawbacks associated with work, adults with ASD reported unemployment or under-employment as well as a lack of opportunity for career advancement. The social aspects of a job were also challenging, such as interacting with supervisors and customers, which led to some workers with ASD being fired. Critically, employment readiness programs need to focus on social skill development as these skills appear to be the ones that individuals with ASD struggle with the most at work. Finally, individuals with ASD struggled with disclosure, with some choosing to disclose their condition to people at work while others did not for fear of being stigmatized. This finding is consistent with other research and may depend on the nature of the disability and whether they believe disclosure will improve their experience at work (Lindsay, Mcdougall, & Sanford, 2013).

One area of future research and policy development involves finding ways to facilitate the transition from high school to post-secondary education and employment among individuals with ASD. This was an area that was under-represented in our review, but we found one study showing individuals with ASD having different concerns than their typically developing peers (Browning et al., 2009). That is, those with ASD were concerned about losing relationships after they graduated, whereas those with typical development were concerned about their education (Browning et al., 2009). Thus, individuals with ASD need to be educated about their options after graduating from high school, such as continuing their education or entering into the

workforce. This is critical given the low participation rates among those with ASD in post-secondary education and paid employment after graduation (Shattuck et al., 2012).

Another area for future research involves more focus on the lived experiences of children and adolescents with ASD. This age group was under-represented in our review. More research is also needed to examine the positive lived experiences among young people with ASD as opposed to focusing on negative experiences. Many of the children and adolescents with ASD in the studies included in this review focused on their experiences with bullying and other forms of social victimization. Finally, more work is needed to understand experiences and perspectives of living with ASD and how this varies by gender, age, disorder severity, and other socio-demographic factors.

It is important to note the limitations of this review. First, it is based mostly on the perspective of males with ASD. Although the sex ratio for this disorder is 4:1 (Fombonne, 2005), this ratio was not always reflected in the articles included in this review. Second, the majority of our samples involved individuals with high-functioning ASD who were able to verbally report their experiences with this disorder. Future studies should examine the perspectives from all individuals with ASD to ensure their experiences are representative. Third, limited information was provided about the cultural backgrounds and socio-economic contexts of the samples included in this article. Thus, more research is needed to understand how lived experiences might be shaped by disability and culture. Finally, the majority of the articles included in this review were published in the last 6 years. However, our understanding of ASD has changed since then, including the removal of the diagnostic criteria for Asperger syndrome, which some individuals were diagnosed with in our samples. More research exploring the lived experiences of those with ASD is needed, especially as our understanding of this disorder changes over time.

Our synthesis examined the experiences of individuals with ASD across different areas of life, including school and work. The review explored how these experiences were shaped by their development in childhood, adolescence, or adulthood. The findings inform our understanding of the successes and the challenges at key stages of development so that individuals with ASD, their families, and health care providers can be better prepared. Although there is a need for research on the lived experiences of ASD, our synthesis highlights that children and adolescents are under-represented in the literature, and thus, is an area for future research.

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