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Parents' Experiences of Caring for a Child With Autism Spectrum Disorder

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Abstract

Autism spectrum disorder (ASD) is a developmental disorder involving abnormal communication, repetitive and restrictive interests, and impaired social functioning. ASD can have a profound impact on family life, including the roles and responsibilities that parents assume. In this metasynthesis, we explore the experiences of parents who care for a child with ASD. We undertook a thematic synthesis to integrate qualitative evidence, searching 10 electronic databases and reviewing 4,148 abstracts. We selected 31 articles for inclusion (involving 160 fathers and 425 mothers) and examined the articles using a constant comparative approach. We identified six themes: prediagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward. Our findings can inform the development of programs and services for families, provide insight for health care workers who advocate on behalf of parents, and provide valuable information to parents, particularly those of children newly diagnosed with ASD.

Keywords

autism; caregivers / caregiving; families; parenting; qualitative analysis; systematic reviews

Autism spectrum disorder (ASD) involves abnormal communication, repetitive and restrictive interests, and impaired social functioning (American Psychiatric Association, 1994). Given the nature of this disorder, parents face some unique challenges as caregivers. For example, the symptoms of ASD persist across the lifespan (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004), requiring parents to devote significant time to caregiving. The behavioral deficits displayed by individuals with ASD can be difficult for parents to manage. Those with ASD are less able to express what they want (Peppé, McCann, Gibbon, O'Hare, & Rutherford, 2007) or might become upset when routines are disrupted (DeGrace, 2004). Individuals with ASD can also have a secondary diagnosis, such as epilepsy or intellectual impairment (Fombonne, 2003), which can make parenting challenging and render experiences across parents highly variable. Not surprisingly, parents of children with ASD experience higher stress levels than parents of children without ASD (Sivberg, 2002). Understanding their experiences is critical because it provides a glimpse into daily family realities and the ways that ASD can impact parent–child dynamics.

Parents of children with ASD face challenges both at home and in the community. Compared to parents of children without ASD, they are at heightened risk of financial strain (Jarbrink, Fombonne, & Knapp, 2003) and poor physical and mental health (Allik, Larsson, & Smedje, 2006); they are also likely to experience higher divorce rates (Hartley et al., 2010). In the community, they might have to pay out of pocket for services or drive long distances to access treatment facilities (Fletcher, Markoulakis, & Bryden, 2012). Consequently, some might need to relocate their family or make career changes to ensure they are able to cover the costs associated with services. Health care professionals need to be aware of such issues and how they might impact a parent's ability to care for his or her child with ASD.

In this article, we synthesize and critically interrogate the qualitative research on parents' experiences of caring for a child with ASD. Qualitative research allows investigators to explore the experiences of individuals and develop a rich understanding of social phenomena (Tong, Morton, Howard, & Craig, 2009). It helps them understand phenomena that cannot be quantitatively measured and allows them to report experiences "from the participant's

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point of view rather than as an expert who knows more about the experience than those living it" (O'Day & Killeen, 2002, p. 10). Metasyntheses of qualitative research allow investigators to uncover patterns and develop a deeper appreciation of a topic than can be gained from a single study (Erwin, Brother-son, & Summers, 2011). To our knowledge, no previous authors have published a metasynthesis on this topic.

Qualitative research findings can inform evidence-based practice (Grypdonck, 2006), which is important for ensuring quality of care to individuals with ASD and their families. Parents have expert knowledge that can inform our understanding of ASD and how this disorder impacts family life. They also play a critical role in mediating the relationship between their child and health care workers. As such, their knowledge can inform family-centered models of care and help researchers identify gaps in programs and services available to individuals with ASD and their families. With this in mind, we aimed to examine the challenges and benefits of caregiving from the perspective of parents throughout the family life cycle.

Theoretical Perspective: The Family Life-Cycle Model

The Family Life-Cycle Model is a theoretical pers-pective that can help researchers and health care professionals situate parents' experiences in context (Carter & McGoldrick, 1988). It can help them understand how families develop in response to challenges at each stage of the model, including single young adults leaving home, families joining through marriage, families with young children, families with adolescents, launching children, and families in later life. Similar developmental models have previously been applied in research among families of a child with a disability (Bennett, DeLuca, & Allen, 1996).

The Family Life-Cycle Model prompts researchers to explore how parents of a child with a disability have concerns that might change from one stage to another (Carter & McGoldrick, 1988). For example, during the "families with young children" stage, parents of a child with ASD might feel sadness and disappointment about their child's diagnosis and guilt for having such feelings. In the "families with adolescents" stage, they might face issues with peer groups and accessing learning oppor-tunities for their child at school. Moreover, although researchers have found that families of children with a disability experience similar challenges as other families, those challenges are often magnified (Miller, Gordon, Daniele, & Diller, 1992). Depending on the nature of a child's disability, some stages of the Family Life-Cycle Model—such as "launching children"—the stage at which individuals move out of the family home to exercise their independence—might occur later than typically expected or not at all (Farley et al., 2009). It is critical that researchers and health care workers consider parents' positions within this model and how challenges at different stages might affect caregiving.

Methods

Search Strategy

We developed a search strategy in consultation with a hospital librarian. We searched the following databases for relevant articles: CINAHL, MEDLINE (OVID), Healthstar, PubMed, EMBASE, Web of Science, PsychInfo, Social Science Citation Index, Scopus, and Google Scholar. We used the following subject headings and search terms to identify potential articles for inclusion: autism spectrum disorder, Asperger, parents, parenting, mother, father, family, experience, psychological or sociological concepts (i.e., lived experience, coping, adaptation, quality of life), qualitative research, focus group, ethnography, phenomenology, grounded theory, and hermeneutics. After our initial search, we also man-ually reviewed the reference lists of selected articles.

Using this search strategy, we aimed to identify peer-reviewed articles published between 1980 and 2013 that were focused on the experiences of parents of children with ASD. Articles selected for inclusion met the following criteria: the child had a primary diagnosis of ASD (e.g., autistic disorder, Asperger syndrome, high-functioning autism, or pervasive developmental disorder not otherwise specified); the diagnosis did not include comorbid symptoms, reflecting our focus on ASD as a primary diagnosis; the majority of the sampled children were 18 years of age or younger; the majority of the sampled children had a diagnosis of ASD; the children were living in the parental home; the authors focused on parents' experiences in the form of benefits and/or challenges of caring for a child with ASD; and the researchers employed qualitative design for data collection and analysis (for the primary approach of the study). We excluded unpublished work and articles that contained only quantitative data, opinions, editorials, or case studies.

The second author and a hospital librarian conducted the initial literature search, identifying 4,148 articles for potential inclusion. Next, the second author and a research assistant reviewed the titles and abstracts of those articles. After removing duplicates and applying the inclusion criteria, the first author read 125 selected articles in full, in consultation with the second author. Both authors agreed that 31 articles met the inclusion criteria. After manually searching the reference lists of those selected articles, we identified no additional articles for inclusion. We did not require ethics approval to conduct this study because we performed no experimental testing and we

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synthesized parents' experiences from previously published works.

Analytical Approach for Review and Synthesis

After reading each article selected for inclusion, the first author summarized the key attributes of each study. She abstracted and compiled the reported data, which the second author independently verified, using a structured abstraction form based on previous research (Tong et al., 2009). Then we applied a thematic analysis to independently group findings by topic. To synthesize our findings, we drew on narrative synthesis guidelines developed by Petticrew and Roberts (2005). First, we organized the studies into categories (Petticrew & Roberts). We used a lumping approach to create broad categories based on the domains (e.g., family, career, health, school, and community) in which parents reported experiencing challenges and/or benefits to caregiving. We also drew on the Family Life-Cycle Model (Carter & McGoldrick, 1988) to inform these broad categories, focusing on the experiences and challenges faced by parents at particular stages of family development. Next, we analyzed the findings grouped within each category (Petticrew & Roberts). We identified subcategories that allowed us to examine each category in more detail; for example, under the "family" category, we identified subcategories including "impact on spouses," "finances and career," and "impact on siblings."

Finally, we synthesized the findings across all included studies, which differed with respect to their stated research purpose (Petticrew & Roberts, 2005). Some studies examined general parenting experiences, such as challenges and benefits of caregiving; others examined specific parenting experiences, such as managing behavior problems associated with ASD. Despite these differences in research purpose, we found that parents' reported experiences of caring for a child with ASD were remarkably similar across studies. Parents described how their lives had changed as a result of the diagnosis, and in turn the impact it had on multiple areas of their lives. Ultimately, it was this similarity across studies that allowed us to synthesize a large number of articles on this topic.

During our final stage of synthesis, the first author reread all of the articles selected for inclusion using a constant comparison approach to map out themes (Saini & Shlonsky, 2012). Through this synthesis, we identified six emergent themes: prediagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward. We found that all of the articles selected for inclusion contributed to these themes, allowing a range of parental voices to be represented in our review. We recorded representative quotations from each theme.

Quality Appraisal

We appraised the quality of included studies using the Critical Appraisal Skills Programme (2010), which involves 10 checklist items (Critical Appraisal Skills Programme International, 2010; see Supplemental Table S1, available online at qhr.sagepub.com/supplemental). Both authors independently appraised the studies reported in each article. The first author made notes of each checklist item, which the second author verified. We resolved any discrepancies in our analysis through discussion. We found that the quality of the reported research was generally good, and none of the selected articles were excluded from our analysis following quality appraisal, which is consistent with previous research (Petticrew & Roberts, 2005; Sandelowski & Barroso, 2003).

Results

Characteristics of Included Studies

We identified 31 articles meeting our inclusion criteria and passing our quality appraisal (see Supplemental Table S2, available online at qhr.sagepub.com/supplemental). All of the reported studies entailed semistructured interviews as the primary method of data collection. In two cases, the authors reported using a theoretical approach to guide their interpretation of participant responses.

The majority of the reported studies involved parent samples from the United States (n = 9); the remaining involved parent samples from Australia (n = 5), Canada (n = 4), England (n = 2), India (n = 2), Taiwan (n = 2), Turkey (n = 2), Belgium (n=1), China (n=1), Israel (n=1), Saudi Arabia (n=1), and Wales (n=1). In total, the studies engaged 160 fathers and 425 mothers who were caring for a child with ASD. In most of the studies (n = 26), the researchers examined more mothers than fathers because mothers were the primary caregivers, the mothers were single parents, or fathers were unavailable to participate; in four of the studies, the researchers examined an equal number of fathers and mothers; and the remaining study involved more fathers than mothers. Parents ranged in age from 21 to 60 years, and they had between one and five children living at home. For most of the studies (n = 24), authors reported that parents had one child with ASD; for the remaining studies (n = 7), authors reported two or more children with ASD in the same household.

Authors of 10 of the articles reported the ethnic background of participants, with 84.4% identifying as non-Hispanic White, 7.8% identifying as Asian, 3.3% identifying as African American, 0.6% identifying as Hispanic, 0.6% identifying as Arab American, and 3.3% identifying as mixed descent. Authors of 10 articles reported the highest level of education attained

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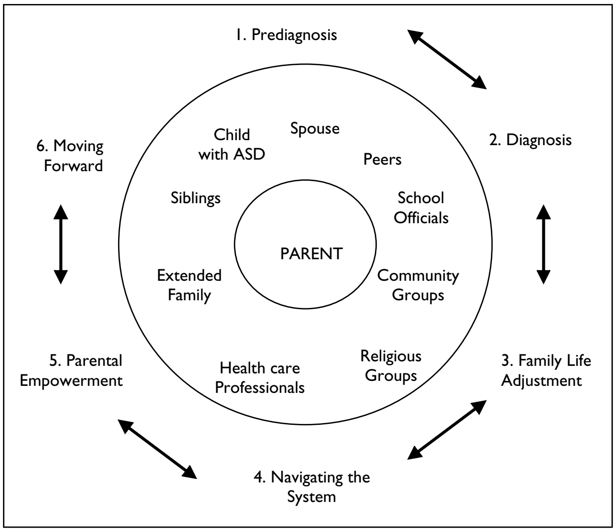

Figure 1. Model of parents' experiences with autism spectrum disorder.
Themes identified in this review were incorporated into our theoretical framework using the Family Life-Cycle Model (Carter & McGoldrick, 1988).

among participants, with 57.4% reporting college or university education, 33.6% reporting high school education, 4.1% reporting grade school education, and 4.9% reporting other schooling. In seven articles the authors reported the socioeconomic status of participants, with 32.0% identifying as upper class, 56.7% identifying as middle class, and 11.3% identifying as lower class. Finally, authors of seven articles reported the marital status of participants, with 96.6% identifying as married, 2.5% identifying as separated, and 0.9% identifying as single.

Parents' Experiences With ASD

Through our synthesis of selected articles, we identified six themes of parental experiences: pre-diagnosis, diagnosis, family life adjustment, naviga-ting the system, parental empowerment, and moving forward (see Supplemental Table S3, available online at qhr.sagepub.com/supplemental). These key themes represent stages or experiences that parents of children with ASD went through, starting with the birth of their son or daughter in the "prediagnosis" stage and ending with their hopes for their son or daughter's future in the "moving forward" stage (see Figure 1). In many cases, these themes map onto one or more stages of the Family Life-Cycle Model (Carter & McGoldrick, 1988), reflecting our theore-tical approach to exploring the ways that parents' experiences were influenced by their child's diag-nosis and the challenges they faced at particular stages of family development. Parents experience each stage in sequential order, but they might cycle backward in the model to re-experience a stage, which is consistent with developmental theory (e.g., Baltes, 1987). We share representative quotations for each theme in Table 1.

Prediagnosis

Six of the selected articles reported data related to prediagnosis. In this stage, parents detected at different points in their child's development that something was wrong and began searching for answers from health care professionals (Altiere & von Kluge, 2009; Desai, Divan, Wertz, & Patel, 2012; Hutton & Caron, 2005; Lasser & Corley, 2008; Midence & O'Neill, 1999; Ryan & Salisbury, 2012). This theme corresponds to the "single young adults leaving home" and "joining of families through marriage" stages of the Family Life-Cycle Model (Carter & McGoldrick, 1988).

Typical development. Some parents reported that their infant did not display any usual behaviors that might be expected among children who are later diagnosed with ASD (Altiere & von Kluge, 2009; Desai et al., 2012). The majority of parents in one study described their children displaying typical behaviors in the first 12 to 18 months after birth (Altiere & von Kluge). One parent said, "As a baby, he was smiling all of the time, frequently making eye contact" (Altiere & von Kluge, p. 144). Some parents expressed their joy and celebration over typical milestones, such as their child's first birthday (Desai et al., 2012).

Atypical development. Other parents disclosed that there was something atypical about their child's early development (Altiere & von Kluge, 2009; Hutton & Caron, 2005; Lasser & Corley, 2008; Midence & O'Neill, 1999; Ryan & Salisbury, 2012). Most parents said they noticed behaviors in their child that were consistent with ASD, such as delayed verbal communication or lack of eye contact (Hutton & Caron; Midence & O'Neill; Ryan & Salisbury). Other parents noticed early atypical behaviors, but did not immediately suspect ASD. One parent said, "We thought he was deaf because he would not respond when we called his name" (Altiere & von Kluge, p. 144). Parents attempted to make sense of atypical behaviors through reference points; for example, by comparing their child's behavior to that of a sibling (Lasser & Corley). Parents also received feedback about their child's development from teachers and neighbors (Lasser & Corley).

Searching for answers. Parents began searching for answers after recognizing that something was developmentally wrong with their child (Altiere & von Kluge,

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Table 1. Representative Quotations From Themes.

Theme	Quotation
Prediagnosis	"I noticed at two to three months of age that my child did not have good eye contact, was sensitive to certain sounds and movement, and did not interact with others" (Hutton & Caron, 2005, p. 182). "They said he was totally deaf, which I knew he wasn't. We went for a second opinion because we knew he was not deaf. We wanted to find out what was wrong" (Midence & O'Neill, 1999, p. 279). "This is just a stage that he will eventually grow out of" (Altiere & von Kluge, 2009, p. 144).
Diagnosis	"It [diagnosis] made me feel better, a lot better about my parenting" (Farrugia, 2009, p. 1016). "When the doctor told me, I had the same feeling as when my grandmother died" (Hutton & Caron, 2005, p. 184).
Family Life Adjustment	"I placed more value on caring for my daughter than on caring for myself. I didn't exercise regularly, I chose easy food rather than healthy food; my energy was low" (Fletcher et al., 2012, p. 56). "His brother is angry with us, saying, 'You are not paying attention to me, you are only interested in him.' Since the ill child is older, he hits his brother. We are constantly alarmed" (Aylaz et al., 2012, p. 399). "We used to donate to several different charities.…Now that we are paying for [our son's] expensive treatments…we are now struggling with being the charity" (Altiere & von Kluge, 2009, p. 146). "[You] have to really be committed to the idea that that's what you want to do is have a family together.… Your relationship switches from being lovers and partners to being the leaders in the family" (Hock et al., 2012, p. 411). "People don't understand, and sometimes I feel like his normalcy or his appearance of normalcy has been more of a disability sometimes than his actual disability, because people look at him…and they expect normal behavior" (Lasser & Corley, 2008, p. 343).
Navigating the System	"The school is stigmatizing my son. The resource person said I should not expect other kids in Grade 1 to buddy with him. They are saying, 'Why would another kid want to play with your kid?'" (Woodgate et al., 2008, p.1078). "My child was put on a waiting list for being assigned to a case manager. I was told that in the meantime, I should do the case management and coordination of services, which was appalling" (Hutton & Caron, 2005, p. 185).
Parental Empowerment	"We did a lot of reading, so we know what he needs" (Altiere & von Kluge, 2009, p. 147). "Anything that we plan to do, I think about the effect it's going to have on him and the effect he's going to have on it, and whether it's worth it or not and whether there's another way" (Farrugia, 2009, p. 1017).
Moving Forward	"Gradually you get better. You have to, though. I accepted the disability and I accepted my child. I love him so much. He is no different to me than my daughter" (Koydemir-Özden & Tosun, 2010, p. 60). "[I worry about] what's going to happen in the future.…I lay there in bed sometimes before I go to sleep and I think, 'Will [my son] ever get a job? Will he ever get married?'" (Gray, 2003, p. 635).

2009; Desai et al., 2012; Hutton & Caron, 2005; Midence & O'Neill, 1999; Ryan & Salisbury, 2012). Their search for answers usually started with family doctors (Altiere & von Kluge; Hutton & Caron; Midence & O'Neill). In some cases, they immediately got the answers they needed (Hutton & Caron); for the majority of parents, however, the search for answers took longer (Altiere & von Kluge; Hutton & Caron; Midence & O'Neill; Ryan & Salisbury). One parent said, "When I went to my doctor and told him something was wrong, he said not to worry, that sometimes boys are just slower than girls" (Hutton & Caron, p. 184). Other parents received an incorrect diagnosis about their child, including deafness (Altiere & von Kluge; Hutton & Caron; Midence & O'Neill). Besides their family doctor, parents also received misinformation from family members who believed their child's behavior was consistent with their family history, such as a son having delayed speech like his father (Desai et al., 2012).

Diagnosis

Authors of 14 articles reported data related to diagnosis, including the mixed emotional responses reported by parents (Alqahtani, 2012; Altiere & von Kluge, 2009; DeGrace, 2004; Desai et al., 2012; Farrugia, 2009; Gray, 2002, 2003; Hock, Timm, & Ramisch, 2012; Hutton & Caron, 2005; Lasser & Corley, 2008; Lin, Tsai, & Chang, 2008; Lutz, Patterson, & Klein, 2012; Midence & O'Neill, 1999; Safe, Joosten, & Molineux, 2012). Depending on the age at diagnosis, this theme corresponds to the "families with young children" and "families with adolescents" stages of the Family Life-Cycle Model (Carter & McGoldrick, 1988).

Relief and devastation. Some parents described contradictory feelings following their child's diagnosis, including both relief and devastation (Altiere & von Kluge, 2009; DeGrace, 2004; Farrugia, 2009; Gray, 2003; Hock et al.,

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2012; Hutton & Caron, 2005; Lin et al., 2008; Lutz et al., 2012; Midence & O'Neill, 1999; Safe et al., 2012). Their feelings of relief stemmed from the fact that they had finally received a label representing the atypical behaviors of their child (Farrugia; Hutton & Caron; Midence & O'Neill). Equipped with this label, parents could learn what steps to take next. One parent said, "Once the diagnosis was made it did help.…If there is a label on the child, you know where to go for help" (Midence & O'Neill, p. 280).

Sometimes, their relief was mixed with feelings of devastation as parents processed the implications of their child's diagnosis (Midence & O'Neill, 1999). Some parents felt devastation only as they started to worry about the long-term impact of the diagnosis (Altiere & von Kluge, 2009; DeGrace, 2004). Some spoke about lost dreams for their child, including marriage and family (Hock et al., 2012; Lin et al., 2008; Lutz et al., 2012; Safe et al., 2012). For other parents, the devastation was so overwhelming that they compared it to a death in the family (Altiere & von Kluge; Gray, 2003; Hutton & Caron, 2005).

Guilt and blame. After receiving a diagnosis, parents started to think about the causes of ASD (Alqahtani, 2012; Altiere & von Kluge, 2009; Desai et al., 2012; Gray, 2002; Hutton & Caron, 2005; Lasser & Corley, 2008; Lutz et al., 2012; Midence & O'Neill, 1999). Parents often blamed themselves; mothers, especially, reflecting on factors that occurred during or after their pregnancy, such as lack of breastfeeding (Alqahtani; Gray, 2002; Lasser & Corley; Lutz et al.; Midence & O'Neill). Cultural and religious beliefs sometimes factored into suspected causes. One parent said, "I think my child is a victim of a black magic" (Alqahtani, p. 19). Other suspected causes of ASD included genetics, brain abnormalities, and allergies (Altiere & von Kluge). Parents also experienced blame from people outside of their family, including health care professionals (Desai et al., 2012; Hutton & Caron, 2005).

Family Life Adjustment

Authors of 27 of the articles reported data related to the effects of ASD on family life, including aspects related to the household (e.g., daily routines) and how parents were perceived by others (e.g., family and strangers; Altiere & von Kluge, 2009; Aylaz, Yilmaz, & Polat, 2012; DeGrace, 2004; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Farrugia, 2009; Fletcher et al., 2012; Fong, Wilgosh, & Sobsey, 1993; Gray, 2002, 2003; Hock et al., 2012; Hutton & Caron, 2005; Koydemir-Özden & Tosun, 2010; Lasser & Corley, 2008; Lin et al., 2008; Ludlow, Skelly, & Rohleder, 2011; Luong, Yoder, & Canham, 2009; Lutz et al., 2012; Markoulakis, Fletcher, & Bryden, 2012; Marquenie, Rodger, Mangohig, & Cronin, 2011; McCabe, 2010; Meirsschaut, Roeyers, & Warreyn, 2010; Midence & O'Neill, 1999; Neely-Barnes, Hall, Roberts, & Graff, 2011; Safe et al., 2012; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011; Shu, Hsieh, Hsieh, & Li, 2001; Woodgate, Ateah, & Secco, 2008). The challenges that we identified under this theme were ongoing; as such, it can relate to any stage in the Family Life-Cycle Model (Carter & McGoldrick, 1988).

Daily life. Caring for a child with ASD affected many aspects of daily life (Aylaz et al., 2012; DeGrace, 2004; Fletcher et al., 2012; Fong et al., 1993; Hutton & Caron, 2005; Ludlow et al., 2011; Marquenie et al., 2011; Meirsschaut et al., 2010; Safe et al., 2012; Schaaf et al., 2011; Shu et al., 2001). Parents felt frustrated by the lack of time they had for themselves and their family (Fletcher et al., 2012; Meirsschaut et al.). Many parents felt overwhelmed by family demands (Hutton & Caron). Some felt apprehensive, such that they were always waiting for the next crisis to occur (DeGrace). Others experienced a range of behavior problems with their child, such as tantrums, that they were unsure how to manage (Fong et al.; Shu et al.). Sometimes it was easier to give in to the child, but parents often said they later paid the price. One parent said, "If the child wants to get into the car and have a ride, you must do it.…I had to drive him around…then I slept for two to three hours and went to work" (Aylaz et al., p. 399). Common triggers for behavioral issues involved changes to routines (Fong et al.; Ludlow et al., 2011; Marquenie et al.) and sensory problems (Safe et al.; Schaaf et al.).

Finances and career. Parents reported changes in their financial situation following their child's diagnosis (Altiere & von Kluge, 2009; Aylaz et al., 2012; Fletcher et al., 2012; Gray, 2003; Koydemir-Özden & Tosun, 2010; Luong et al., 2009; McCabe, 2010). They described the need to work to provide financially for their child with ASD (Fletcher et al.). For some, work also had a positive impact on their well-being (McCabe). Compared to mothers, fathers reported less adjustment to their careers following their child's diagnosis, with one study reporting employment among all of the fathers and only half of the mothers (Gray, 2003).

The commitment of some fathers to work increased following their child's diagnosis. One said, "I was not working forty hours. Paid for forty hours a week, but I worked an average of sixty-five.…I think I did it to get away from [my daughter]" (Gray, 2003, p. 635). Other parents had to quit their job because the demands of caregiving were too great, and this produced mixed emotions among them (Altiere & von Kluge, 2009; Koydemir-Özden & Tosun,

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2010; Luong et al., 2009; McCabe, 2010). Relying on one income hurt families financially, such that they had to use retirement funds or take a second mortgage (Altiere & von Kluge, 2009). Ultimately, some parents revealed they could not cover the expenses they incurred as a result of caring for their child with ASD (Aylaz et al., 2012).

Impact on parents. Some parents felt overwhelmed as caregivers, and this had a negative impact on their well-being (Altiere & von Kluge, 2009; Fletcher et al., 2012; Gray, 2003; Koydemir-Özden & Tosun, 2010; Ludlow et al., 2011; McCabe, 2010; Neely-Barnes et al., 2011; Safe et al., 2012; Shu et al., 2001). Parents felt stressed, exhausted, and drained from the care they provided to their child with ASD (Altiere & von Kluge; Koydemir-Özden & Tosun; Ludlow et al.). Some parents suffered health problems, including high blood pressure (Altiere & von Kluge; Safe et al.). Other parents were overwhelmed because they thought things would never change (Ludlow et al.). Still others wanted to escape their family situation (Shu et al.).

Some parents were put on medication to manage their stress (Fletcher et al., 2012). Mothers sometimes coped by expressing their emotions, whereas fathers tended to suppress their emotions (Gray, 2003). For some parents, the stress from caregiving led to increased pressure on themselves. One parent said, “I am afraid my hard work will not result in a return of my child to normal or nearing normal.…I am afraid I will waste this precious time” (McCabe, 2010, p. 128). For other parents, stress led to negative self-appraisals, such as viewing themselves as inadequate caregivers (Ludlow et al., 2011; Neely-Barnes et al., 2011).

Impact on spouses. Parents reported that caring for a child with ASD had positive and negative effects on their spousal relationship (Aylaz et al., 2012; Divan et al., 2012; Fletcher et al., 2012; Gray, 2003; Hock et al., 2012; Luong et al., 2009; Markoulakis et al., 2012; Meirsschaut et al., 2010). Some parents reported growing closer to their spouse in the process of caring for their child with ASD (Aylaz et al.; Hock et al.; Markoulakis et al.). In other cases, it pushed spouses away from each other, with mothers and fathers occupying distinct roles in their family (Aylaz et al.). Filling these distinct roles sometimes fostered resentment, particularly among mothers who believed they received inadequate support from their husband (Gray, 2003; Luong et al., 2009). One parent said, “Nine times out of ten it’s the mother who is [caring for the child]…because the father is working.…The father essentially has…respite care five days a week” (Gray, 2003, p. 635). Strain also arose when one parent blamed the other for their child’s diagnosis (Fletcher et al.). Ultimately, some parents divorced (Meirsschaut et al.); others worried that the constant care they provided to their child with ASD would put their marriage at risk for divorce (Divan et al., 2012).

Impact on siblings. Caring for a child with ASD affected the relationship that parents had with their other children (Aylaz et al., 2012; Divan et al., 2012; Hutton & Caron, 2005; Lin et al., 2008; Markoulakis et al., 2012; Neely-Barnes et al., 2011; Schaaf et al., 2011; Shu et al., 2001). Parents reported their other children feeling they were not treated the same as their brother or sister with ASD (Aylaz et al.; Divan et al.; Schaaf et al.; Shu et al.). Some parents reached out to these children to compensate for the extra time they spent with their child with ASD (Hutton & Caron). In some families, the impact of living with a brother or sister with ASD affected the sibling’s health. One parent said, “My other child has a diagnosis of anxiety disorder, which may be due to his high level of alertness and fear of being hurt by his brother with autism” (Hutton & Caron, p. 187). In other families, an older sibling assisted parents in the care of their brother or sister with ASD (Aylaz et al.; Lin et al.). Some siblings acted as mediators for their sibling with ASD (Neely-Barnes et al.). Others showed increased patience and maturity that might have resulted from their relationship with their sibling with ASD (Markoulakis et al.).

Going out in public. Parents often received criticism from strangers when they were out in public (Farrugia, 2009; Gray, 2002; Lasser & Corley, 2008; Ludlow et al., 2011; Midence & O’Neill, 1999; Neely-Barnes et al., 2011; Safe et al., 2012; Woodgate et al., 2008). Strangers believed their children were acting out and should be disciplined (Farrugia; Lasser & Corley; Safe et al.). In some cases, parents related such incidents to the fact that ASD is an invisible disorder (Lasser & Corley; Midence & O’Neill; Neely-Barnes et al.). One parent said, “It would make a difference if my child had a physical handicap instead…because people would see…you are behaving in that way because you are in that chair” (Midence & O’Neill, p. 280). Parents reported different reactions in response to the judgment of strangers; for example, some ignored such strangers, others confronted them, and still others educated them about the nature of ASD (Gray, 2002; Neely-Barnes et al.; Woodgate et al.).

Navigating the System

Authors of 11 of the articles reported data related to navigating the system. This theme captured the experiences of parents attempting to access the best programs and services for their son or daughter with ASD (Alqahtani, 2012; Altiere & von Kluge, 2009; Aylaz et al., 2012; Divan et al., 2012; Fong et al., 1993; Hutton & Caron,

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2005; Koydemir-Özden & Tosun, 2010; Luong et al., 2009; Safe et al., 2012; Shu et al., 2001; Woodgate et al., 2008). The challenges that we identified under this theme were ongoing; thus, it can relate to any stage in the Family Life-Cycle Model (Carter & McGoldrick, 1988).

School system. Parents mentioned a variety of experiences with their child's school system (Aylaz et al., 2012; Divan et al., 2012; Fong et al., 1993; Koydemir-Özden & Tosun, 2010; Safe et al., 2012; Shu et al., 2001; Woodgate et al., 2008). Some teachers had limited understanding of ASD and how to resolve behavioral issues stemming from the disorder (Aylaz et al.; Divan et al.; Woodgate et al.). Their lack of understanding sometimes led teachers to make inappropriate comments to parents. One parent said, "The teacher called me one day and said, 'Why did you hide this from us?'…She said, 'Don't you know that she has some problem!' while pointing to her head" (Divan et al., p. 195). Some parents were dissatisfied with the support they received from their school system (Fong et al.; Safe et al.). Other parents wanted to be more involved, but they were faced with competing demands, such as their career needs (Koydemir-Özden & Tosun). Some parents worked with the system (Aylaz et al.; Fong et al.) and others educated teachers about ASD to help their child adjust to school (Shu et al.).

Accessing treatment. Parents described the challenges they experienced while trying to access services for their child with ASD (Alqahtani, 2012; Altiere & von Kluge, 2009; Fong et al., 1993; Hutton & Caron, 2005; Luong et al., 2009; Woodgate et al., 2008). Some parents described only positive experiences with this process (Hutton & Caron); other parents experienced numerous challenges. Ineffective communication often left parents wondering if health care professionals had the required expertise to care for their child (Fong et al.). Some parents paid out of pocket for treatment, which produced a financial strain on the family (Altiere & von Kluge). Other challenges involved driving long distances (Hutton & Caron) or the need to relocate to be closer to treatment facilities (Fong et al.).

Researchers in one study found that parents implemented between 2 and 12 treatments for their child, with speech therapy being the most common therapy (Altiere & von Kluge, 2009). Other parents opted for religious-based treatments that could be administered alongside traditional Western medicine. One parent said, "Daily…day after day, I am keeping reciting some verses of Al-Quran.…Allah will cure her from autism" (Alqahtani, p. 19). Some parents stressed the importance of starting services as early as possible (Woodgate et al., 2008), and others advocated for the importance of parental involvement in a child's treatment plan (Luong et al., 2009).

Parental Empowerment

Twenty of the articles provided data related to parental empowerment. Under this theme, parents reported educating themselves about ASD and implementing strategies that worked for their family (Altiere & von Kluge, 2009; DeGrace, 2004; Divan et al., 2012; Farrugia, 2009; Fong et al., 1993; Hock et al., 2012; Hutton & Caron, 2005; Lasser & Corley, 2008; Lin et al., 2008; Ludlow et al., 2011; Luong et al., 2009; Lutz et al., 2012; Markoulakis et al., 2012; Meirsschaut et al., 2010; Neely-Barnes et al., 2011; Safe et al., 2012; Schaaf et al., 2011; Shaked, 2005; Shu et al., 2001; Woodgate et al., 2008). The challenges that we identified under this theme were ongoing; thus, it can relate to any stage in the Family Life-Cycle Model (Carter & McGoldrick, 1988).

Super parents. Parents were not always satisfied with the information they received about their son or daughter with ASD, and this prompted them to find out all they could about the disorder (Altiere & von Kluge, 2009; Fong et al., 1993; Lin et al., 2008; Ludlow et al., 2011; Luong et al., 2009; Lutz et al., 2012; Markoulakis et al., 2012; Safe et al., 2012; Shaked, 2005; Shu et al., 2001; Woodgate et al., 2008). Some parents obtained this information by reading and joining support groups (Altiere & von Kluge). Some parents became teachers at home for their child with ASD. One parent said, "Other kids learned things very quickly, but he needed more time.…I believed that if I remained patient, he would finally succeed" (Shu et al., p. 205). Other parents became therapists and implemented new techniques at home (Luong et al., 2009; Safe et al., 2012). Some parents educated family and friends about ASD (Safe et al.,), and others advocated for their child in the community (Shaked). This empowerment led to parents challenging the information about ASD they received from others (Woodgate et al.), and it gave them some sense of control over their lives (Fong et al.; Ludlow et al.; Luong et al.; Lutz et al.; Markoulakis et al.).

Coping strategies. Some parents created their own strategies at home to cope with caregiving (DeGrace, 2004; Divan et al., 2012; Farrugia, 2009; Hock et al., 2012; Hutton & Caron, 2005; Lasser & Corley, 2008; Lutz et al., 2012; Meirsschaut et al., 2010; Neely-Barnes et al., 2011; Safe et al., 2012; Schaaf et al., 2011; Woodgate et al., 2008). For example, parents recommended preserving established routines with their child (Farrugia; Hutton & Caron; Schaaf et al.) and planning ahead (Lutz et al.; Meirsschaut et al.). One parent said, "You have to rearrange your life.…There is no more spontaneous…everything is planned" (Lutz et al., p. 211). This constant planning created a hypervigilance among parents

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who always had to look ahead to avoid problems (Hutton & Caron; Lasser & Corley; Schaaf et al.).

As another strategy, parents took two cars to social events to allow some family members to stay out late if their child with ASD wanted to return home (Divan et al., 2012; Schaaf et al., 2011). Some parents also learned to remove the people in their life who were not supportive of their child with ASD (Altiere & von Kluge, 2009). Some found videos useful because they entertained their child and helped them manage behavioral problems (DeGrace, 2004). Parents also emphasized the need to think positively about their situation and take time for themselves or with their spouse (Hock et al., 2012; Neely-Barnes et al., 2011; Safe et al., 2012; Woodgate et al., 2008).

Moving Forward

Authors of 13 of the articles reported data related to moving forward, a process through which parents accepted their child's diagnosis and discussed the benefits of caregiving. Parents also looked ahead to the future and wondered about the long-term outcome for their son or daughter with ASD (Altiere & von Kluge, 2009; Aylaz et al., 2012; DeGrace, 2004; Fong et al., 1993; Gray, 2003; Hock et al., 2012; Koydemir-Özden & Tosun, 2010; Ludlow et al., 2011; Luong et al., 2009; Lutz et al., 2012; Markoulakis et al., 2012; Midence & O'Neill, 1999; Shu et al., 2001). This theme maps on to the "families with young children," "families with adolescents," "launching children," and "families in later life" stages of the Family Life-Cycle Model (Carter & McGoldrick, 1988).

Feelings of normalcy. Some parents found a new normal for their family (DeGrace, 2004; Koydemir-Özden & Tosun, 2010; Luong et al., 2009; Midence & O'Neill, 1999). Some parents got in the routine of caring for their child with ASD and stopped trying to fix their child (Koydemir-Özden & Tosun, 2010; Luong et al., 2009). This acceptance of ASD also came in fleeting moments when parents experienced normalcy. One parent said, "We were out eating at a [local restaurant], and we were all sitting there as a family, and he's dipping his French fries into the ketchup, and he's not making noises.…We feel like a family" (DeGrace, p. 547).

Benefits. Some parents described benefits of caring for their child with ASD (Altiere & von Kluge, 2009; Hock et al., 2012; Luong et al., 2009; Markoulakis et al., 2012; Midence & O'Neill, 1999; Shu et al., 2001). Some became closer in their relationship with their child. One parent said, "Our son has made us closer, this bonds us together.…He is part of the family" (Midence & O'Neill, p. 281). Others described how caring for their child with ASD had brought them closer to their spouse (Hock et al.). Some parents believed they had changed personally; for example, by gaining increased patience and tolerance (Altiere & von Kluge) and improved ability to cope (Altiere & von Kluge; Markoulakis et al.). Some parents believed that caring for their child with ASD had changed them spiritually, including their worldview (Luong et al.). Overall, this led to parents feeling appreciative of their child with ASD (Shu et al.).

Concerns for the future. Some parents were concerned for their child's future (Aylaz et al., 2012; Fong et al., 1993; Gray, 2003; Koydemir-Özden & Tosun, 2010; Ludlow et al., 2011; Lutz et al., 2012; Midence & O'Neill, 1999; Shu et al., 2001). Most parents wanted their child to live independently in adulthood (Aylaz et al.; Gray, 2003; Koydemir-Özden & Tosun; Ludlow et al.; Midence & O'Neill; Shu et al.). One parent said, "By the time he is twenty I don't want him to live at home because it would not be fair to him" (Midence & O'Neill, p. 282). This independence was considered important not only in terms of personal development, but also for parents who were concerned about what would happen to their son or daughter with ASD after they passed away (Aylaz et al.; Gray, 2003; Koydemir-Özden & Tosun; Ludlow et al.). Some parents worried about their child being able to secure employment (Midence & O'Neill; Shu et al.) and form relationships (Fong et al.). Other parents expected their child would be unable to function independently and hoped he or she would be happy (Lutz et al.).

Discussion

In this article, we aimed to synthesize and critically interrogate the qualitative research on parents' experiences of caring for a child with ASD. Using the Family Life-Cycle Model (Carter & McGoldrick, 1988) as our theoretical framework, we examined how parents' experiences were influenced by their child's diagnosis and the challenges they faced at particular stages of family development. We identified six themes: prediagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward. Although our review was focused on parents caring for a child with ASD, we found that our themes had implications for parents at all stages of the Family Life-Cycle Model (Carter & McGoldrick).

The first theme we identified was prediagnosis, which corresponds to the "single young adults leaving home" and "joining of families through marriage" stages of the Family Life-Cycle Model (Carter & McGoldrick, 1988). Under prediagnosis, we identified three subthemes: typical development, atypical development, and search for answers. We found that some children developed typically for at least the first year, whereas others displayed

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early warning signs of ASD in their behaviors. It is critical for health care professionals to understand the developmental trajectory that a child has experienced because it might impact a parent's ability to cope with his or her diagnosis.

It is also important that parents be educated about the early signs of ASD so they can recognize these aspects as soon as possible if they appear in their child's behavior. According to the articles we reviewed, parents' search for answers usually started with family doctors and often involved a prolonged and confusing process in which some parents received an incorrect diagnosis for their child; for example, some children were labeled as being deaf. This reflects one early warning sign of ASD, in which the child does not respond when his or her name is called (Osterling & Dawson, 1994). In fact, research shows that the majority of individuals with ASD have sensory processing issues (Baker, Lane, Angley, & Young, 2008; Crane, Goddard, & Pring, 2009), which entail being more sensitive or less sensitive than normal to sensory stimuli (Kern et al., 2006). It is critical that health care professionals be aware of these issues, which are not part of the diagnostic criteria for this disorder but affect how quickly those with ASD receive care.

Our second theme was diagnosis, which corresponds to the "families with young children" and "families with adolescents" stages of the Family Life-Cycle Model (Carter & McGoldrick, 1988). Under this theme, we identified two subthemes: relief and devastation, and guilt and blame. Most children are diagnosed with ASD around 5.5 years old, but some might not receive a diagnosis until much later (Howlin & Asgharian, 1999). A diagnosis usually involves a long-awaited process that can bring mixed emotions to parents. We found that many parents initially felt both relief and devastation after receiving a diagnosis for their child: Relief arose when the diagnosis provided answers about their child's development; devastation occurred when parents learned that ASD was a lifelong disorder with many implications for them as caregivers.

We also found that parents experienced guilt and blame when they started to wonder about the suspected causes of their child's disorder. Parents often blamed themselves or were blamed by others, including health care professionals whom they trusted. For instance, parents in Goa (India), which is known for its relatively high socioeconomic status (Desai et al., 2012), and parents in rural New England (United States; Hutton & Caron, 2005) reported experiencing blame from health care professionals. These findings point to a gap in knowledge among some health care professionals about the contributing factors of ASD.

Our third and largest theme was family life adjustment, which involved data from almost all of the articles in our review. Under this theme, we identified six subthemes: impact on daily life, finances and career, impact on parents, impact on spouses, impact on siblings, and going out in public. The challenges that we identified under this theme were ongoing; thus, this theme can occur at any stage in the Family Life-Cycle Model (Carter & McGoldrick, 1988). We found that daily life for parents changed drastically as a result of caring for a child with ASD. For example, parents were unsure how to manage behavior problems associated with this disorder, such as a child throwing a tantrum when a routine was changed. Parents sometimes responded by using negative reinforcement, which might have stopped the unwanted behavior in the short run while making it more likely to occur again in the future (Martin & Pear, 2011). These findings suggest that health care professionals need to help parents develop effective strategies to manage behavioral problems among children with ASD.

Another subtheme in our review addressed the impact of caring for a child with ASD on parents' health, which reflected the high demands placed on them as caregivers. Many parents reported physical (e.g., high blood pressure), emotional (e.g., sadness), and cognitive (e.g., thinking their situation would never change) signs of stress. It is critical that health care professionals be aware of these signs and educate parents about adaptive ways of coping. Research has found that mothers of children with disabilities who used problem-focused coping strategies (e.g., problem solving) showed less psychological distress than those who used emotion-focused coping (e.g., distancing; Miller et al., 1992).

Another subtheme in our review addressed spousal relationships. Although some parents reported becoming closer, others grew apart as a result of caring for their child with ASD. Sometimes mothers and fathers occupied distinct roles in the family, which might have been influenced by their cultural environment. For example, researchers in one study from Turkey reported that mothers were often blamed for having a child with a disability and were held responsible for their care (Aylaz et al., 2012). In other countries (i.e., Australia and United States), researchers found that some mothers were resentful for not receiving enough help with childcare from their husband (Gray, 2003; Luong et al., 2009). This potential for marital stress is consistent with past research, which found higher divorce rates among parents of children with ASD than those of children with typical development (Hartley et al., 2010). Health care professionals need to be aware of this increased risk for divorce among parents of children with ASD because it can impact the social, emotional, and financial well-being of the family.

Another subtheme in our review addressed the reactions experienced by parents from strangers when out in public. They reported experiencing criticism from

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strangers for being “bad parents” when their child with ASD was perceived to be misbehaving. This experience is consistent with enacted stigma, which takes the form of disparaging looks and unsought advice from strangers (Gray, 1993; Scambler & Hopkins, 1986). Parents suggested that the invisible nature of ASD made it particularly challenging to go out in public. Children with ASD look like typically developing children, so their behavior is likely to be judged by strangers according to how typically developing children should behave. This difference might set parents of children with ASD apart from parents of children with a physical disability. It is important that health care professionals work to increase public awareness about ASD and provide support to parents to help them actively participate in their communities.

Our fourth theme captured the experiences of parents navigating the system, as they attempted to access the best programs and services for their son or daughter with ASD. Although we focused on the experiences of parents caring for a child with ASD, this access to programs and services can occur at any stage in the Family Life-Cycle Model (Carter & McGoldrick, 1988). Under this theme, we identified two subthemes: the school system and accessing services in the community. We found that some teachers had limited knowledge about ASD, which is consistent with previous research (Lindsay, Proulx, Scott, & Thomson, 2014). Some teachers failed to socially integrate the child with ASD in the classroom or acknowledge how the disorder affected his or her learning. Some teachers also blamed parents for their child’s condition, which isolated parents and left them feeling dissatisfied with the school system.

When it came to accessing treatment for their child in their community, parents experienced many challenges, including poor communication with health care professionals, paying out of pocket for services, and driving long distances to access services. Many children with ASD were also involved in multiple therapies, which made it difficult to determine if any one treatment was effective. Children often received speech and language therapy; however, other less-well-known therapies were also sometimes implemented (Altiere & von Kluge, 2009). One of the articles, reporting on a study in Saudi Arabia, described cultural interventions for ASD, including reciting the Al-Quran, which might be implemented alongside traditional Western medicine (Alqahtani, 2012). It is important for health care professionals to realize that some parents might want to use medical and cultural interventions to treat ASD. It is also critical for them to educate parents about the strengths and weaknesses of those interventions so they can make informed decisions about their child.

The fifth theme was parental empowerment, the process through which caregivers educated themselves about ASD and implemented coping strategies at home. Although we focused on the experiences of parents caring for a child with ASD, this empowerment process can occur at any stage in the Family Life-Cycle Model (Carter & McGoldrick, 1988). Under this theme, we identified two subthemes: super parents and coping strategies. We found that super parents evolved from parents who were dissatisfied with the information they received about their child with ASD. Some parents decided to learn all they could about ASD by reading and joining support groups. They also learned to advocate for their child and challenged the information they received from others if they felt their child’s interests were compromised. This behavior challenges the traditional medical model, in which authority figures—such as doctors—are seen as gatekeepers of knowledge and patients are seen as passive to the care they receive (Weinstein, 2001).

When it came to creating caregiving strategies at home, many parents promoted planning ahead and maintaining routines. These strategies are particularly important given the repetitive and restrictive interests associated with ASD. Given these behavior tendencies, it is critical for health care professionals to build some familiarity into their treatment plans to increase compliance among clients with ASD.

Our last theme was moving forward, the stage in which some parents accepted their child’s diagnosis and looked ahead to the future. This theme corresponded to the “families with young children,” “families with adolescents,” “launching children,” and “families in later life” stages of the Family Life-Cycle Model (Carter & McGoldrick, 1988). Under this theme, we identified three subthemes: feelings of normalcy, benefits of care, and concerns for the future. We found that some parents accepted the “new normal” that characterized their family. They accepted their child with ASD, such that they could not imagine their family without this disorder. This acceptance phase is consistent with the last stage in the grief model by Kübler-Ross (1969).

Some parents also described the benefits of caring for a child with ASD. For example, parents became more patient, less judgmental, and better able to cope as a result of caring for their child with ASD. These benefits might be explained by the fact that parents were using more problem-focused coping strategies, which research shows is more psychologically adaptive than emotion-focused coping strategies (Miller et al., 1992).

Parents also reported concerns for their child’s future. Many wanted their child to achieve typical milestones, such as living on their own or securing meaningful employment. These concerns correspond to the challenges experienced in the “launching children” stage of the Family Life-Cycle Model (Carter & McGoldrick, 1988), when individuals are expected to leave the parental home to start their own family and secure employment

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in their community. Research shows that approximately 15% of adolescents with ASD are employed (Wagner, Cadwallader, & Marder, 2003). This statistic is alarming given that work-related experiences in high school predict employment outcomes in adulthood (Carter, Austin, & Trainor, 2012).

In addition to synthesizing parents' reported experiences, our review identified some gaps in programs and services. These gaps must be addressed to ensure that individuals with ASD and their families receive the best possible care. First, most of the articles reviewed mentioned programs and services that were available only to individuals with ASD; however, our findings suggest that all family members are affected by a diagnosis of ASD, including parents, siblings, and grandparents. Therefore, more programs and services should be provided to family members to help them receive necessary support.

Second, we found that many families experienced long wait times for therapy; for example, some children with ASD waited up to 4 years to receive intensive behavior therapy (Gordon, 2012), which uses behavior modification principles. More government funding is needed to reduce wait times and ensure that children with ASD get the care they need as early as possible.

Finally, it is essential for health care professionals and others to appreciate how cultural background can impact attitudes about disability. The Family Life-Cycle Model (Carter & McGoldrick, 1988), for instance, is based on the societal expectation that individuals leave the parental home to form their own family. Although this expectation was held by many of the parents in our review, it is important for health care professionals to realize that the "launching children" stage might not be a desired endpoint for all families. For example, some parents in Singapore did not expect their older children with ASD to work in the community or live on their own, which is consistent with cultural beliefs (Poon, 2013).

The studies included in our review have several limitations that should be addressed in future research. First, the studies in our review engaged fewer fathers than mothers. This gender imbalance reflects the fact that some authors aimed to examine only the experiences of primary caregivers. It is important for future research to examine how the experiences of fathers might be similar to or different from those of mothers who are caring for a child with ASD.

Second, most parents included in the samples were caring for a son with ASD. For every four boys with ASD, there is one girl with ASD (Fombonne, 2005); however, this sex ratio was not always reflected in the included studies. It is important to understand how the gender of a child with ASD might impact parenting behaviors. Third, our review was focused on studies of parents of children with a primary diagnosis of ASD, which included Asperger syndrome. However, recent changes to the *Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994)* eliminated Asperger syndrome as an ASD subtype. More research is needed to determine how different subtypes of ASD, including those on the low end of the ASD spectrum, and related disorders, might impact parenting behaviors.

Fourth, each study did not contribute equally to each theme in this review; more research is therefore needed to confirm the pattern of results found across studies. Fifth, we used the Family Life-Cycle Model (Carter & McGoldrick, 1988) as our theoretical framework because of its developmental approach to understanding family experiences; however, other models could have been used to provide a different perspective on this topic. Finally, our review identified themes that were incorporated into developmental stages using the Family Life-Cycle Model. These stages need to be empirically validated in future research. This research would inform the factors that help or hinder completion of each stage. This research would also address issues not examined in the included articles. For example, how much time do parents spend in each stage? Does having multiple children with ASD have a cumulative effect on parents' experiences? This information would be valuable to health care professionals and parents of children with ASD.

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References

Allik, H., Larsson, J., & Smedje, H. (2006). Health-related quality of life in parents of school-age children with Asperger syndrome or high functioning autism. *Health and Quality of Life Outcomes*, *4*(1), 1–8. doi:10.1186/1477-7525-4-1

Alqahtani, M. M. J. (2012). Understanding autism in Saudi Arabia: A qualitative analysis of the community and cultural context. *Journal of Pediatric Neurology*, *10*(1), 15–22. doi:10.3233/JPN-2012-0527

Altiere, M. J., & von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual Developmental Disabilities*, *34*(2), 142–152. doi:10.1080/1366825090284-5202

American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.). Washington, DC: Author.

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Aylaz, R., Yilmaz, U., & Polat, S. (2012). Effect of difficulties experienced by parents of autistic children on their sexual life: A qualitative study. *Sexual Disabilities*, *30*(4), 395–406. doi:10.1007/s11195-011-9251-3

Baker, A. E., Lane, A., Angley, M. T., & Young, R. L. (2008). The relationship between sensory processing patterns and behavioural responsiveness in autistic disorder: A pilot study. *Journal of Autism and Developmental Disorders*, *38*(5), 867–875. doi:10.1007/s10803-007-0459-0

Baltes, P. B. (1987). Theoretical propositions of life-span developmental psychology: On the dynamics between growth and decline. *Developmental Psychology*, *23*(5), 611–626. doi:10.1037/0012-1649.23.5.611

Bennett, T., DeLuca, D. A., & Allen, R. W. (1996). Families of children with disabilities: Positive adaptation across the life cycle. *Children Schools*, *18*(1), 31–44. doi:10.1093/cs/18.1.31

Carter, B., & McGoldrick, M. (Eds.). (1988). *The changing family life cycle: A framework for family therapy* (2nd ed.). New York: Gardner Press.

Carter, E. W., Austin, D., & Trainor, A. A. (2012). Predictors of postschool employment outcomes for youth adults with severe disabilities. *Journal of Disability Policy Studies*, *23*(1), 50–63. doi:10.1177/1044207311414680

Crane, L., Goddard, L., & Pring, L. (2009). Sensory processing in adults with autism spectrum disorders. *Autism*, *13*(3), 215–228. doi:10.1177/1362361309103-794

Critical Appraisal Skills Programme International. (2010). *Critical appraisal skills programme*. Retrieved from www.caspinternational.org/?o=1012

DeGrace, B. W. (2004). The everyday occupation of families with children with autism. *American Journal of Occupational Therapy*, *58*(5), 543–550. doi:10.1177/1362-361310386505

Desai, M. U., Divan, G., Wertz, F. J., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry*, *49*(3–4), 613–637. doi:10.1177/1363461512447139

Divan, G., Vajaratkar, V., Desai, M. U., Strik-Lievers, L., & Patel, V. (2012). Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism Research*, *5*(3), 190–200. doi:10.1002/aur.1225

Erwin, E., Brotherson, M., & Summers, J. (2011). Understanding qualitative metasynthesis. *Journal of Early Intervention*, *33*(3), 186–200. doi:10.1177/1053815-111425493

Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., & Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*, *2*(2), 109–118. doi:10.1002/aur.69

Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health and Illness*, *31*(7), 1011–1027. doi:10.1111/j.1467-9566.2009.01174.x.

Fletcher, P. C., Markoulakis, R., & Bryden, P. J. (2012). The costs of caring for a child with an autism spectrum disorder. *Issues in Comprehensive Pediatric Nursing*, *35*(1), 45–69. doi:10.3109/01460862.2012.645407

Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, *33*(4), 365–382. doi:10.1023/A:1025054610557

Fombonne, E. (2005). Epidemiological studies of pervasive developmental disorders. In F. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 42–69). Hoboken, NJ: Wiley.

Fong, L., Wilgosh, L., & Sobsey, D. (1993). The experience of parenting an adolescent with autism. *International Journal of Disability, Development and Education*, *40*(2), 105–113. doi:10.1080/0156655930400204

Gordon, A. (2012). The autism project: Children face up to four-year wait for therapy. *The Star*. Retrieved from www.thestar.com/news/gta/2012/11/23/the_autism_project_children_face_up_to_fouryear_wait_for_therapy.html

Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness*, *15*(1), 102–120. doi:10.1111/1467-9566.ep11343802

Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health and Illness*, *24*(6), 734–749. doi:10.1111/1467-9566.00316

Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science and Medicine*, *56*(3), 631–642. doi:10.1016/S0277-9536(02)00059-X

Grypdonck, M. H. (2006). Qualitative health research in the era of evidence-based practice. *Qualitative Health Re-search*, *16*, 1371–1385. doi:10.1177/1049732306294089

Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, *24*(4), 449–457. doi:10.1037/a0019847

Hock, R. M., Timm, T. M., & Ramisch, J. L. (2012). Parenting children with autism spectrum disorders: A crucible for couple relationships. *Child & Family Social Work*, *17*(4), 406–415. doi:10.1111/j.1365-2206.2011.00794.x

Howlin, P., & Asgharian, A. (1999). The diagnosis of autism and Asperger syndrome: Findings from a survey of 770 families. *Developmental Medicine & Child Neurology*, *41*(12), 834–839. doi:10.1017/S001216-2299001656

Hutton, A. M., & Caron, S. L. (2005). Experiences of families with children with autism in rural New England. *Focus on Autism and Other Developmental Disabilities*, *20*(3), 180–189. doi:10.1177/10883576050200030601

Jarbrink, K., Fombonne, E., & Knapp, M. (2003). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: A pilot study. *Journal of Autism and Developmental Disorders*, *33*(4), 396–402. doi:10.1023/A:1025058711465

Kern, J. K., Trivedi, M. H., Garver, C. R., Grannemann, B. D., Andrews, A. A., Savla, J. S., & Schroeder, J. L. (2006). The pattern of sensory processing abnormalities in autism. *Autism*, *10*(5), 480–490. doi:10.1177/1362361306066564

Koydemir-Özden, S., & Tosun, Ü. (2010). A qualitative approach to understanding Turkish mothers of children with

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autism: Implications for counseling. *Australian Journal of Guidance & Counselling*, *20*(1), 55–68. doi:10.1375/ajgc.20.1.55

Kübler-Ross, E. (1969). *On death and dying*. New York: MacMillan.

Lasser, J., & Corley, K. (2008). Constructing normalcy: A qualitative study of parenting children with Asperger's disorder. *Educational Psychology in Practice*, *24*(4), 335–346. doi:10.1080/02667360802488773

Lin, C.-R., Tsai, Y.-F., & Chang, H.-L. (2008). Coping mechanisms of parents of children recently diagnosed with autism in Taiwan: A qualitative study. *Journal of Clinical Nursing*, *17*(20), 2733–2740. doi:10.1111/j.1365-2702.2008.02456.x

Lindsay, S., Proulx, M., Scott, H., & Thomson, N. (2014). Exploring elementary school teachers' strategies for including children with autism spectrum disorder in mainstream classes. *International Journal of Inclusive Education*, *18*(2), 101–122. doi:10.1080/13603116.2012.758320

Ludlow, A., Skelly, C., & Rohleder, P. (2011). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health & Psychology*, *17*(5), 702–711. doi:10.1177/1359105311422955

Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast Asian parents raising a child with autism: A qualitative investigation of coping styles. *Journal of School Nursing*,*25*(3), 222–229. doi:10.1177/1059840509334365

Lutz, H. R., Patterson, B. J., & Klein, J. (2012). Coping with autism: A journey toward adaptation. *Journal of Pediatric Nursing*, *27*(3), 206–213. doi:10.1016/j.pedn.2011.03.013

Markoulakis, R., Fletcher, P., & Bryden, P. (2012). Seeing the glass half full: Benefits to the lived experiences of female primary caregivers of children with autism. *Clinical Nurse Specialist*, *26*(1), 48–56. doi:10.1097/NUR.0b013e31823-bfb0f

Marquenie, K., Rodger, S., Mangohig, K., & Cronin, A. (2011). Dinnertime and bedtime routines and rituals in families with a young child with an autism spectrum disorder. *Australian Occupational Therapy Journal*, *58*(3), 145–154. doi:10.1111/j.1440-1630.2010.00896.x

Martin, G., & Pear, J. (2011). *Behavior modification: What it is and how to do it* (9th ed.). Upper Saddle River, NJ: Prentice-Hall.

McCabe, H. (2010). Employment experiences, perspectives, and wishes of mothers of children with autism in the People's Republic of China. *Journal of Applied Research in Intellectual Disabilities*, *23*(2), 122–131. doi:10.1111/j.1468-3148.2009.00512.x

Meirsschaut, M., Roeyers, H., & Warreyn, P. (2010). Parenting in families with a child with autism spectrum disorder and a typically developing child: Mothers' experiences and cognitions. *Research in Autism Spectrum Disorders*, *4*(4), 661–669. doi:10.1016/j.rasd.2010.01.002

Midence, K., & O'Neill, M. (1999). The experience of parents in the diagnosis of autism. *Autism*, *3*(3), 273–285. doi:10.1177/1362361399003003005

Miller, A. C., Gordon, R. M., Daniele, R. J., & Diller, L. (1992). Stress, appraisal, and coping in mothers of disabled and nondisabled children. *Journal of Pediatric Psycho-logy*, *17*(5), 587–605. doi:10.5463/DCID.v23i2.119

Neely-Barnes, S. L., Hall, H. R., Roberts, R. J., & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualize-tions. *Journal of Family and Social Work*, *14*(3), 208–225. doi:10.1080/10522158.2011.571539

O'Day, B., & Killeen, M. (2002). Research on the lives of persons with disabilities: The emerging importance of qualitative research methodologies. *Journal of Disability Policy Studies*, *13*(1), 9–15. doi:10.1177/1044207302013-0010201

Osterling, J., & Dawson, G. (1994). Early recognition of children with autism: A study of first birthday home video tapes. *Journal of Autism and Developmental Disorders*, *24*(3), 247–257. doi:10.1007/BF02172225

Peppé, S., McCann, J., Gibbon, F., O'Hare, A., & Rutherford, M. (2007). Receptive and expressive prosodic ability in children with high-functioning autism. *Journal of Speech Language & Hearing Research*, *50*(4), 1015–1028. doi:10.1044/1092-4388

Petticrew, M., & Roberts, H. (2005). *Systematic reviews in social sciences: A practical guide*. Malden, MA: Wiley Blackwell.

Poon, K. K. (2013). Parental expectations regarding postschool social attainments of adolescents with autism spectrum disorders in Singapore. *American Journal on Intellectual and Developmental Disabilities*, *118*(2), 95–107. doi:10.1352/1944-7558-118.2.95

Ryan, S., & Salisbury, H. (2012). 'You know what boys are like': Pre-diagnosis experiences of parents of children with autism spectrum conditions. *British Journal of General Practice*,*62*(598), 378–383. doi:10.3399/bjgp12X641500

Safe, A., Joosten, A., & Molineux, M. (2012). The experiences of mothers of children with autism: Managing multiple roles. *Journal of Intellectual Developmental Disabilities*, *37*(4), 294–302. doi:10.3109/13668250.2012.736614

Saini, M., & Shlonsky, A. (2012). *Systematic synthesis of qualitative research*. Oxford, United Kingdom: University of Oxford Press.

Sandelowski, M., & Barroso, J. (2003). Focus on research methods towards a metasynthesis of qualitative findings on motherhood in HIV-positive women. *Research in Nursing & Health*, *26*(2), 153–170. doi:10.1002/nur.10072

Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health and Illness*, *8*(1), 26–43. doi:10.1111/1467-9566.ep11346455

Schaaf, R. C., Toth-Cohen, S., Johnson, S. L., Outten, G., & Benevides, T. W. (2011). The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *Autism*, *15*(3), 373–389. doi:10.1177/1362361310386505

Seltzer, M. M., Shattuck, P., Abbeduto, L., & Greenberg, J. S. (2004). The trajectory of development in adolescents and adults with autism. *Mental Retardation Developmental Disabilities Research Reviews*, *10*(4), 234–247. doi:10.1002/mrdd.20038

Shaked, M. (2005). The social trajectory of illness: Autism in the ultraorthodox community in Israel. *Social Science*

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and Medicine, *61*(10), 2190–2200. doi:10.1016/j.socscimed.2005.04.022

Shu, B.-C., Hsieh, H.-C., Hsieh, S.-C., & Li, S.-M. (2001). Toward an understanding of mothering: The care giving process of mothers with autistic children. *Journal of Nursing Research*, *9*(5), 203–212. doi:10.1097/01.JNR.0000347577.24468.ae

Sivberg, B. (2002). Family system and coping behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism*, *6*(4), 397–409. doi:10.1177/136236130-2006004-006

Tong, A., Morton, R., Howard, K., & Craig, J. (2009). Adolescent experiences following organ transplantation: A systematic review of qualitative studies. *Journal of Pediatrics*, *155*(4), 542–549. doi:10.1016/j.jpeds.2009.04.009

Wagner, M., Cadwallader, T., & Marder, C. (2003). *Life outside the classroom for youth with disabilities*. Menlo Park, CA: SRI International.

Weinstein, M. C. (2001). Should physicians be gatekeepers of medical resources? *Journal of Medical Ethics*, *27*(4), 268–274. doi:10.1136/jme.27.4.268

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*, 1075–1083. doi:10.1177/1049732308320112

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