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Aging in Place in Every Community: Social Exclusion Experiences of Parents of Adult children With Autism Spectrum Disorder

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Abstract

This article offers an examination of aging processes of lifelong caregivers and the possibilities for social exclusion place experienced by parents of adult children with autism spectrum disorder (ASD). This study of parental caregivers ($n = 51$) sheds light on how enduring caregiving roles can lead to social exclusion in three ways: misunderstanding of ASD and stigma, the complexity of the caregiving roles, and impact on daily routines including challenges with long-term planning for both the adult children and the parental caregivers. Implications for practice to address social exclusion include education and building greater communication ties among family member for family members and advocacy for more and higher quality services including respite care. This article concludes with discussion of the impact of this aging, yet caregiving population and the need for knowledge about aging processes and anticipating aging for these caregivers.

Keywords

caregiving; social exclusion; autism; aging in place

Background

This article explores experiences with social exclusion among parents of adult children with autism spectrum disorder (ASD). Parents of these adult children with ASD face social exclusion in older adulthood, often experiences that are developmentally incongruent to their peers, such as not having an “empty nest” rite of passage. Instead, they must maintain their “nest” in light of their own aging processes. Despite some experiences of social exclusion, others want their adult child to remain in their homes as long as possible, emphasizing that care is best provided by parents. Social exclusion has been shown to occur with parents of adult children diagnosed with ASD, as they may feel that they cannot leave home, go out

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with friends, or engage in spontaneous, last-minute plans (Higgins, Bailey, & Pearce, 2005). Scholars have defined social exclusion in the following way:

Social exclusion is a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole.

(Levitas et al., 2007, p. 9)

This article presents the nuances of social exclusion for this caregiving population of adult children diagnosed with ASD and offers suggestions for supportive approaches to help lifelong caregivers.

Literature Review

Although considered a juvenile disorder, individuals diagnosed with ASD continue to exhibit symptomology throughout adulthood and often require lifelong support from their parents (Brugha et al., 2011). According to Anderson, Shattuck, Cooper, Roux, and Wagner (2014), young adults with ASD, when compared with young adults with other types of disabilities, were the least likely to have lived independently and more likely to have coresided parent or guardian. Individuals with ASD often lead restricted lives, have difficulty with employment, are isolated from peers, have problems accessing postsecondary education, and often place considerable challenges on their family members due to their dependency (Chamak & Bonniau, 2016; Roux et al., 2013).

Most studies have focused on the parenting of children with ASD under 18 years of age. A paucity of research addresses the experiences of grown children and their parents, and if the studies exist, they typically address intellectual or development disabilities (I/DDs) rather than ASD specifically (Wang & Brown, 2009; Wright, Brooks, D'Astous, & Grandin, 2013). Woodgate, Ateah, and Secco (2008) found that parents of young children with autism experienced adverse social consequences resulting from four main sources, including: (a) parents felt disconnected from their family, (b) the "system" was unsupportive, (c) they missed their typical way of life, and (d) society lacked understanding of their child's condition. Many parents perceived that their community lacked an understanding of ASD, making life more challenging.

Limitations of adult children with ASD can have a profound effect on parents who often continue to be primary caregivers from childhood through adulthood. As parental caregivers age, a delicate balance must be maintained between caregiving obligations to adult children and pursuing personal fulfillment in older adulthood (Hines, Balandin, & Togher, 2014). Even when adults with ASD live separately from their parents, their parents continue to be involved in their lives. This involvement, regardless of living arrangement, provides impetus for taking a "life-span perspective" when studying families of adults diagnosed with ASD. In essence, this lifelong condition of ASD can be viewed as having intergenerational effects (Hines, Balandin, & Togher, 2012).

One reason for exclusion is that the behaviors of their adult children with ASD make it difficult for parents to engage typically in terms of social opportunities and obligations. Dillenburger and McKerr (2011) reported that dealing with behavioral problems was one of the greatest challenges for parents of adult children with I/DDs. Empirical evidence provided support for the prevalence of behavior problems and their adverse effects (e.g., strain and depressive symptoms) on parents with adult children with ASD (Barker et al., 2011; Orsmond, Seltzer, Greenberg, & Krauss, 2006).

While social exclusion has been documented in other studies of parents caring for autistic children (Myers, Mackintosh, & Goin-Kochel, 2009), a major contributor to social exclusion for these parents is that they never experience relief from caregiving. The realization that there is no finality to their role as caregivers was described as being stressful for mothers of adults with ASD (Krauss, Seltzer, & Jacobson, 2005). These mothers reported stress about their need to provide care constantly and being unable to leave their adult child with ASD alone (Krauss et al., 2005). Caregiving can result in fatigue (Smith et al., 2010) and decreased time available for family, friends, and their spouses (Altiere & von Kluge, 2009). Some parents reported adverse social effects (e.g., not having time for family and friends), less frequent involvement in activities and events, and feeling trapped due to parenting demands (Lee, Harrington, Louie, & Newschaffer, 2008). Parents of individuals with ASD indicated that they missed their typical way of life and were described as living in their own world (Blanche, Diaz, Barreto, & Cermak, 2015). These caregivers experience what researchers have described as “time dependence burden,” which refers to a caregiver’s burden due to restrictions of time (Novak & Guest, 1989).

According to Altieri and von Kluge (2009), an upsetting reality for parents was the recognition that their social exclusion may result from needs of the adult child that impacted the parent’s social network. A recent study of caregivers of adult children of ASD found that parents who had an informal social support network experienced lower levels of caregiver burden and higher levels of quality of life (QOL; Marsack & Samuel, 2017). Parents with high caregiver burden and low informal social support had the lowest levels of QOL of all the study participants, indicating the need to understand social exclusion among this population.

Structural and systemic limitations exacerbate social exclusion among parents who continue caregiving roles. Many parental caregivers of adults with I/DDs experienced a lack of support and respite care options (Dillenburger & McKerr, 2011). Most participants (72%) had not made future long-term plans for their child with disabilities, while others worried about future planning. According to Dillenburger and McKerr (2011), parents of adult children with disabilities, including autism, need additional support in order to make long-term plans for their child’s future. Many parents worried about the adequacy of residential options for their adult children with I/DDs and worry about poor care and possible abuse (Dillenburger & McKerr, 2009). Parents indicated that these concerns hindered planning for their child’s future.

Other conceptual and intervention research on the intersection of aging and I/DDs remains important to advancing support for adult children with ASD. For example, understanding the

complexity and historical trajectory around diagnosing practices of I/DDs as the disability field moves toward a multifaceted approach to be person centered, and the insurance coverage afforded by these “naming practices” has tangible implications for available supports that often benefit individuals with disabilities and their parents (Schalock & Luckasson, 2013). Second, scholars in both aging and disability are developing caregiver interventions (Heller & Caldwell, 2006) and have also started analyzing differences in orientations. Heller, Gibbons, and Fisher (2015) suggested that the disability field focuses on caregiver interventions to ultimately strengthen family support for the individual with the disability, encourages future planning, and promotes self-direction of the individual with disabilities, whereas interventions to support the aging caregiver should incorporate creative approaches to reduce negative health and mental health outcomes.

Statement of Need

The majority of the literature on parents of individuals with ASD focuses on parents of children, rather than adults, with ASD (Lounds, Seltzer, Greenberg, & Shattuck, 2007; Wright et al., 2013). The literature on aging parental caregivers focuses mainly on caregivers of individuals with I/DDs rather than with ASD (Wang & Brown, 2009; Wright et al., 2013). Given the increase in the number of individuals diagnosed with ASD reaching adulthood who often require assistance from aging parental caregivers, a need exists to understand the experiences (e.g., rewards, challenges, responsibilities, overall QOL) of parents who continue to provide care for their children with ASD into adulthood. Research to investigate caregivers of adults with ASD is emerging (e.g., Cadman et al., 2012; Fairthorne, de Klerk, & Leonard, 2015; Smith, Greenberg, & Seltzer, 2012); however, additional efforts are needed. A study of aging parents of adult children with ASD is essential to understand their caregiving experiences and overall QOL.

Problem Statement

The purpose of this study was to examine the experiences of older parents providing care for their adult children with ASD. The study questions sought to learn more about participants' QOL and experiences of caring for an adult child with ASD, including learning how participants felt about caring for their adult child. The interviews attempted to understand the types of organizations that provide support to parents and the parents' satisfaction with them. The interview questions also sought to know whether and how having an adult child with ASD had affected parents' finances and personal health. This qualitative portion explored the rewards and challenges associated with caring for an adult child with ASD.

In this study, many parents indicate not being aligned with their peers (e.g., wanting to be an “empty nester” like their friends) contributes to social exclusion and separation from others. They face “developmental burden” or the perception for parents of adult children with ASD to perceive not being aligned with other parents of an individual without disabilities (Novak & Guest, 1989). In addition, as caregivers reach older adulthood, challenges external to parenting a child with a disability can become problematic. The parental caregivers of adult children of ASD are also experiencing their own aging processes, including mental and physical health concerns, and may be caring for partners' concerns. As older adults imagine

their own aging trajectories and mortality, they are concerned by the future of their children's housing and care needs in addition to their own. Many parents of adult children with ASD experience developmentally incongruent realities that show the need for targeted practice interventions to address the concerns of this population.

Recruitment

This qualitative study was a follow-up of a larger web-based study of 320 caregivers of adult children with ASD (see Marsack, 2016) focusing on examining the effects of caring for an adult child with ASD on parents' QOL and social support. After receiving institutional review board approval from Wayne State University, the researcher contacted organizations and professionals that provide support and services to parents and individuals with ASD to obtain permission to place links to the web-based survey on their websites, in their newsletters, and through e-mail to encourage their members to participate in the study. In addition, the researcher engaged in face-to-face recruiting efforts (e.g., support groups and conference booths). Some participants were recruited through snowball sampling through referral from parents of adult children with ASD. At the end of the web-based survey, respondents were asked if they would participate in a follow-up interview. A total of 186 of the 320 participants indicated interest. A random sample of 51 (27.4%) parents completed the interviews. Interviews were scheduled and conducted by the principal investigator.

Sample

Fifty-one parents (aged 50 and above) of adult children with ASD participated. Forty-six of the 51 parents were mothers and 5 were fathers. The parents ranged in age from early 50s to 70s. Parents varied in geographical locations in the continental United States, including individuals both suburban and rural areas. Most parents had at least one other child in addition to their adult child with ASD. The children's ages range from 18 to 44. Many adult children were receiving public education (either the high school or a postsecondary setting) or had recently aged out of public schooling. Most parents indicated having a male adult child with ASD, with 10 parents indicating having a daughter who supports the tendency that males are diagnosed approximately 4 times more often than females (Christensen, 2016). Adult children with ASD, as described by parents, varied in their abilities to function in the following domains: social, communication, education, daily living, and employment. Names of participants have been changed to pseudonyms.

Method

Although pilot interviews were not conducted, professionals in the area of ASD and DDs checked the readability and the thoroughness of the questions. Eight professionals were given the interview questions and asked for their critical feedback and suggestions. They offered suggestions to improve the readability of some items. Improvements were made to the phraseology of questions.

Data collection took place over approximately a 2-month period. For purposes of this study, in-depth, semistructured interviews were conducted via phone (with the exception of one

interview conducted in person). An interview script, with corresponding questions, was used for parent interviews. Questions sought to learn more about participants' QOL and experiences of caring for an adult child with ASD, including learning about how participants felt about caring for their adult child with ASD. The interview attempted to gain an understanding of the types of organizations that provide support to parents and their satisfaction with organizations. The interview questions also sought to know if and how having an adult child with ASD had affected parents' finances and personal health. In addition, this study attempted to explore the rewards and challenges associated with caring for an adult child with ASD. Although social exclusion was an emerging theme, this study did not explicitly examine social exclusion, which is why a question focusing on social exclusion was not specifically asked.

Individuals participating in one-on-one interviews received a US\$20 gift card as a token of appreciation for their time and for sharing their experiences. The interviews ranged in length; however, most took approximately 1 hr. Individuals were provided information about the follow-up interview. All participants consented to allowing his or her interview to be recorded. Interviews were transcribed by an experienced transcriber. Any identifying information in the recordings was deleted from the transcripts. Qualitative interviews were analyzed by the primary investigator (PI) using Atlas.ti 7 software, grounded theory approach, and line-by-line analysis to determine present themes (Charmaz, 2011). To check for accuracy, the typed interviews were proofread and corrections made by the PI. Using grounded theory informed principles, member checking was completed by corresponding with all study participants to clarify the meaning of their responses to ensure the validity of interview data. The PI communicated with interviewees via e-mail to develop and confirm codes. For example, the PI included a quote and her interpretation of the statement followed by a question on whether the interpretation could be affirmed by the study participant. This correspondence allowed clarification and provided confirmation of longer responses.

Findings

When analyzing the interviews for experiences of social exclusion, three key externally homogeneous themes emerged: misunderstanding and stigma, complexity of caregiving roles, and impact on daily routines. In our discussion, we focus on how these three themes lead to an emphasis on living in the present, which may result in a lack of planning for the future.

Misunderstanding and/or Stigma

First, many participants recounted the misunderstanding that comes from lack of knowledge of ASD and variations within the spectrum that contributes to relatives, friends, professionals, and the general public not understanding what behaviors to expect from adults diagnosed with ASD. Respondents expressed that these misunderstandings can lead to stigma experienced by the caregiver. Stigma was explicitly mentioned in interviews. For example, a mother of two children with ASD said, "There's a hell of a stigma that comes with this."

Stigma can result as an assumption that ASD behaviors are reflections of parenting ability. Mr. Smith from the Midwest says, “Well I think it’s a, it’s, the culprit is a lack of awareness and so the—when a, when a kid is quirky, they kind of blame the parents—it suggests somehow the parenting skills.” This parent discussed challenges faced in dealing with the school system, including resistance regarding individualized education plans (IEPs) designed for students receiving special education services.

They just did not get it and, and so we were, we were the fanatic goofy, goofy parents that, the parents from hell that, that more, so there, it just got to a point where there was just huge posturing—and resistance and so in order to compensate for it, they’d have IEP meetings where they’d invite fifteen people.

He used the word “fanatic” and “goofy” to describe his perceptions of how others viewed his parenting rather than demonstrating an understanding of ASD. His feelings of being disconnected and misunderstood by the school system resulted in many battles, leading to “bitter” feelings for him and his wife. He said, “I call it criminal!” Mr. Smith described the district not “treating her ability, rather than her disability”—finding this to be a problem “ever since she entered the public school system.”

Several interviewees talked about misunderstanding among relatives, friends, professionals, and the general public with regard to specific behaviors by adults with ASD. Mrs. Norman described the questions she heard from others about her adult son with ASD who almost finished his PhD in graduate school. She said,

... “why is he doing that, why does he act like that, why can’t he talk to us, why can’t look us in the eye?” That’s been an issue for him since he was 2 years old. “Why can’t he look at me when I talk to him?” ... And then we have to try to explain it, it’s hard when he’s right there, trying to explain it. ... it’s an ongoing issue.

In ASD, lack of eye contact is a recognized behavioral manifestation, yet Mrs. Norman had difficulty in communicating the rationale for her adult son’s atypical behavior, especially when these questions occur in her son’s presence.

Parents also shared the difficulty of everyday tasks like shopping in public places.

You know what the hardest part is? When you go out in public, how come people still stare at you? ... And you know that’s the part that bothers me. It’s like you’re in [name of store] checking out and [name of child] might be pacing a little bit. He’s quiet, but he’s not acting like a difficult person. Why do people have to stare? Aren’t they over this? 1 in 68 kids has autism. Everybody knows somebody (*emphasized*).

Mrs. Noori brought up the behavior of pacing, common among this population, expressing disappointment that despite ASD’s prevalence, shopping is an activity where she is subject to being on display and judged. The existence of ASD could lead to a different kind of stigma, questioning the reality of the diagnosis itself. Mrs. Bolton, parent of a 38-year-old son diagnosed in his early 30s, said, “... there seems to be something of ... a backlash, but a

lot of people ... [don't] think Autism Spectrum is real. You know, it's kind of ... the newest trendy diagnosis."

Study participants found it difficult to convey information about ASD even to family members. Mrs. Norman, mother of a coresiding adult son with ASD, illustrated, "Relatives don't get it at all." This mother elaborated,

They don't understand and they don't want to understand and when we try give them information or try to share reading material or anything that ... they don't bother to read what we give them, they don't bother educate themselves about this issue ... I said to him [son] one time ... when he was in college if he missed his cousins ... and he said, "no, they don't me, they never did."

As an only child with deceased parents, she did not have relatives of her own and she perceived that her husband's family did not want to understand ASD. Her words illustrated a lack of understanding for herself and her adult child with ASD.

Parents felt stigmatized from perceived misunderstanding by others of behaviors of their adult children with ASD. Even leisure activities can be affected, even if one's adult child is living independently. Ms. Blake, mother of a 29-year-old daughter with ASD, who was not diagnosed until the age of 27. This mother offered sentiments of social judgment,

... when you're on your way somewhere and your daughter calls and they know that your daughter is 29 and you say, "I'm sorry. I no longer can come to dinner with you cause I've got to go home and take care of an adult woman." You start to experience a lot of prejudice and a lot of people who think, "What's wrong with you?"

Ms. Blake also experienced these questions from coworkers.

... because the initial reaction is, "What's wrong with you that you are-"
Coworkers when I have to take phone calls during the day at work because she's in her, as she calls it her "crazy mind." It's just hard to explain to everybody that this is a person with special needs and I am the person that takes care of her most ...
And the, and then later they're like, "What do you mean your daughters thirty, or almost thirty? And-" So it's a very general prejudice.

These data suggested that the misunderstanding of ASD led to stigma and a misunderstanding of the caregiving roles that these parents continue to occupy. Importantly, those with ASD may not display physical markers of disability so they are perceived to be neurotypical adults. In Ms. Blake's case, her adult daughter is verbal, employed full time, and has nearly completed her associate's degree, making it difficult for others to understand her daughter's nonnormative needs. Therefore, reactions of family, friends, and strangers may occur as if the adult children do not have disabilities.

Complexity of the Caregiving Roles

A second theme is insight into the complexity of caregiving roles for this population. First, the all-encompassing obligation on the caregiver's life is expressed by Mrs. James, mother of an adult son who has exhibited previous violent behaviors. She notes, "So it's like

walking on egg shells all the time.” Interviewed separately, Mr. and Mrs. Dundee discuss the sacrifices they made to provide care for her son with extreme behavioral manifestations, including 7–10 “violent outbursts” per day. After their son was refused public schooling and inadequate organizational supports, their family moved across a Midwest state in hopes of a better life. Mrs. Dundee stated, “I thank God we did pick up and move. I’m miserable, have no family, no friends here, but look at how far my son has come, we bankrupted out, we cannot really work jobs outside of the home ... “ She described a “lack of acceptance from society” and a lack of understanding for the need for supports. Her son continued to require around the clock care but is fully integrated into the public school setting at this time and is receiving supportive services. Mr. Dundee echoes a number of sacrifices including filing for bankruptcy and leaving his job. This couple continues to be impacted on a daily basis to navigate the 24/7 needs of their adult son but are grateful for the progress their son has made over the last few years.

Ms. Tall, a single mother of an adult daughter living in the south, provides more detail,

And I think there’s nothing wrong with feeling this, but it’s still to this day hard for me to say, I want something different, I do want to have an empty nest. I want it, I crave it, it’s in my, every cell of my body. I want time alone. I don’t, I want time to be “off” instead of “on”. I don’t go down the street, I don’t go down to the grocery store, I don’t even take a walk. And it’s like, she’s not the most severe person in the world, but still, I don’t leave her alone. That is something significant 24/7 for, for anyone, but especially someone that’s nearing retirement age. I want to breathe.

In the interview, Ms. Tall compares her life to others of her same age and man of her peers, and how she views herself as different, both in her emotions and in the actions she foregoes like having dinner with a friend. For her, social exclusion sometimes becomes inherent of the caregiving role. Now, at the age of 55, she expresses wanting the developmentally typical reality which includes “pining for an empty nest.” She describes this reality being threatened due to the lack of services in her particular state, services indicated as being “the big black hole, the big abyss.”

The presence of the adult child with ASD may affect the activities of other members of the household. Mr. McCain, from the southwestern region, says,

Well, I mean, it, it, it—his, his—sort of, one thing that affects things is his, he doesn’t like violent movies or movies that are very loud or anything. But my other kid, likes that stuff and so, when he’s in the house, they can’t even, they can’t play any of that stuff so he could hear it, they can’t, or see it obviously, and in fact you really can’t talk about that stuff, it really gets him upset.

Other children have and continue to also be affected by the experience of growing up in this type of household as it can strain relationships.

There’s a lot of resentment from my other kids to go to their rooms and, and they don’t wanna. They’re in, they’re all in therapy too and my old, one of my daughters, one of the things she’s working through is her resentment growing up with Sam (*son with ASD*). So, it’s just when he’s home, the situation has to be

controlled if we want him to be okay. I want it to be that way, cause if he's okay, mom's okay, if mom's okay, I'm relaxed.

Since parenting an adult child with ASD consumes much energy and time, other children's milestones must be balanced over time.

And as a family unit, it's been difficult for us because we always have to do things separately and so that's another reason why we wanted to have a staff member. Because of her (*staff member*), all five of us were able to go to Cecelia's (*name of daughter graduating*) graduation. And of course we didn't bring Mark (*name of adult child*), I wouldn't put him through that.

This mother of four, Mrs. O'Neill, discusses the challenges of having an adult son with ASD and supporting the competing needs in supporting all of her children. Throughout the interview, she illustrates some really great staff members and some staff members that have been challenging (e.g., the staff member sent to care for her son with no training or the staff member sent who was physically unequipped to provide care due to a heart condition).

However, sometimes, the needs of the other children provided respite. One mother from the Midwest discusses the supports offered by her other children by saying, "Actually all the children are very supportive." Another mother of an adult daughter with ASD has the support of her other two other adult college-aged adult children for to help with the provision of care during her work day. For another mother, Mrs. Young, moving her other child (without ASD) into a dorm room was a moment of respite and dread. She explains,

And I was gone for those days and I just remember, she goes to school in Chicago and I just remember sitting out there in her bedroom and just crying and crying because I had to come home. I had to come back and I didn't wanna come back and I knew I had to.

She cried not for the child she was leaving but for her adult child with ASD she would be returning.

Impact on Daily Routines

Due to the first two themes, misunderstanding and stigma and complexity of caregiving roles, parents recounted compromises to their routines that can lead to experiences of social exclusion. The third theme, impact on daily life, provides insight into the ways parents navigate their other relationships and personal interests and also provides evidence to areas where support is needed. The impact on daily life also shows a double bind of caregiving in this population, which misunderstanding and stigma, complexity, and related impacts on daily life may actually promote exclusion.

Respondents talk about the strain on other important relationships including the relationship between the two parents. Mr. Connor, parent of an adult daughter with ASD, expresses, "... it can be stressful in a marriage ..." Mr. Thomas, parent from the southwest region coresiding with his adult son with ASD, echoes this same marital stress,

Well I think it's mainly put a strain on our marriage, we have deep commitment to him, but we learned a long time ago, you never stop being a parent, no matter how old your kids are, but we never expected this level of parental involvement.

And with the caregiving comes logistical navigation on the mind of couples. Mr. Norman goes on to say, "I think it's the emotional drain, and the emotional worry, the, constantly, okay if we do a shift in the schedule how is it going to affect Matt (*adult son's name*) if Martha (*wife's name*) and I go out on our—if it's our Friday night date, which we always have, if we want to switch it to Saturday night, how is that going to play for him." Other interviews mentioned areas where couples struggle in the following ways: dividing and managing caregiving responsibilities, differing views of how to best meet the needs of the child, and the absence of one spouse in caregiving roles.

Some parents, even with the presence of coparenting, struggle with the pervasive caregiving needs of their adult child with ASD. For example, Mrs. James says, "My husband and I can't do anything really once he's home from school everything has to revolve around who's going to watch him right now." For this mother, she describes the task to watch her adult son to be so challenging due to his inappropriateness, including undressing himself outside.

Other parents talked about how it impacts how they navigate their homes. Mrs. O'Neill (introduced earlier) stated, "So the biggest stressor is lack of privacy, lack of quality time, sacrifices time, just having no normalcy." A father, Mr. Norman, echoed Mrs. O'Neill's statements,

There's certainly less privacy, much less privacy you can't have—our house is two stories, but it's got an open living room and there's literally no place to have a conversation any place in the house that someone else elsewhere can't hear.

And for others, going out itself was not a realistic option, so parents experienced social exclusion due to feeling like one can't leave the house due to needs of adult child. Mr. Dundee recounted, "For me, it is trying to empower her to be able to leave the home and just feel that she can leave the house and to trust the staffing that's available." These expressions illustrated willingness of one partner to allow a respite care worker to provide care, and the other parent wanting to care for her child. However, sometimes, the result is that the couple does not go out, and this dynamic promotes experiences of social exclusion. In other interviews, professionals were seen as improving the families' QOL including marital relationships, transitions out of high school, and other support needs.

For those where going out may not be an option, receiving visitors might be an important way to maintain social ties. Several interviews revealed difficulty having friends over particularly due to their adult children's atypical behavior and/or outbursts. Even with preparation, it is difficult for many parents to invite guests into their home. Another mother, Mrs. Norman, indicates,

A lot of friends don't really understand this and they never have ... Let's see what else ... I guess I would just say, in general we tend to isolate more because he's living with us (crying).

Daily life can be challenging for many parents. In fact, for some families to participate in this study, arranging interview times when the adult child was not present was essential to participating. Completing the interview while her son was out of the home, Mrs. Norman said, “We would not have called you at a time where he was in the house.” Despite high-functioning status, his parents both acknowledged that they would not have participated had he been disturbing to him.

In the end, the impact on daily life is significant. Ms. Tall says,

I could certainly look around me and see people have it a lot worse but it does, I can't be spontaneous and even though I've had the same, I've lived in [name of state] for 14 years and I've had the same friends for 14 years, they still don't get I can't be spontaneous.

Because of the need for individuals with ASD to require some form of provision of care into adulthood, and for some constant provision of care, many families must negotiate the daily changes such as preparing an adult child for a change of a meal, different TV show, or arranging for a caretaker to leave the house.

However, due to the uniqueness of their caregiving roles, there is a need to balance the challenges of providing routine, day-to-day care with long-term planning. Most parents indicated that they are worried who is going to care for their adult children with ASD. For example, Ms. Blake states,

... part of my head goes, “If something happens to me, who's gonna help her? Who's gonna get her through her meltdown? Who's gonna explain what her boss means when her boss sends this e-mail? Who's gonna do those things?”

Sadly, many parents not only worried about the future but also felt limited by time as they were caring for their adult children and/or confined to the subpar services.

Discussion

This study found that parental caregivers of adults with ASD experience challenges of social exclusion along three themes: misunderstanding and stigma, complex caregiving burdens, and daily life impacts. A better understanding of this population with enduring caregiving roles will lead to more nuanced ways of understanding the variability of pathways of aging and its impact on social exclusion. Research demonstrated the impact of location on parents and their adult children with ASD often being associated with variations in service availability based on location (e.g., state-to-state variation, within-state variation, rural vs. suburban variation in services; Antezana, Scarpa, Valdespino, Albright, & Richey, 2017). This study illuminates the meaning of enduring caregiving roles, often affected by the impact of location, in an older adult's social convoy model.

Figure 1 describes the contributing factors to social exclusion for this population as found in our data analysis. We suggest that there is a cyclical nature to these challenges. Particularly, salient is its impact on long-term planning, both in planning for the care of the adult child with ASD and in planning for and addressing the older adult's own health concerns and

aging processes. In addition to health, the lack of age concordance with other older adults with empty nests means that planning for the older adult's housing needs in terms of mobility, safety, and affordability are possibly underexamined. Lastly, this cohort of parents of adult children with ASD likely experience greater financial strain, perhaps at a lesser rate than future cohorts. Some reported quitting their job, foregoing work promotions and opportunities, for some quitting their jobs to provide care, and relocating in the hopes of better services leads to financial concerns. Due to the adoption of autism insurance, enabling the availability and accessibility of specialized services for individuals with ASD, future cohorts may have less strain. This should counter families spending their own savings and retirement on care. Many older adults seek advice on health, housing, and financial concerns from family, friends, peers, and professionals. For example, these caregivers may not be able to spend time in senior centers and support groups. Since the experiences of these parental caregivers limit such contact, social exclusion may lead to knowledge asymmetries on such important topics. Thus, social exclusion may have great impact on how they age in place. We should also consider how can such caregiving experiences be viewed as a social determinant of health and well-being.

Although this work focuses on the challenges of social exclusion, it is important to also illustrate the presence of rewards among most parental caregivers. In this same study, results demonstrated both changes in the parental caregiver, such as greater patience and a changed perspective, and noted progress in the development of the adult children with ASD. Additionally, changes in interpersonal relationships at both the family level and the community at large as members advocate for increased awareness and services on behalf of individuals with ASD. Other rewards to caregiving in the relationship between parents and their adult children with ASD also could include reciprocity in care. Both emotional and tangible reciprocity in care have been demonstrated to be of particular importance and benefit for aging parental caregivers of adult children with ASD (Perkins & Haley, 2010, 2013; Williams & Robinson, 2001).

Study Limitations

First, this study primarily recruited participants who were members of many ASD support groups and national organizations. Although snowball sampling was attempted, the sample may not have included parents of adult children diagnosed with ASD who were not part of such groups. In addition, some organizations may not have been included and/or represented in the recruitment efforts. A second limitation of this study was the lack of information using a formal measure regarding the severity and degree of ASD for the adult children. In addition, as this qualitative investigation is comprised of participants from the larger study, there was an overrepresentation in both studies of people who had higher family incomes and education levels than the average American. A third limitation is that we oversampled female caregivers and most interviewees parented male adult children. The role of gender is underexplored, and future research should address the role of gender, especially given the prevalence of caregiving roles assumed by females.

Most participants found the interviews to be therapeutic and enjoyed the experience despite the sensitive nature of the questions. Although the interview guide did not explicitly ask

about social exclusion, given this article's focus on supports, rewards, challenges, and QOL, key elements and thematic findings related to feelings and experiences of social exclusion were illustrated in participants' responses. We would also have liked to know more about how the caregivers understand the link between their child's well-being and domains of their own aging processes. While a few of the interviews were short (approximately 20 min), most were lengthy. For the shorter ones, the need to provide care made it challenging to expansively answer questions. If an alternative interview format could have included respite care, perhaps the interviews would have been more in-depth.

Implications for Practice

The results of this study, consistent with other research findings, elucidate the need to educate mainstream society and develop programs and services to support the lives of adult children with ASD and their parental caregivers (Hines et al., 2014). To address the first theme, misunderstanding and stigma, social workers and other mental health professionals should be supported in educating family members and the public about ASD. Specifically, education should focus on illustrating the range of characteristics associated with this disorder. Through the efforts of social workers, greater awareness and increased understanding of ASD could result in the public becoming more accepting of individuals with ASD. Through this acceptance, parents and their adult children with ASD could gain access to formal and informal social support, which is important in decreasing their social exclusion. To address the second theme, the complexity of caregiving challenges, such as the need to help with the sustaining marital relationships and providing care to other siblings, programs, and services need to target the needs of parental caregivers and their families. Other service issues that promote social exclusion include (a) subpar staff and services/lack of services that place greater burden (including burden from a time perspective) on these care-givers and (b) service navigation/advocating for quality service that takes energy and time, making it difficult to engage and feel included socially. Yet, when compared to formal supports, informal social support networks have a greater effect on promoting social inclusion (Marsack, 2016).

Social workers and other professionals should take an active role in developing and refining services to help parents obtain needed assistance for their adult children. Specifically, the need for reliable respite care is essential, given the needs imposed on these lifelong caregivers. Additionally, professionals should be aware that siblings may provide future care for individuals with ASD. These siblings may need access to education, support, and services to assist in their caregiving roles (Tomeny, Barry, & Fair, 2016). The final theme emphasized the challenges from daily routines parents experience on a daily basis. In addition to educating those in these parents' social networks (family members, employers/ coworkers) on challenges that ensue from daily routines, support could be given to parents on effective ways to address these concerns in the moment. For instance, strategies on shopping or letting relatives know how essential the communication is and how to derive visits/phone calls that are understood and agreed upon.

It is also relevant to consider the high levels of comorbidity between intellectual disability and ASD in this study's sample, as similar to current literature, making it difficult to

ascertain the manner in which parents' experiences are impacted by either of these two conditions (Srivastava & Schwartz, 2014). Regardless, many individuals with ASD and their families are impacted by the inseparable reality of both conditions, posing potential additional challenges for aging parental caregivers that are relevant for practitioners to consider and address support approach.

Conclusion

Older adults in our study experienced social exclusion. As these caregivers age, they will experience personal challenges as well as structural challenges such as the cost of health care and long-term care. More attention to understanding the unique experiences of social exclusion of this population is needed, including how the spheres of exclusion might differ by gender, socioeconomic status, and state where they reside. The latter is particularly relevant, given the variety of respite and support services for caregivers. Even within states, understanding the rural, suburban, and urban experiences of caring for adult children with ASD is important to advocate for and enact policies that address unique challenges. These needs include knowledge about aging processes and anticipating aging for these caregivers, including how to consider "care replacements" such as other children in the family. Equally important is knowledge is needed about caregiving differences between children/adolescents with ASD and adults with ASD. For example, parents of children and adolescents with ASD often prioritize navigating school-based services, while the priorities of parents of adults may include employment, transportation, and independent and/or group housing options. Indeed, the intersection of aging and disability is highlighted with this population; and to truly serve these caregivers, we must draw from the resources and expertise from both sectors.

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Figure 1.
Contributors to social exclusion for parental caregivers of adults with autism spectrum disorder.