


Tensions in Maternal Care for Children, Youth, and Adults With Autism Spectrum Disorder

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Abstract

This study explored the experiences of mothers caring for an individual with autism spectrum disorder (ASD) ranging from 5 to 25 years of age, and examined pervasive tensions in caregiving. Guided by ethnographic methods, a retrospective cross-sectional study was conducted. Interviews with 85 mothers were analyzed inductively. Prevalent tensions in maternal caregiving were identified: (a) difficulties obtaining, yet resistance to, an ASD diagnosis; (b) identified giftedness of the child versus notions of deficit imposed by others; (c) disability-related behaviors erroneously interpreted as ‘poor parenting’; (d) contradictory considerations in diagnosis disclosure; (e) the invisibility yet pervasiveness of ASD; (f) extensive need for, yet the lack of, accessible services; (g) ASD-related care demands versus other pressing responsibilities; (h) arguments for inclusive versus exclusive services; and (i) aims of nurturing independence versus managing safety risk. Tensions were heightened by insufficient supports relative to need. Implications and recommendations for practice and policy are offered.

Keywords

autism, mothers, mothering, caregivers, lived experience

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Introduction

Maternal caregiving for a young person with autism spectrum disorder (ASD) is multifaceted, extensive, and long term (Nicholas et al., 2016). Considerable energy must be expended to navigate and manage ASD interventions, while attending to the typical needs of the child or adult with ASD, managing other household needs, and maintaining employment. Predictors of heightened stress include lower parental education (Dabrowska & Pisula, 2010), lower socioeconomic status (Zablotsky et al., 2013), and minority race (Zablotsky et al., 2013). Mothers have identified challenges associated with raising children with ASD, including guilt, worry, stress, and fear (Fairthorne et al., 2014; Ingersoll & Hambrick, 2011; Kiami & Goodgold, 2017; Meirsschaut et al., 2010; Myers et al., 2009; Nealy et al., 2012; Safe et al., 2012; Sim et al., 2018), along with familial and spousal relational strain (Fairthorne et al., 2014; Myers et al., 2009; Nealy et al., 2012; Safe et al., 2012), decreased time for self-care (Al-Kandari et al., 2017; Fairthorne et al., 2014; Meirsschaut et al., 2010; Myers et al., 2009; Nealy et al., 2012; Safe et al., 2012), diminished social support (Fairthorne et al., 2014; Meirsschaut et al., 2010; Myers et al., 2009; Nealy et al., 2012; Safe et al., 2012), financial tension (Fairthorne et al., 2014; Myers et al.,

2009; Nealy et al., 2012), and mental health concerns such as depression and anxiety (Fairthorne et al., 2014; Ingersoll & Hambrick, 2011; Langley et al., 2017; Meirsschaut et al., 2010; Myers et al., 2009; Nealy et al., 2012; Safe et al., 2012; Weiss et al., 2011). Sim et al. (2018) noted that higher family stress coincides with the less social engagement, a lack of access to individualized therapy, negative relational impacts of ASD on parents, and high monetary costs associated with ASD. Maternal stress is also correlated with ASD symptoms and behavioral issues (Miranda et al., 2019). Despite some variation reported in the literature, maternal stress is noted to

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decrease as the mother and child age (Benson, 2014; Gray, 2002). Such decreased stress over time is hypothesized to reflect service accessibility, parental coping, and greater ability to manage care for the child with ASD (Gray, 2002), though mothers' perceptions of parenting efficacy do not appear to increase concomitantly (Benson, 2014).

According to Corman (2013), mothers may be affected by broader societal discourses that suggest what it is to be a 'good mother'; as such, a child's challenging behaviors may be attributed to negative judgments about mothering, and thus result in stigma toward mothers (Corman, 2013). The potential of placing a child with ASD in a care environment outside the family home may cause maternal guilt and worry (Corman, 2013). Mothers of offspring with Asperger's Syndrome were reported to experience a sense of inadequacy, with conflicting feelings of being too involved in their child's care, yet not doing enough for them (Gill & Liamputtong, 2011); similar feelings of inadequacy have been noted in other studies (DePape & Lindsay, 2015).

Previous research has detailed that mothers of children with ASD assume increased responsibilities compared with mothers of neurotypical children (Kuhaneck et al., 2010; Safe et al., 2012). These added responsibilities of care may conflict with employment possibilities, potentially resulting in work schedule modifications or mothers leaving employment altogether (Fairthorne et al., 2014; Meirsschaut et al., 2010). Gill and Liamputtong (2011) reported that mothers of children with Asperger's Syndrome experience guilt associated with engaging in employment rather than focusing on caregiving.

Additional caregiving responsibilities may impose possible relational strain with a spouse and other family members (Fairthorne et al., 2014; Nealy et al., 2012; Safe et al., 2012). Mothers have described "put[ting] on a mask" with their partner, friends, or in public, in an effort to hide negative thoughts and feelings, and convey strength and ability to cope (Gill & Liamputtong, 2011, p. 51).

However, positive elements are also noted in the literature. Raising a child with ASD has been described as a process of redefinition and adaptation (Lutz et al., 2012). There may be a shift in perspective to seek positive outcomes that result in "joy and peacefulness" (Kuhaneck et al., 2010, p. 347). A metasynthesis by DePape and Lindsay (2015) reported instances of increased closeness between parent and child as well as between spouses, gains in coping abilities, and adjustment to one's worldview.

Although a growing body of research has examined mothering in ASD, there is a vast array of experiences and little is known about how ASD-affected mothering is experienced over time, particularly as the mother and their child ages. To address this gap, this analysis explored the experiences of mothers of children with ASD across the developmental course (up to 25 years of age), with a focus on maternally reported experiences in care. Of note, the roles and tasks of maternal care, based on an earlier review of this data set, is

reported elsewhere by this research team (Nicholas et al., 2016). This article expounds on what mothers indicated to be dilemmas or tensions in their everyday care for their son/daughter with ASD. Research questions addressed herein are: (a) What challenges and tensions are experienced by caregiving mothers? (b) How are these challenges navigated? and (c) What would assist mothers as they provide care? This analysis and article, thus, are novel by distinctly focusing on mothers' commonly expressed tensions, incongruities, inconsistencies of experience, and daily struggles associated with ASD-based caregiving.

Method

This retrospective cross-sectional study utilized semistructured interviews conducted with mothers of children, youth, and adults with ASD, based on a purposive sample, stratified by offspring age (5–25 years). An ethnographic approach was selected to orient personal experience in mothers' socio-cultural context and related elements of experience—in this case, motherhood and ASD. The overall study from which this substudy was drawn, also included participant observation; however, only interview data were used for this article.

The sample consisted of mothers who resided in or near one of three Canadian cities, which were selected for convenience relative to researcher location as well as diversity in the range of services to individuals with ASD and their families. Regional variation thus allowed for inclusion of service and resource policy diversity. All mothers had offspring with a formal diagnosis of ASD and provided substantial care to that individual in the family home. Youth with ASD tended to be current or past recipients of support services related to ASD. Recruitment processes were identical across regions, with potential participants initially informed of the study by a service provider who was known to them, but was otherwise uninvolved in the research. Upon learning of the study, mothers were asked about their potential interest in hearing more about the study and if so, their contact information was shared with the research team (with their permission). These individuals then were contacted by a research assistant who described details about the purpose and procedures of the study. If study participation was desired, informed consent was obtained and an individual interview was scheduled. Institutional ethics board review and approval was received by host institutions (University of Alberta, University of Calgary, and The Hospital for Sick Children) prior to study commencement.

Data Collection and Analysis

An interview schedule outlining broad, open-ended questions was developed by engaging content expert clinicians and researchers/methodologists in determining salient questions that addressed research aims in the context of the practice experience with families and the literature. Interview

questions developed and ultimately addressed to participants were: “how are you involved in your son/daughter’s care?” “how is autism a part of your life?” “what is this like for you?” “how would your life be different if your child did not have autism?” “how has autism-related experiences and needs changed (or stayed the same) over time?” “what has helped you in what you do for your family?” “what has hindered you in what you do for your family?” and “how have the services provided to your son/daughter been a part of your experience?”

Interviews were held at times and locations convenient for participants, and lasted 1.5 to 2 hr. Interviews were audio-recorded and transcribed verbatim by a professional transcriptionist, with identifying information removed from transcripts. The analysis of transcripts was independently completed by two research assistants. Transcripts were subjected to line-by-line qualitative coding, concept saturation and categorization, which was supported by NVivo data management and analysis software (QSR International, 2012). This process reflected McCracken’s (1988) ethnographic long interview approach in generating codes, categories, and themes. Analysis drew on established traditions of ethnography, with “on-the-ground” implications sought in the aim of informing practice and policy communities.

Interviewers and data reviewers brought extensive backgrounds in qualitative inquiry, and were trained and supervised by the principal investigator. As an indicator of methodological rigor, trustworthiness of study findings were demonstrated by multiple means such as *interrater reliability* (review of the data by multiple coders who reached consensus on themes), *negative case analysis* (review of the data for divergence from emerging codes and categories), and *peer debriefing* (confirmation of “expert” resonance with emergent themes; Erlandson et al., 1993).

Results

A total of 85 mothers participated in the study, stratified by offspring age grouping (5 years and less: $n = 22$; 6–12 years: $n = 34$; 13–17 years: $n = 24$; 18–25 years: $n = 20$); some families included more than one child with ASD. We sought to explore experiential similarities and differences across child/youth/adult development. Furthermore, sample diversity was sought across a wide range of cognitive, communicative, and behavioral expression, based on represented individuals with ASD. Beyond diversity in age and phenotypic expression, sought-after sample variation included parent employment status and socioeconomic demographics (however, we did not reach extensive income variation in the sample; see Table 1). Upon data review, saturation of findings was determined to be achieved based on our observation of the robustness of emergent findings, with relative consistency in thematic representation.

Mothers generally reported that ASD-related caregiving tends to absorb significant portions of their daily life.

Pressing demands included continually thinking about, planning, monitoring, advocating and nurturing their child and her or his care needs (see more details in Nicholas et al., 2016). Yet, mothers described protective factors such as employment, social support, nonchallenging behavior of their offspring, an increased sense of personal mastery over care demands, and personal coping. Generative outcomes included relational strength, a sense of mastery, and evolved purpose and focus.

From this analysis; however, results further revealed several prevalent tensions in maternal caregiving. These tensions were often perceived by mothers to be introduced or heightened by ASD and its associated experiences, including care and resource requirements. Identified tensions included: (a) recognizing ASD-related symptoms yet struggling to obtain or conversely resisting a diagnosis; (b) recognizing inherent gifts in the child versus imposed messages depicting deficit; (c) grappling with the “pros and cons” of the potential disclosure of the ASD diagnosis; (d) the invisibility yet pervasiveness of ASD in daily life; (e) the need for services yet simultaneous lack of service availability or accessibility; (f) responsibility to respond to ASD-related care needs amid other pressing responsibilities; (g) facing accusations and/or internalization of “poor parenting” versus extraordinary care provision; (h) considering inclusive versus specialized or segregated environments; and (i) fostering independence versus fear of heightened safety risk.

These tensions sometimes were mediated (e.g., tempered or exacerbated) by pressing needs at a given juncture in child-to-adult development or circumstance (e.g., heightened ancillary mental health issues), although some elements were pervasive across time. For instance, seeking a diagnosis of ASD, along with associated worries and tensions for mothers, primarily emerged during children’s young years. Conversely, tensions of unmet service needs were experienced across all age strata, but often were initially experienced. Also across ages, the invisibility yet pervasiveness of ASD yielded tenuous instances of the need for, yet lack of, understanding and support from others. In the following section, each reported tension is described.

Initial Indicators of ASD: Recognizing Symptoms Versus Obtaining a Diagnosis

An early tension experienced by mothers arose with their recognition that something seemed amiss in their child’s development, as compared with neurotypical peers or expected milestones. In some instances, a physician, family member or friend had identified indicators of delay and/or felt that missed milestones warranted assessment and/or concern. Mothers described internal conflict and sometimes disagreement with these opinions. They described responding with shock, fear and anger, and initially wanted to avoid further “bad news,” yet at the same time desired help for their child.

Table 1. Sample Demographic Data.

Sample Characteristics	M (SD)	n (%)
Total no. of participants		85 (100)
Community (by population)		
Rural (>1,000 population)		5 (6.9)
Small population center (1,000–29,999)		4 (5.6)
Medium population center (30,000–99,999)		6 (8.3)
Large population center (above 100,000)		70 (92.9)
Family constellation ^a		
Married		73 (89.0)
Separated or divorced		7 (8.5)
Single		2 (2.4)
Age of mother (years) ^b	43.4 (7.1); range: 28–57	
Employment status of mother ^c		
Full-time		29 (36.7)
Part-time		21 (26.6)
Unemployed		29 (36.7)
Highest level of education—mother ^d		
High school		7 (9.6)
College		17 (23.3)
University		49 (67.1)
Household income (CAD) ^e		
Under 20,000		2 (3.3)
20,000–39,999		6 (9.8)
40,000–59,999		5 (8.2)
60,000–79,999		9 (14.8)
80,000–99,999		6 (9.8)
Above 100,000		33 (54.1)
No. of children in the family		
One		11 (12.9)
Two		44 (51.8)
Three or more		30 (35.3)
No. of families with one child/youth with ASD		68 (80)
No. of families with two or more children/youth with ASD		17 (20)
Age of children/youth with ASD (years)		
5 and less		22 (21.8)
6–12		34 (33.7)
13–17		24 (23.8)
18–25		20 (19.8)

Note. Responses were not captured from all participants. ASD = autism spectrum disorder.

^aThree missing. ^b10 missing. ^cSix missing. ^d12 missing. ^e23 missing.

This precarious and emotional experience often evoked emotional struggle that resulted in maternal action for some, and a stifling of feelings and avoidance for others. Generally, mothers described action such as buffering professional and personal opinions, “standing up” for their child, and researching emerging symptoms, as exemplified below:

At the time, the doctor kind of had a millisecond of a flicker in his eye, and said, “It’s probably nothing, we’ll see at fifteen months.” And that flicker stuck with me and so I came home and

... played around on the internet and it took about ten seconds to find the red flag page, cause I just typed in all the various things that he wasn’t doing . . . So it was at that point that I called the doctor and said, “I don’t think we’re going to wait until fifteen months. I think we’ll come back tomorrow. How’s that?”

Despite recognizing concerns, several mothers relayed feeling “dismissed” by others. In such cases, a “wait and see approach” often was recommended, with several mothers being viewed by others as overly negative about their child’s

development. Such judgment and messaging came from both formal (e.g., health care providers) and informal (e.g., relatives, friends) sources. A mother exemplified this messaging by stating:

At first, I was upset with [my in-laws] because they weren't looking at this as a problem. It was, like, "Well, so-and-so used to do that, and so-and-so used to do that," and "Don't worry, you're just being . . . a crazy new mother."

Indicators of ASD: "Gifts" Versus "Deficits"

Some mothers recalled internal tensions that reflected their child's behaviors or abilities being viewed negatively by others despite conversely being viewed as desirable and revered by the mother. As an example, stereotypic or repetitive behaviors, such as lining up toys in a straight line by size or color, were described as indicative of early "strength" and remarkable development and intelligence in their child. Yet when they engaged with professionals (e.g., diagnosticians), the gratification and wonder initially felt about the child's ability was sometimes usurped by comments of concern that indicated that these behaviors demonstrated potential markers of ASD. What had been considered a sign of "giftedness" or "specialness" was cast problematically in alternative terms related to disability which variably invoked a range of responses including uncertainty and sometimes fear. Similarly, children who previously had been more nebulously considered "late starters," now had a diagnosis of ASD which was variably viewed as challenging versus helpful/explanatory by mothers. This was illustrated by a mother whose son's signs of ASD were not initially associated with ASD or developmental impairment:

My husband and I were not at that time trained to identify symptoms so we just thought [child], at the age of say two, wasn't talking. . . . So what, you know, you just put it to some kids come along later with language. He's a bit of a loner . . . he's not playing with the other kids in the sandbox at the park. . . . When given gifts, toys, he's not really playing with them. Oh well, he's brilliant, he's a genius, he must be interested in more sophisticated things.

Such an experience of a "changed view" of the child within mothers' consciousness was echoed by multiple participants. For instance, the following excerpt reflects a mother's perception of her child's uniqueness and giftedness, which in turn, were recalibrated as concern:

Interviewer: Looking back, at what age did you recognize maybe symptoms of ASD or that something was different for [child]?

Participant: I'd have to say at 2½ years, [the child] always had language; in fact, he seemed to have really good pronunciation, and he knew the alphabet and could differentiate alphabet letters and numbers at 18 months.

He would say, "That's the letter W, that's the number 10." So none of the other kids in nursery school or my friends' children were saying things like that. To me, he seemed precocious.

Upon receiving her child's diagnosis of ASD, this mother, like others, conveyed feeling devastated that the child's "giftedness" actually offered tangible evidence of "disability."

Developmental Disability Versus Accusation of Poor Parenting

Although multiple positive examples of support and engagement were noted, several mothers exemplified challenges based on others' negative attitudes associated with ASD, as described by the following mother:

Often times, you know, I'm in public, and they're probably thinking what an anal person! It's where you have these kids that are actually quite nice looking, because they look so nice, everything they do, people, at that age, think is just behavioral . . . [and] bad parenting. So you've always got this sort of mixed anxiety thing going on.

When encountering negative attitudes or responses, mothers variably described frustration as well as developing responses, over time, to cope with, respond to, and/or avoid such innuendos. For instances, several mothers described using these occasions to inform others and advocate for a better understanding about their child's differences or challenges. Some described intentionally "choosing their battles" and periodically avoiding instances of imposed stigma or negative comment by others.

To Tell or Not to Tell?

Most mothers spoke about the significance of their child's diagnosis of ASD in daily life, but were divided about whether or not they considered it helpful to convey this information to others. For many, the diagnosis was thought to have facilitated access to funding and therapies, and the "label" allowed them to more easily explain their child's behavior to others. Yet for some mothers, the diagnosis was viewed as inaccurately reflecting and/or stigmatizing their child. These mothers generally responded in corresponding ways by seldom disclosing the diagnosis. Not sharing (or selectively sharing) their child's diagnosis was described to buffer against what otherwise risked negative comment and judgment.

Yet withholding such information about the diagnosis was also reported to result in less social and emotional support to mothers and families, and sometimes led to misunderstanding and/or criticism about the young person's ASD-related behaviors. Irrespective of mothers' positioning regarding diagnosis disclosure, many described an internal process of

considering the “pros and cons” of sharing this information. In the following excerpt, a mother opted to withhold diagnostic information in her aim of avoiding negative attributions that she believed might be imposed on her child if such information was to be divulged:

My feeling is that the only upside to disclosing [the diagnosis] at this point, is that it might make my life a little bit easier, in that I might get a little more sympathy at work, you know, that kind of stuff. A little more tolerance of whatever my own frailties are. But up against that, I have to weigh the impact on him. And, I don't know, at age three, what he's going to look like at age five or ten or fifteen, or thirty. And, while I'm not in denial . . . if there's any chance whatsoever that he can go through life, being, quirky, eccentric, a little odd, different, I am not going to take that away from him, by putting a giant “A” on the top of his head, for autism. It's not my right to do that. . . . And I re-evaluate that all the time, and the time may come when his behaviors are so obvious that it makes more sense from his perspective, to disclose it publicly, but we're not there at this point.

Several mothers similarly described “weighing” and ultimately determining what, how, how much, and to whom diagnostic information would be conveyed. For instance, mothers described, but also variably felt conflicted about, negatively presenting symptoms which, in some instances, assisted in meeting criteria for service eligibility. They described not wanting to accentuate or dwell on negative, deficit-focused portrayals of their child, but did so purposefully in this instance to present a case for support. Mothers generally managed information flow in the aim of desirable outcomes for their child, as exemplified by a participant who stated, “We do not openly tell people or discuss that [my child] is a special needs child.”

Although some mothers avoided or limited disclosure of ASD, others widely disclosed and felt that sharing the diagnosis with others was beneficial in representing who the child is, heightening understanding, and facilitating access to services. For example, a mother explained that “the diagnosis has changed our life in that it has allowed some doors to be opened to services that we could not access before. . . . So this diagnosis has taken that stress away for us.”

ASD as Invisible yet Pervasive

Some mothers noted with concern that some of their child's ASD-related challenges (e.g., behaviors, anxieties) were discounted and/or negatively construed by others partly because the individual was variably viewed as “typical,” resulting in what mothers conveyed as less latitude or understanding among others for “variant expressions of being” than otherwise would be afforded if the disability was more visible. Despite its relative invisibility for some, ASD was described by some mothers to profoundly affect daily life.

Mothers conveyed action taken to respond to quandaries in daily life by “planning for challenges,” including management

of the child's daily routine and/or environment. For example, a trip to the grocery store reportedly evoked questions such as, “How will he or she behave on our way there? In the store? And on our way back?” Planning yet being flexible were identified by most mothers as strategies for managing the unpredictability and pervasiveness of ASD in daily life. Some described sharing the diagnosis with others in the aim of accounting for or seeking greater understanding about their child's potential difficulty in various settings. Some mothers conveyed being “on guard” and attuned to their child. As an example of this vigilant attunement, a mother responded as follows when asked how ASD is a part of her life:

Woo! How is it not? It pervades every aspect of everything we do. It pervades every aspect of my life, of my daughter's life [sibling of the child with ASD], and certainly of [child with ASD's] life. There is nothing that we can do that doesn't require a massive amount of forethought, planning, scanning the environment for pitfalls, and anticipating what sort of stimuli are going to be problematic, in the house and out of the house.

Another mother concurred:

Autism is not part of it, it rules everything. There's nothing that's done that doesn't sort of involve [child with ASD], or involve some part of making sure that [child with ASD] is looked after. There's nothing I take him to that doesn't require planning you know. . . . Always sort of looking ahead, and saying in your mind, well what's the worst thing that could happen here? Am I prepared for that? Do I have an exit plan?

Need for Services Yet Lack of Services

Mothers described the need for services, yet frequent insufficiency of services, particularly noted as challenging at transitional times such as after diagnosis, entry into high school, and exit from high school as well as at points of episodic crises (e.g., health or mental health issues). Services reportedly ebbed and flowed, with schools generally providing the foundation or “hub” for services in some regions whereas in other jurisdictions, there was a separation between resources in schools and community-based disability services (e.g., treatment). Several mothers described this division in service orientation as variably challenging.

Upon a youth's graduation from high school, several mothers identified insufficient transition and adult services. In response to this and other perceived gaps in services, several mothers across ages of their child/adult, sought to learn about ASD interventions via the internet, yet were sometimes frustrated by the volume of information to “wade through,” challenges in ensuring credibility of information, and ultimately barriers to service access, as illustrated by the mother of a young child:

It goes without saying that the [government] absolutely has to find a way to build a system that provides for timely diagnosis,

timely access to treatment, . . . proper research so that the right treatments can be ascertained. Funding, universal funding, you know, the wait lists have to be obliterated. . . . The only thing we know about autism, is that to the extent anything helps, the window of opportunity is small and it's at the early age. So to have a wait list that just sails you through until the window closes is absolutely beyond belief.

Meeting ASD-Specific Needs Versus Other Responsibilities

Mothers described an ongoing challenge of balancing attention to the needs of their offspring with ASD along with other pressing responsibilities in family life and household management. ASD imposed maternal roles of “nurturer,” “therapist,” “advocate,” and “case manager”; these roles exponentially were layered onto co-existing (non-ASD-specific) responsibilities such as sibling care, being a spouse/partner, caring for aging parents, and employment—cumulatively viewed to require extraordinary maternal time and energy. Given pressing demands, time limitations, and exhaustion, several mothers described a narrowing of their previous social circle, resulting for some in increased isolation. In several cases, mothers described gratitude for family support and new friendships with “allies,” including other parents of an individual with ASD. When engaging in social activities, several mothers described needing to integrate accommodations for their child/adult with ASD, such as hosting gatherings at their own home to mitigate environment-related or other potential challenges for their child. As an example, a mother stated:

Our social life as adults is a small social circle, and we tend to host a lot of people in our home because that's where [youth with ASD] is most comfortable. He can mingle when he wants to, and then he retreats to his little cave in the basement or bedroom or wherever to get away from people.

Inclusion Versus Specialization or Segregated Services

Several mothers described a struggle of deciding whether their child should have access to inclusive environments and activities with neurotypical peers or alternatively attend specialized environments—a decision complicated by identified challenges and questions. The “choice” of environment and level of support available was sometimes limited by restricted options and prohibitive costs. For example, funding issues and a shortage of educational assistants available in schools sometimes impeded success in integrated classrooms. Reported challenges in integrated classrooms typically included a larger class size, with fewer opportunities for individualized support, a lack of specialized training among educators, and concerning experiences of peer bullying. Conversely, some mothers worried that placement in a specialized classroom would

impede their child's learning and opportunity for engagement with neurotypical peers. Some mothers further expressed concern about their child's potential exposure to undesirable behaviors displayed by other students in specialized settings. In some cases, mothers managed this by becoming actively involved in their child's school and advocating for her or his needs. Examples of such concern and response are illustrated in the following comment from a mother:

Our kids are not going anywhere, and they're increasing in numbers, and it seems to me now that they're either high functioning enough to be floundering in a regular classroom without an educational assistant, unless the parent can build a safety case, or they're in a segregated classroom with a whole hodge-podge of needs . . . which I don't understand. I don't know; the education system is really not doing justice to these kids.

Independence Versus Safety

Several mothers of adolescents and young adults described a conundrum and tension of nurturing independence in their youth versus reasonably managing safety. They felt that their experience was markedly different from mothers of a youth or adult without ASD who can independently navigate her or his environment and generally recognize and mitigate safety concerns. For most mothers of adolescents and adults with ASD, nurturing independence reflected a sense of “trial and error,” yet evoked worry about the youth/adult's safety.

Some mothers described managing this tension by teaching their youth/adult about social nuances, safety and broader community engagement, often through concrete instruction and hypothetical examples of danger. Some described a calculated risk of “letting go,” which involved limited and incremental opportunities for wayfinding toward independence. A mother, as exemplified below, described challenge yet relinquishment:

He was so determined that he was going to make this [junior high] work, and how could I crash his dreams and say, “No, [peers] are just mean to you. I'm going to take you ‘under my wing,’ and we're going to find some place where people are going to be nice to you.” But I had to let him fight that battle on his own. . . . To have to back off and watch him struggle was just—yeah, it was hard.

A dilemma for some mothers of adults with no or minimal cognitive impairment, was a reported lack of accessible and affordable community-based services due to the individual not meeting criteria for service eligibility. Generally, when an individual exceeded IQ eligibility thresholds, they were excluded from adult-based funding. In such cases, some mothers felt that their adult with ASD had been unduly underserved which was particularly challenging as the structure offered in high school had also ended and in many cases, the individual with ASD reportedly needed support to

manage daily life and sustain meaningful activity (e.g., employment). For several mothers, withdrawing daily maternal support to their adult with ASD was viewed as untenable, particularly without augmentative community support. The lack of systemic support for adults with ASD thus was viewed to destine some mothers to unending “hands on” care for their adult with ASD.

Discussion

Findings revealed a range of difficult challenges and tensions associated with maternal care for a child, adolescent or adult with ASD—dilemmas that generally resulted from an under-serviced resource system and a general lack of societal understanding about the needs of individuals with ASD and their families. In response, mothers typically cared for their offspring with ASD amid discursive conditions that by default relied on maternal care. Consistent with international literature in this area, including a synthesis review of data from 12 countries (DePape & Lindsay, 2015), and studies from Australia (Sim et al., 2018) and Spain (Miranda et al., 2019), maternal caregiving emerged as stressful due to intersecting demands and challenges. Stress existed at multiple levels: extraordinary care demands, resource deficiencies, negative societal discourses, and nonhelpful attitudes of others. Negative discourses and/or resource gaps were largely met by extraordinary “mother work,” irrespective of personal costs to mothers.

Consistent with tenets of the transactional model of stress and coping, inherit stressors among mothers in this study were met with emotional and/or problem-solving coping, whereby mothers managed stressors via problem-solving and the provision of daily care. This intersection of the need for care and maternal responsiveness in providing that care amplifies feminist and caregiving concern and critique. For instance, in her early work, Traustadottir (1991) described complexities of maternal caregiving, noting salient distinctions between “caring for” and “caring about.” “Caring for” is distinguished from “caring about” in that the latter implies maternal “responsibility” to provide extraordinary levels of support (Traustadottir, 1991). Such a depiction of mothering reflects role and gender inequities, including imposed work demands and potential role tensions. This positioning of motherhood in mitigating system inadequacies, amplifies tensions and a lack of other choices for mothers in their life path.

These findings offer challenging questions about service systems and family life relative to ASD and caregiving. For instance, we question whether troublesome historical and debunked notions of mothering in ASD (e.g., notions of “refrigerator mother”) may have been supplanted or layered within more contemporary notions of mothers as “warrior-heroes” (Sousa, 2011, p. 221). Although recognizing the validity of contemporary heroic metaphors of mothering, these findings invite critical reflection that challenges

assumed roles of mothers as filling gaps of an underresourced resource and support system.

Implications for Practice

Multiple practice and policy implications emerge from these findings. For instance, the study informs practitioners about the tensions that mothers experience in raising a child with ASD across life stages. Other studies have noted that nurses, for instance, can use such knowledge in advancing intervention (Bonis & Sawin, 2016). For health care and other service practitioners, continued consideration of the influence of family members on one another, along with a renewed focus on family-centeredness in resource provision, are critical to establishing constructive relationships with, and better supporting, families (Nicholas & Kilmer, 2015). Phetrasuwan and Miles (2009) invite nurses working with families in which a child has ASD, to consider parenting needs, stress, and challenges as part of their assessment, and they further recommend supportive listening and connecting parents to other supports as needed. Emergent themes collectively call for improved pathways of support and resource access for individuals with ASD and their families. Heightened practice and program development are invited, as follows:

- ASD-related support to families commensurate with need, that includes relevant information, emotional assistance and tangible help (e.g., respite support, etc.),
- Greater focus on transition and adult-based program development, in recognizing that service needs continue along with advancing development,
- Public education that heightens awareness about ASD, including individual and family impacts,
- Resources that redress gender and role inequities that require extraordinary levels of maternal caregiving.

Study Limitations

Limitations of the study include its retrospective cross-sectional design rather than a prospective longitudinal methodology that would assess maternal experience over time. Prospective longitudinal research is thus recommended to more robustly elicit maternal experiences and outcomes. Of further limitation, this study examined caregiving only through mothers’ perspectives. We acknowledge that caregiving is negotiated and navigated within a broader context of family life, and may be shared among parents (and others). Accordingly, caregiving likely is more broadly nuanced within contexts such as how mothers, their partners and others (e.g., adult siblings of individuals with ASD, grandparents, partners, friends, paid caregivers) jointly navigate caregiving and other aspects of family and community life. Considering the experience of only one member of the family—in this case, mothers—risks a potentially limited view

of the multilayered phenomenon of ASD and caregiving. In addition, the majority of mothers in this study reported above-average income and education levels. This gap may underestimate the challenges faced by less financially resourced mothers; such a concern invites study with diversity relative to the Social Determinants of Health. Notwithstanding this gap and caution in interpreting these findings, this study indicates that mothers, as included in this sample, largely shoulder ASD-related care; hence, these findings support concerns related to pressing tensions of maternal caregiving.

Although the sample offered differences in the range of cognitive, communicative and behavioral manifestations of ASD, as represented by the individuals with ASD in sampled families, mothers' (participants') experiences did not seem to be largely moderated by these variations alone, although these issues indeed had a bearing on maternal experience (e.g., access to publicly funded services). Although maternal caregiving experience evolved over time, care challenges tended to present early and last over time.

Further research is recommended that specifically examines temporal and contextual considerations related to mothers' experiences, as well as inclusion of the perspectives of other key family members (e.g., children/adults with ASD, siblings, fathers, grandparents, etc.). Practice- and policy-based research is needed that focuses on interventions and policy responses that could proactively redress identified challenges faced by mothers and their families. Finally, while dilemmas and difficulties were amplified in this study, additional exploration of maternal and familial growth and resilience is invited.

Conclusion

Notwithstanding study limitations and the need for further research as noted, this study amplifies tensions experienced by mothers of children, youth, and adults with ASD. Findings identify system gaps and their impact on caregiving mothers, with implications for resource development. Recommendations reflect a commitment to more justly responding to the needs of mothers and their families affected by ASD.

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