

# Online Social Support Experiences of Mothers of Children with Autism Spectrum Disorder

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**Abstract** This exploratory study examines how mothers of children with autism spectrum disorder (ASD) make sense of their experiences of looking for and subsequently finding (or not finding) online emotional and informational support. Using interpretative phenomenological analysis, we analyzed semi-structured interviews with 14 mothers of children with ASD. The analysis yielded two main themes, (a) seeking is an ongoing part of my life, and (b) I need to be connected and to be understood. Our findings suggest that the Internet and associated online activities serve as important sources of both emotional and informational support. These findings can be used to inform future research in addition to suggesting ways for clinicians and healthcare professionals to improve online support services and resources for parents of children with ASD.

**Keywords** Autism · Mothers · Online · Phenomenology · Social support

## Introduction

Autism spectrum disorder (ASD) diagnoses are increasing at an accelerated rate, making it the fastest growing developmental disability in the United States (Bloch and Weinstein 2010). According to the most recent statistics,

one in every 68 children is diagnosed with ASD, including one in 42 boys [Centers for Disease Control (CDC) 2014]. ASD can be defined as a severe disability that affects an individual's social and communicative skills, requiring intensive, individualized, and long-term care. Autism is a spectrum disorder meaning that individuals with ASD have varying degrees of impairment in communication skills, social interactions, reciprocity in relationships, and repetitive and stereotyped patterns of behavior (Dyches et al. 2004). Since further descriptions of this disorder and delineations of the specific diagnoses within the overarching diagnostic label of ASD are extensive and complicated, the term ASD will be primarily used throughout the paper, as it is the most inclusive diagnostic label.

Due to increased demands for their time, energy, and other resources, parents of a child with ASD may experience a prevailing elevated level of stress. Parents' felt stress can be described as being on a continuum, from intermittent moments of distress to full blown crises (Weiss and Lunskey 2011). In addition to normative family stressors, parents of children with ASD may experience strained marital and extended family relationships, increased financial burdens, social isolation, resentment, challenging educational arrangements, and grief related to the restricted opportunities for their children (Norton and Drew 1994). These stressors may explain why parents of children with ASD, particularly mothers, are more likely to report experiencing somatic symptoms, such as frequent headaches or trouble sleeping (Ha et al. 2011), and meet diagnostic criteria for major depressive disorder and generalized anxiety disorder than parents of children with other developmental disabilities (Shtayermman 2013). Further, mothers are traditionally their children's primary caregiver, which may contribute to their experience of greater stress than fathers (Weiss 2002).

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Social support, broadly defined as assistance given to others (House 1981), has been found to be an important stress-coping resource for parents of children with ASD (Boyd 2002; Molteni and Maggiolini 2014), particularly mothers (Altiere and von Kluge 2009). Though face-to-face support groups, the more traditional mode of accessing social support, may provide parents of children with ASD opportunities to access emotional support by talking with other parents, limited time and resources due to the intensive demands of parenting a child with ASD may create barriers to accessing this important coping resource (Burke and Cigno 1996; Shtayermman 2013).

The availability of communication technologies such as the Internet has created innovative ways of transcending barriers to traditional means of social support. In turn, many parents of children with ASD choose to access social support via Internet-based communication technologies like e-mail, web sites, and chat rooms. These modes of communication allow parents of children with ASD to connect and interact with parents around the globe who may be experiencing similar circumstances. Online social support may be felt in two important ways: either (a) informational support, which is practical in nature and is defined as the information provided to someone at a time of stress that is likely to aid in problem solving; or (b) emotional support, which is considered compassionate and is defined as the provision of empathy, care, love, and trust, as well as the feeling of belonging and being accepted (House 1981).

Earlier research has examined how parents of children with autism use the Internet to seek and engage in social support. For example, Huws et al. (2001) examined the functions of an email group used by parents of children with ASD and found that parents used the group to network and socially interact, provide emotional support and encouragement, and share concerns. Moreover, Fleischmann (2005) examined self-published web-based personal narratives of parents of children with ASD and found that parents used these public spaces to both seek assistance from other parents and establish connections among themselves.

Parents also use the Internet to look for information, specifically information related to their children's health (Blackburn and Read 2005). Primarily, they want to learn more about diagnosing and treating specific pediatric health conditions, including ASD (Altiere and von Kluge 2009; Kirby et al. 2008). Huws et al. (2001) found that parents of children with ASD used an email group to discuss issues and try to resolve common problems by requesting/providing informational support. Parents also used the group as a means of making sense of ASD, which involved seeking and offering informational support related to perceptions of the cause of ASD, anticipated cures, and religious explanations.

Despite research confirming parents of children with ASD utilize social support on the Internet as a coping resource (Fleischmann 2005; Huws et al. 2001), no studies have examined the novel phenomenon of parents' experiences of accessing online social support. Although informational support has generally been perceived as a relational act (Hinson Langford et al. 1997), it is also possible that the mere act of online information seeking serves a supportive function for parents of children with ASD. Therefore, using House's (1981) definitions, this study used a hermeneutic phenomenological approach to explore how parents experience emotional and informational and social support in the contemporary and increasingly more common online environment. Given the growing size of the ASD population and the increase in modern communication technologies, results are expected to provide insight into how clinicians and healthcare practitioners working with families of children with autism might expand their provision of service delivery in opportune and meaningful ways.

## Method

### Participants

Inclusion criteria for this study were: (a) being the parent of one or more children with an ASD diagnosis, (b) use of the Internet, (c) residence in the United States, and (d) ability to speak English. Using public access electronic mailing lists, we sent an IRB-approved email message inviting professionals who worked with parents of children with ASD in a large metropolitan area in the Midwest. Professionals contacted the researcher by phone or email if they were willing to recruit study participants through their organization's communication mechanisms. If they agreed, we provided information about the study to parents through an email from the organization, a post on the organization's website, or information in an organizational flyer or newsletter. Parents were directed to contact the researcher with any questions or interest in being interviewed. Organizations that assisted with recruitment were not told who responded to the invitation. Several parents in other states indicated their interest in participating when they learned about the study through social networking sites. As a result, we modified our initial recruitment and interview methods. Specifically, we posted recruitment messages on a national ASD-focused website, as well as in statewide ASD-related newsletters.

We conducted interviews with a purposive, self-selected sample of parents of children with ASD. We interviewed all parents who contacted the researcher with interest in participating and met the inclusion criteria until recurrence

**Table 1** Participant demographics (N = 14)

Name	Geographic location	Age of child(ren) with ASD	Sex of child(ren) with ASD
Karen	Midwest, urban	6, 9	M, M
Nina	East coast, suburban	9	M
Demi	Midwest, rural	4, 8	M, M
Anne Marie	Midwest, urban	3, 5	M, M
Nadine	Midwest, rural	2	F
Taryn	Midwest, urban	2	M
Candace	Southeast, urban	9	F
Marybeth	East coast, suburban	Adolescent	M
Jaqueline	Midwest, urban	12	M
Rachel	Midwest, urban	8	M
Hope	Midwest, urban	9	M
Sadie	Midwest, urban	11	M
Julisa	Midwest, urban	17	M
Connie	East coast, urban	3	F

ASD autism spectrum disorder

of primary themes emerged. We declared recurrence after 14 interviews, when we identified a theme in at least half of the interviews (Smith et al. 2009).

Though there was broad recruitment effort, only mothers responded and participated. They reported learning about the study through an email listserv ( $n = 6$ ), a flyer or newsletter from the organization providing ASD-related services to their children ( $n = 5$ ), a nationally recognized ASD-focused website ( $n = 2$ ), or a flyer from a friend ( $n = 1$ ). Ten mothers lived in the Midwest, three in the Northeast, and one in the Southeast regions of the U.S. Participants lived in urban ( $n = 10$ ), suburban ( $n = 3$ ) or rural areas ( $n = 1$ ). Most of the mothers ( $n = 11$ ) had only one child with ASD, though three reported having two children on the autism spectrum. The children (with an ASD diagnosis) ranged from 2 to 17 years ( $M_{\text{age}} = 7.76$ ). See Table 1 for Participant Demographics.

### Procedure

We collected data using semi-structured interviews to explore the lived experiences of mothers of children with ASD as they sought and received online emotional and informational support. Interviews lasted approximately 1 h each and took place at a time and location that was convenient for the participant; 12 interviews were conducted over the telephone, and two were conducted in person. We obtained informed consent before the interviews began. Interviews were audio-recorded. We completed all transcriptions within 1 week of each interview, and checked each written transcript against the audio recording to

ensure accuracy. We de-identified the transcriptions and stored them electronically in a secured file.

### Measures

Following a hermeneutic phenomenological approach, interview questions were open-ended and designed to avoid assumptions about participants' experiences or concerns (Dahlberg et al. 2008). Some of the interview questions were: When your child reaches milestones, how and with whom do you share this information?; What is it like for you to interact with other parents of children with autism online?; and Will you tell me about a time when you shared information online related to parenting a child with autism? We periodically confirmed understanding throughout the interview by asking questions such as, "It sounds like... is that correct?", and "Are you saying that...?"

### Data Analyses

The purpose of this study was to understand the meaning and sense-making processes that parents attribute to accessing emotional and informational support online. Accordingly, we used a hermeneutic phenomenological approach in order to gain a deeper understanding of participants' lived meaning, which is the way a person experiences and understands the world (van Manen 1990). Hermeneutic phenomenology uniquely engages the researcher's own interpretations of the participants' interpretations of their lived experiences, defined as a double hermeneutic (Smith et al. 2009). In contrast to descriptive phenomenology in which data are summarized in a general statement of the phenomenon of focus (Smith et al. 2009), results of the current hermeneutic phenomenological study are shared as interpretative commentary, interlaced with excerpts from the participants' narratives.

We used the six steps presented by Smith et al. (2009) as a guide for data analysis: (1) reading and re-reading, (2) initial noting, (3) developing emerging themes, (4) searching for connections across emerging themes, (5) moving to the next case, and (6) looking for patterns across cases. Following Smith et al. (2009), we used an idiographic approach, in which we examined one interview in detail before examining others. Beginning with the first interview, we read and re-read the transcript to become familiar with the data and develop an understanding of how the different sections of the interview fit together. We underlined significant phrases and noted initial themes by inserting comments in the margins. At the conclusion of this phase of data analysis, we identified 12 emerging themes. Next, we sought connections across emergent themes, resulting in three robust thematic clusters.

We then moved to the second interview and repeated the process. Here, it is important to acknowledge the influence that working through the first interview had on the second interview. In order to treat the second interview as an individual case, Smith et al. (2009) suggests bracketing the pre-formed ideas that have emerged from the first interview (p. 100). However, the concept of bridling is more appropriate here (Dahlberg et al. 2008, as cited in Vagle 2009), as it allows for greater reflexivity to not only consider interpretations of the first interview, but also question and challenge them while working through the second. Because it is nearly impossible to entirely set aside learnings from the first interview (and preconceived ideas even before the first interview), we used these pre-formed ideas as a tool to understand the remaining interviews in addition to subsequent learnings about the phenomenon. After reading and re-reading, initial noting, and developing emerging themes, we identified six additional themes. Finally, we proceeded to the final step, which involved looking for patterns across all of the interviews. After working through the verification process with another researcher trained in phenomenology, the final two themes, seeking is an ongoing part of my life and I need to be connected and to be understood emerged, along with several subsequent threads.

## Results

Two themes, (1) Seeking is an ongoing part of my life and (2) I need to be connected and to be understood are discussed here, followed by several threads that illustrate each theme. We acknowledge that these findings represent one analysis of the lived experiences of online mothers of children with ASD; other interpretations are possible. All names have been changed to pseudonyms to protect participants' identities.

### Theme 1: Seeking is an Ongoing Part of My Life

Participants described how they made sense of their experiences looking for and consequently finding (or not finding) informational support online, particularly informational support related to ASD. Three threads are reflected in this theme, including (1) never done looking, (2) quick access, and (3) being an active participant.

#### *Thread 1: Never Done Looking*

Despite notable accolades of the usefulness of the Internet, mothers expressed the exhaustion of being online searching for answers, and sometimes found themselves lost while navigating for information. The sense of wandering and losing one's way in the online world comes through when

one mother said, "There's so much stuff out there and it gets confusing, like you can't even remember how you got to some site" (Julisa, mother of a 17-year-old son). Due to the difficulty in navigating the overwhelming amount of information, several participants described the searching process as never-ending and used phrases such as, "it feels like you're never done looking because there's just so much out there, and you can never really stop (searching for answers)" (Marybeth, mother of an adolescent son). One mother, in describing her experiences of relentlessly pursuing informational support online, simply stated, "You keep looking, you keep looking, you keep looking" (Candace, mother of a 9-year-old daughter).

Consistent with the literature on the general trajectory of ASD, participants echoed that the informational support they sought and found one day might not be relevant in the future, due to the natural progression and regression of ASD symptoms. Mothers reflected that their endless searching was related to the perpetual fluctuations of their children's needs, and used descriptive phrases like, "I still never stop looking because what if there's something out there that might work a little better or that might work when this stops working...what works today might not work next week" (Nina, mother of a 9-year-old son).

Mothers also mentioned the overwhelming amount of ASD-related information available online, which made it challenging and time-consuming to locate information that applied to their particular situation. They recognized that because ASD is a spectrum disorder with characteristics ranging from mild to severe, ASD-related information on the Internet is similarly broad and much of it irrelevant to their children. Participants used descriptors like frustrating, overwhelming, and confusing to describe their search experiences. One mother emphasized her searching frustrations:

Because the spectrum is so large, a lot of information that is out there may not pertain to what would work for your child, my child, because it can range from nonverbal to very high functioning. You have to go through a lot of information before you can actually get to what would pertain to or what would be most effective for your own child. But I think that's the most frustrating part, whereas if it were diabetes or something else that's more cut and dry, everyone is more typical, the same overall as far as their symptoms and their challenges. It's so different with autism; it's so much more complex. (Jacqueline, mother of a 12-year-old son)

#### *Thread 2: Quick Access*

Several mothers in this study explained what it meant to them to have convenient and instant access to the Internet

for informational support. Several participants referenced the usefulness of having immediate access to informational support online, and what it means to their unique situations of parenting a child with ASD. For example, one mother described how she was able to quickly find information on the Internet to avert a potential behavioral issue when her son was concerned about his school district's policy on backpack searching.

There's so many instances where, within a matter of 15 min, I feel like I've been able to solve something. ...Within 15 min I was able to get the district's policy on backpack searches, get these emailed to me from the district, I was able to read through them quickly, find the information I needed, send this information to his autism teacher and say, "this is what's going on." I could not have so quickly headed off this catastrophic thing that would have occurred if I wouldn't have gotten that information so quickly. ...I don't know how I would have handled that, how I would have helped him fix this issue he was having if we didn't have such quick access to the information. (Sadie, mother of an 11-year-old son)

### *Thread 3: Being an Active Participant*

Although many mothers want to be actively involved in their children's education, mothers of children with ASD must learn to navigate an education system that involves multiple meetings with teachers and staff, Individualized Education Plans (IEPs), and a new vocabulary of legal jargon and medical terms. Participants' narratives highlighted the time-consuming nature of this parental task, using descriptions such as, "being online every evening for the past 3 months" (Candace, mother of a 9-year-old daughter) and "having three binders of notes and printouts and just tons of information" (Marybeth, mother of an adolescent son) to describe their experiences.

The Internet, however, was a resource that mothers identified as a time-saver and source of empowerment. They were able to access important informational support online that helped them prepare for advocating for their children, particularly in instances involving their child's treatment plans. Phrases like, "I wanted to know what I was talking about so that I could try to at least provide input" (Nina, mother of a 9-year-old son) and "The more information, the more tools you have to parent, the more effective you are" (Candace, mother of a 9-year-old daughter) reflected the importance mothers placed on being a contributing member of the care team for their child. Several mothers experienced knowledge as power, and described the significance of being an informed parent. Perhaps no one captured this better than Sadie:

In (researching different medications), it helps me to, as a parent, feel like I was more informed and go back and have a better conversation with his practitioners and say, "No, this is the route we need to go at this point." It just, it made me so much more involved, I was much more a participant in making decisions about my child's care. ...If I had not had the Internet to actively seek out information and gain some comfort and feel like I was an active participant in those choices, I could not have done it. I just could not have blindly followed along with doctors saying, "Give him these drugs." Being able to feel like I am an active participant in making those choices is... I can't say enough about it. It makes me feel like I am an active parent and I am an advocate for my son, and that's really important. (Sadie, mother of an 11-year-old son)

### *Theme 2: I Need to be Connected and to be Understood*

The second theme represents the meaning that participants associated with the Internet serving as a sense of community and how they made sense of this online community. Nearly all of the participants expressed the importance of being connected with other parents of children with ASD. Five threads are reflected in this theme, including (1) they 'get' it, (2) 'a comfort zone,' (3) normalizing, (4) interpersonal differences, and (5) intrapersonal dilemmas.

#### *Thread 1: They 'Get' It*

Being connected to other parents of children with ASD was meaningful for the mothers in this study who spoke about the importance of connecting with other parents who share their reality and can relate to their feelings and experiences. Using phrases such as relief from isolation and automatic kinship, mothers described the meanings they associated with having access to their online communities. Their engagement with others was reciprocal—they received support and provided support to others. Their experiences in a mutually supportive environment was expressed by Karen, mother of two sons, ages 6 and 9: "It feels good to give support to parents who need it, only because I know exactly what they are going through, and to validate those feelings gives me a good feeling."

Participants also reflected that parents of children with ASD are immediately unified because they instantly understand something about each other that other people do not. Sadie, mother of an 11-year-old son, described the relationship that exists between two parents of children with ASD as immediate, an automatic kinship, regardless of practically being 'real life' strangers, and explained the

connection by saying, “You just know they get something about your life and you get something about theirs.”

The importance of this sense of unity they found online with other parents was amplified when they spoke about their experiences with staff on their children’s treatment team: “The doctors don’t really know what it’s like when you go home” (Candace, mother of a 9-year-old daughter) and, “After the 2 h shift is over the professionals leave and they don’t call and they’re not here all the time...Nobody knows what it’s like in any of our houses at the end of the day when you shut the door” (Nina, mother of a 9-year-old son).

Several mothers expressed that even their family members just do not get it in the same way as other parents of children with ASD. One mother said:

I share more with the online groups than I do with my real in life people. Because sometimes I think they don’t understand that if something might not look like a huge milestone, it is. And so sometimes it’s a little disappointing when you get all excited because you’ve been working on this goal for a really long time but, ok, instead of eating the pasta with your fingers at the dinner table, we’re going to use a fork. ...If I go to somebody like my mother and say, “Oh my gosh, you’re never going to believe what happened! Ricky finally ate his noodles with a fork instead of with his fingers!” She would look at me and go, “Well yeah, he’s nine! He should eat with a fork.” If I go online, I’m going to have 10 emails back going, “Outstanding!”, “Way to go Ricky!”, “Good job!”, “He finally did it!” They get it more. How hard sometimes it is for the little stuff. I just found that I have to be kind of careful how I share it with people that don’t live the life because sometimes they don’t understand why that’s a big deal. Sometimes it’s easier to share it with the online folks just because they get it. (Nina, mother of a 9-year-old son)

#### *Thread 2: A Comfort Zone*

Participants belonged to online groups or discussion forums that were open only to parents with children with ASD or in some cases, parents with children with other special needs. Due to this exclusivity, several mothers referred to the Internet as a safe place and a comfort zone, a place where they could be honest about their experiences without fear of being judged. Using phrases such as, “I’m not alone” (Nina, mother of a 9-year-old son), and “it makes me feel less alone” (Hope, mother of a 9-year-old son), and “sometimes it’s just nice to know you’re not alone” (Sadie, mother of an 11-year-old son). Participants also expressed

the relief from isolation they experienced when connecting with other parents online. Several mothers described connectedness to other parents of children with ASD as simply not an option in real life given limited time, resources, or their geographic location. Although social networking experiences are often extensions of face-to-face relationships, these mothers indicated that their online relationships are unique and different from their real life relationships. Three mothers specifically expressed that the Internet is the only opportunity they have to interact with other parents of children with ASD, suggesting that even though they may be interacting with ‘strangers,’ the common bond of parenting a child with ASD connected them in unique ways. Referring to her online social network, one mother shared:

Even if they’re not online right now, they’re all out there saying, “Did you try this? Maybe you could try this.” Or even if they just say, “Oh gosh, I’m sorry, that really stinks”. Sometimes that’s enough, just knowing that I’m not alone. Even though there’s really nobody here in my geographic immediate area that’s dealing with the same thing, I’m not alone because I have all these other people. (Nina, mother of a 9-year-old son)

#### *Thread 3: Normalizing*

Mothers described their online relationships with other parents of children with ASD as being deeply valuable and genuine. Several mothers used other online parents as a sounding board and placed significant worth on other parents’ input and experiences, often referring them as friends. Several mothers admitted they may not openly share information or ask questions online, but they tended to participate passively by reading other parents’ questions and responses to posts (one mother described her membership to an email listserv as voyeuristic). Regardless of whether or not mothers shared their own stories or posted responses to others’ questions, they described their silent participation in such communities as reassuring, and expressed gratitude for their existence. Often, when mothers had a question or concern regarding their child, the first place they went was to online spaces to seek other parents’ ideas. Several mothers described their email listserv membership as particularly helpful because they were able to read stories and seek input from experienced parents whose children with ASD were older. They received first-hand information about situations and decisions they will confront in the future.

Participants sought other parents for assurance that what they were thinking or feeling was normal or that they had made a good decision. Several mothers mentioned that they

go online to see if what their child is doing is normal, and if other parents are experiencing the same things. They described their experiences with phrases such as, “It’s almost this weird affirmation of ‘Oh yeah, I did that right because I tried those things’” (Sadie, mother of an 11-year-old son). One mother described attempting to normalize both her child’s behavior, as well as her own feelings as a parent:

Sometimes I think, “Oh, other parents have the same issues” and I’m like, “Ok, I don’t feel so bad, this is what we’re going to do now.” And so, just like his eating, why doesn’t he swallow his food? This isn’t normal. I have to go to the doctor, and I have to do all of this. I go online and oh, there’s actually a lot of kids on the spectrum that do the same thing that I would have never known. And then I feel ok and then it kind of calms me down. This is ok...and we go to the next step. I’m not the only one that has this weird thing that’s happening. (Demi, mother of two sons with ASD, ages 4 and 8)

#### *Thread 4: Interpersonal Differences*

Though participants generally regarded the Internet as a means to experience community, several mothers expressed that their experience with ASD is individually manifested with the diagnosis. They expressed this with phrases such as, “All their children are different than mine. Every child with autism is different; none of them are the same” (Taryn, mother of a 2-year-old son) and, “Every kid that has it is so different. Each parent’s and each family’s experiences are different” (Connie, mother of a 3-year-old daughter).

Another way that mothers in this study differed was in their attitudes toward the disorder. For example, they commented that there are differences between parents who focus on finding a cure, or curebies as one parent labeled them, and those who focus on just getting through the day. Some participants also noted tension among parents who were generally labeled as negative parents, and the more positive parents who “don’t see (autism) as a death sentence” (Rachel, mother of an 8-year-old son). In addition, mothers described some of the topics discussed on discussion forums or message boards as being so deeply value-laden that the debate among parents often ostracized those with competing beliefs. One mother experienced the tension that comes with such interpersonal differences in an email listserv to which she belonged:

I know at one point when we all started having an argument about vaccines. It was kind of a hot button topic and people got annoyed. And I think that person

might have actually dropped out of the group because that’s always a sensitive topic, the vaccine stuff...it probably was not the best topic to bring up. (Julisa, mother of a 17-year-old son)

#### *Thread 5: Intrapersonal Dilemmas*

Some mothers in the study described intrapersonal dilemmas they experienced while interacting online and expressed feeling tensions within themselves when comparing their family’s situations to others’. They shared the comfort they felt when connecting with parents with stories similar to their own, but also noted their relief when they learned that other families’ struggles were much bigger than their own. “Sometimes I think ‘this sounds just like my kid,’ or sometimes I think, ‘I’m very fortunate I don’t have that problem’” (Anne Marie, mother of 2 sons with ASD, ages 3 and 5). “[The Internet] also just makes you feel better, like I’m not the only one dealing with this. Or sometimes you think, ‘Gosh, that sounds really terrible what that person is dealing with—I feel lucky!’” (Julisa, mother of a 17-year-old son). The realization that their situation might not be as bad as others prompted them to withhold sharing joys and celebrations, fearing that it might make other parents feel worse. Anne Marie, mother of 2 sons with ASD, ages 3 and 5, described the difficulty she had determining how and when (or if) to share her children’s milestones and accomplishments: “I don’t want to feel like I’m boasting...It’s kind of like a punch in the gut if your child isn’t doing stuff that other kids are doing.” Another mother described her decision not to publicly share her son’s achievements:

I’m not going to Tweet ‘Mitch made it through his first day of camp!’ We don’t usually just send an email bragging about something unless you also have a question. Because nobody really has the time for that and besides, what if the person is in a bad mood and you’re just like, ‘And we just did this and had a great success’ and you’re like, ‘my kid’s flunking!’ (Julisa, mother of a 17-year-old son)

## **Discussion**

Using a hermeneutic phenomenological approach, we examined how mothers of children with ASD experienced looking for and finding (or not finding) online emotional and informational support. Mothers’ experiences reflected many of the characteristics embedded in House’s (1981) definitions of emotional and informational support; mothers expressed feeling cared for and accepted, and described receiving information that helped them problem-solve

stressful situations. Though mothers of children with ASD differed in their attitudes and interpretations of their experiences, all mothers valued and identified positive aspects of using the Internet for emotional and informational support.

Findings are congruent with those from earlier studies (Fleischmann 2005; Huws et al. 2001); mothers of children with ASD used Internet communication technologies to share their experiences, as well as provide and access informational and emotional support to and gain similar support from other parents. Though this study lacked measures of how mothers of children with ASD accessed online social support, as noted in existing literature (Fleischmann 2005; Huws et al. 2001), it does provide unique insight about mothers' experiences of online social support resources. For example, mothers in this study expressed an appreciation for quick access to information that will help their child; at the same time, many participants described their feelings of frustration and exhaustion when engaged in a seemingly endless search for information about their child's condition. Though having instant access to information might have helped mothers quickly trouble-shoot a specific challenge with their child, navigating autism-specific information such as behavioral interventions and medications may be more overwhelming or frustrating. Mothers in this study also identified the Internet as a comfort zone, a safe haven in which they experienced community with other parents who share their reality. Regardless of where they lived physically, they had access to a wide network for informational and emotional support, most likely more than was available in their local communities.

This study affirmed Fleischmann's (2005) finding that an online presence through tools such as personal blogs and chat rooms may be meaningful to parents, as these means of communication allow individuals opportunities to share personal stories and experiences. Mothers indicated they reached out online to share their own stories and have their experiences affirmed by other parents of children with ASD. Also consistent with previous research (Huws et al. 2001), mothers in this study accessed online discussion forums and message boards to seek and share informational support, thoughts, and ideas with other parents. From their perspectives, connecting with the larger community of parents of children with ASD allowed mothers to be a part of a reciprocal relationship in which they could both give informational and emotional support when they felt it was appropriate, and receive such support when needed. Being able to reach out to a wide network of parents who get it was important to the mothers in this study. Congruent with previous research on traditional modes of social support (Altieri and von Kluge 2009; Molteni and Maggolini 2014), the online community of support provided space to

connect with people who were experiencing similar challenges. Support flowed among participants, even though the relationships had been formed and nurtured exclusively in cyberspace.

Having an online community of other parents of children with ASD who offered emotional and informational support was an important coping resource for mothers in this study. Although the relational aspect of information seeking was very salient, mothers also described their experiences of online information seeking as a particularly important coping resource that helped them relieve distress. Findings from this study suggest that House's (1981) definition of informational support could be expanded to include an important instrumental dimension of informational support. Information seeking online by mothers in this study occurred in two important ways; in a relational context, which fits with the traditional idea of informational support, and in an individual way, when they were able to seek and find information that helped them cope with stressful situations. An expanded idea of informational support that includes both relational and individual contexts would better reflect these mothers' experiences of seeking and receiving support.

Findings from this study provide a broad understanding of meanings attached to online informational and emotional support seeking experiences of mothers of children with ASD. However, several limitations must be noted. Though there are considerable differences among the various diagnoses within the larger ASD diagnosis on the DSM-IV, participants were not asked to describe where their child fit on the autism spectrum. As a result, it was not possible to discern how the level of their child's functioning influenced daily care demands and related stress levels. Moreover, the children of mothers in this study ranged from 2 to 17 years old, representing a broad developmental spectrum. A narrower range of children's ages could offer an opportunity to go deeper into mothers' online social support experiences. Finally, the information collected on participant demographic information was limited, making it difficult to understand how mothers' personal characteristics like race, socioeconomic status, or educational background may affect their experiences with online social support.

Even though generalizability is not the goal of phenomenological research, findings should be considered in light of the unique nature of this sample.

Results of our study suggest several new directions for research and practice related to parents of children with ASD. First, there is a critical need for research on the experiences of fathers of children with ASD. Understanding fathers' experiences and their needs related to informational and emotional is important, yet currently absent from the literature. Future research might also consider



interesting questions focused on the parenting-related outcomes that come from participating in an online community with other parents of children with ASD. Specifically, researchers might examine how participating in an online community affects parents' efficacy and effectiveness, and what specific tools or support resources parents found most helpful. Further, careful examination of parents' experiences with professionally-facilitated communities of support and communities that are self-directed or parent-led may serve to help us better understand the role of a clinician or healthcare provider in online social support communities, and in what ways online social support enhances or replaces face-to-face support experiences. Future research might also consider how changing developmental needs of children with ASD affect the types of support that parents need.

Our study also suggests several new directions for practice. Mothers in this study were invested in connecting with other parents of children with ASD. Research indicates that this form of informal support serves as a more effective stress-buffer for mothers of children with ASD than do formal supports such as structured parent support groups or informational workshops (Boyd 2002). Therefore, it is important to create safe and comfortable online environments in which parents can informally interact online. As we found, online connections are particularly significant for families who may be geographically isolated from ASD-related resources and support systems (Burke and Cigno 1996).

Participants' narratives reflected the importance of quick and easy access of support. Being able to access emotional and informational support at a time, frequency, and duration of their choosing allowed for greater flexibility and choice in their daily living. Practitioners who work with these families might offer asynchronous ways mothers can access informational and emotional support to allow for 'just-in-time' information or support. Providing online discussion forums, electronic mailing lists, and a collection of reputable informational websites, would allow mothers convenience in accessing critical social support to deal with their stress. In addition to describing positive experiences with seeking informational support, mothers also described spending many hours searching online for reliable and relevant ASD-related information. Professionals who support families of children with ASD are encouraged to consider how to best organize their web content and resource guides to be more user-friendly for parents and to limit the information provided to include only reputable and credible resources.

Mothers in our study expressed that other parents of children with ASD 'get it' in ways that professionals do not. Several participants commented that professionals do not understand what their lives are like on a day-to-day

basis. Though practitioners may not have children with ASD themselves, there are ways they can help families navigate some of the challenges ASD presents. For example, clinicians and healthcare professionals might consider how they can use their knowledge and expertise to monitor the information that is being shared on discussion forums. Parents may take other parents' experiences or advice as fact. This can be troubling given that ASD presents in a wide variety of ways and no single intervention works for everyone on the spectrum. For example, some treatments, such as a gluten and casein free diet, are inconclusive in their effectiveness (Millward et al. 2004) and can be quite costly to families. Other treatments such as chelation therapy can be extremely painful and dangerous (Sinha et al. 2006). Professionals who participate in or monitor ASD online communities have increased opportunities to share research-based information to help parents make informed decisions.

Our findings suggest clinicians and healthcare providers have a critical role in supporting parents of children with ASD online; however, it is important for practitioners to think critically about the nature of their involvement with online communities and must be mindful of their online presence. For example, in parent-led online communities, professionals may be perceived as outsiders and their participation may not be appropriate or welcomed. Or, parents may be overly eager to discuss their situation or may excessively request advice from a professional and challenge the murky boundaries that may otherwise be clear in a more traditional clinical setting (Mishna et al. 2012). Self-monitoring of the frequency and intensity of their participation is not critical to the preservation of the online comfort zones that the mothers in our study described.

The Internet and advancement of online communication technologies have provided practitioners with greater opportunities to engage with the populations they support (Mishna et al. 2012; VanBergeijk and Shtayermman 2005). Clinicians and healthcare professionals can contribute to moving the field forward and expanding the scope of services provided by translating traditional methods of service provision to the contemporary online environment. For example, findings from the current study confirm that many mothers of children with autism use the Internet to seek and access online informational and emotional support; this naturally expands the conceivable role of a practitioner and the breadth of a population a clinician or healthcare professional may support. Professionals may also be well-positioned to host live web chats or moderate discussion forums for parents of children with ASD, or have an active online presence as an advocate of the disability community by promoting progressive family-centered ASD policy initiatives (VanBergeijk and Shtayermman 2005).

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