

A Meta-Synthesis of Experiences of People with Autism Spectrum Disorder and that of
their Family Members in Acute Care and Inpatient Settings

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Approved.

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Abstract

Individuals with Autism Spectrum Disorder (ASD) are 1.25 more likely to be hospitalized and much more likely to display negative behavior (i.e. biting, hurting self or others, and engaging in disruptive behavior) than individuals without ASD. Despite this, little research has been done to capture the experiences they or their caregivers face in acute care settings. This qualitative synthesis used the PRISMA guidelines to search for and integrate what is currently known from published qualitative research on the experiences of individuals with ASD and their caregivers when they require services in acute care settings. Three large databases were searched and resulted in 667 studies that were screened. Inclusion criteria included a) a diagnosis of Autism Spectrum Disorder b) qualitative studies that focused on experiences of either the individual or family member of the person diagnosed with ASD; c) Experiences had to be based on either acute care or inpatient settings d) Articles had to be published within ten years. Only nine articles met the inclusion criteria. Three broad themes were identified: 1) the unique challenges of ASD; 2) the socially constructed barriers encountered in some acute care settings; and, 3) suggestions to make these settings patient and family friendly to ASD needs. The findings highlight that insensitive cultures lead to socially constructed barriers. More research is needed to further uncover how socially constructed barriers develop and contribute to the disability and disparities in this population so that relevant interventions, policies, and research can be implemented.

Keywords: Autism Spectrum Disorder (ASD)

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Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is estimated to have a prevalence of 14.6 per 1,000 children, or approximately 1% of the population in the United States (U.S.). Approximately four times (23.6 per 1,000) more males are diagnosed with ASD than females (5.3 per 1,000). While seemingly low, 14.6 per 1,000 represents a substantial increase of individuals being diagnosed with ASD as compared to 2000 when the rate was 6.7 per 1,000 children. Whether this is due to a higher prevalence of diagnosis or an increase in the actual disorder is not yet clear (Christensen et al., 2016).

The U.S. rate of diagnosis for ASD is not unique and seems to be reflected globally, with the current average in Asia, Europe and North America placing the percentage of individuals diagnosed with ASD between one and two percent (Christensen et al., 2016). Despite the seemingly low incidence of individuals affected by ASD, it is ranked as the fourth leading cause of disability for children ages 5 to 14 years of age and ranked among the top 20 causes of disability among children under the age of 5 years. It is important to note that ASD itself is not considered a disability; rather, the associated symptoms and common co-morbidities are what lead to the individual being considered disabled (Baxter et al., 2015).

The social implications of ASD manifests themselves on the individual in early childhood and affects children's ability to communicate and interact with others. A child with ASD may have trouble understanding the meaning of commonly used communication techniques, such as the use of body gestures, facial expressions, and other forms of nonverbal communication. In

addition, individuals with ASD have a marked need for routines that they become accustomed to, which may cause extreme distress during periods of transitions or disruption in routines (American Psychiatric Association, 2013).

Individuals with ASD may also have hyper- or hypo activity to sensory input, which is often manifested as adverse responses to specific sounds or textures (American Psychiatric Association, 2013). Numerous studies have also found that individuals with ASD have a higher prevalence of other conditions requiring medical care compared with the general population. According to Kohane et al (2012) individuals with ASD have higher rates of bowel disorders (over 10% of patients), epilepsy, CNS or cranial anomalies (over 5%), language disorders, and schizophrenia (over 2%). They also had higher rates of inflammatory bowel disease, type 1 diabetes mellitus, auditory disorders and infections, and sleep disorders to name but a few.

In addition to these physical co-morbidities, individuals with ASD were found to have an increased prevalence of psychiatric disorders compared to individuals not diagnosed with ASD. Estimates have placed individuals with ASD as comprising approximately 10% of the total youth referred for psychiatric care (Meyers, Classi, Wietecha, & Candrilli, 2010). Higher rates of anxiety, depression, obsessive compulsive disorder, borderline personality disorder and psychosis exist in individuals with ASD as compared to the general population (Gadke, McKinney, & Oliveros, 2016). Among youth, 25% of children with ASD were admitted to the hospital because of a mental health condition (Carbone et al., 2015).

These higher rates of medical co-morbidities continue into adulthood. Adults with ASD were more likely (15%) to visit the emergency department (ED) compared to 4.2% of adults without ASD (Vohra, Madhavan, & Sambamoorthi, 2016). Like members of the younger subgroup, adults with ASD were found to have a substantially higher rate of seizure disorders,

depression, hypertension and allergies (Fortuna et al., 2016; Vohra, Madhavan, & Sambamoorthi, 2016).

Children with ASD are also more likely (1.25 times higher) to be hospitalized and have more costly hospitalizations (four times) than children without ASD (Wu, Kung, Li, & Tsai, 2015). In addition, the duration of each hospital stay for individuals with ASD has been found to be substantially longer than for patients without a diagnosis of ASD. While there has been numerous studies that have established the higher financial burden individuals with ASD face when receiving medical care, little research has been done to attempt to analyze the reason why these higher costs exist (Lokhandwala, Khanna, & West-Strum, 2012; Wu et al., 2015).

Purpose

Despite the fact that individuals with ASD have much higher rates of acute care hospitalization rates, (Lokhandwala et al., 2012; Wu et al., 2015) very little information currently exists about their hospital experiences. The closest attempt to create a comprehensive systematic review on this topic focused on reviewing challenging behavior of individuals with ASD and some of the strategies used (Johnson & Rodriguez, 2013).

While dealing with challenging behaviors is certainly relevant to the needs of the healthcare system or the needs of the providers delivering care, we would expect that the needs of the families of individuals with ASD would likely be more than a summation of the challenging behaviors exhibited in acute care settings. In order to provide a holistic plan of care, health care systems must be able to understand what it is like for an individual, and his or her family members, to enter the healthcare realm. Therefore, the purpose of this literature review was to understand what individuals with ASD are undergoing when they require services in acute

care and inpatient settings. Since their family members, especially their parents or caregivers, might also be involved in their hospital care, we also wanted to know their experiences of advocating for them.

Methods

Search strategy

To capture all relevant articles for this qualitative synthesis, we followed the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (Moher et al., 2015). A research librarian was consulted to select appropriate databases. Three databases were used to subject search for relevant literature- PubMed, Embase and PsychInfo. Researchers have established that using PubMed, EMBASE and a database that is discipline specific, such as PsychInfo, provides the most comprehensive results (Kelly, 2008).

With the help of a research librarian the following search terms were created in various combinations in the Title, Abstract and Keyword search field: 1. “Autism” or “Autism Spectrum Disorder” or “Autistic” 2. “Experiences” and/or “challenging behavior” and/or “patient care” and/or “life change event” and/or “quality of care” and/or “behavior management” 3. “Families” and/ or “patient” 4. “Hospitalized” and/or “inpatient” and/or “medical” and/or “acute care” and/or emergency care. A table of the actual search strategy used can be found in Appendix A.

Inclusion and Exclusion Criteria

There were four criteria that research articles had to meet in order to be included: 1) the study had to have either participants who had ASD or include participants that were a guardian or family member of an individual diagnosed with ASD; 2) the focus of the study had to be on the experiences of the individual with ASD, or their family member, in an acute care or inpatient

setting; 3) the studies had to be qualitative in design, so that thick descriptions from their point of view could be garnered; and, 4) The studies had to be in English and be published after January 2007. This cutoff was established so that the articles could incorporate patient and family centered (Swanson & Wojnar, 2004).

In an effort to attempt to capture the opinions and views of individuals with ASD, it was determined that a qualitative design was most appropriate. This was due to our desire to achieve a deep understanding of what social, cultural, physical, and emotional factors within the acute care environment influence the family's experiences and appraisals of the type of care they receive. Qualitative studies have been found to be vital in providing rich descriptions of complex phenomena and analyzing experiences in a manner that allows researchers to understand how participants interpret these experiences (Sofaer, 1999).

After an initial search in which studies were limited to articles conducted in the U.S., we found a paucity of research articles ($n = 2$). Therefore, we broadened the search terms to include journal articles conducted globally.

Quality Assessment

Although no research was excluded based on concerns with quality, in an effort to address the relevance and validity of each study, the Mays & Pope criteria (2000) was used. The Mays & Pope criteria attempts to use several questions to review criteria such as relevancy, clarity, context, sampling, data collection and reflexivity of the accounts. Further details can be found in Appendix B (Mays & Pope, 2000). The Mays & Pope criteria was selected due to its simplicity, ability to generate information that is easy to understand, and its prior use among published systematic reviews focused on qualitative research (Mays & Pope, 2000).

Extraction of Data

The protocol for data extraction included: purpose or aim of the study; authors; year of publication; the ages, diagnosis, and demographic information of study participants; and results identified by the authors of the studies. A chart was developed to address each of these points in a concise manner. Items that were not addressed during our data extraction were further addressed through the use of the meta-ethnography method.

Data Analysis

In an effort to analyze and interpret common themes for the final journals articles included, the meta-ethnography method was used. Meta-ethnography is one of several methods that is being increasingly used in the healthcare field. Its ability to create models that allow for interpretive findings made it particularly useful for this systematic review (Atkins et al., 2008). The meta-ethnography method requires researchers to categorize data into first, second and third orders.

The first order requires data that is directly from participants. In the case of this systematic review, direct quotes were provided from participants. The second order were a condensed summarizations stated by the authors of these 9 research articles. Finally, the third order was a combination of these two orders to create our own themes (Atkins et al., 2008)

Results

Selection of Results

1,061 records were identified through the three database searches while a total of 5 research articles identified by reviewing the references the included articles cited (the ancestry

approach) (cooper, 2010) None of the articles identified by the ancestry approach met the inclusion criteria, emphasizing the fact that the search terms had managed to capture a comprehensive amount of results (i.e. high recall) and the search terms and selection process where detailed enough to capture all relevant articles (i.e. precision) (Margarete Sandelowski & Julie Barroso, 2006). After the exclusion of 399 duplicates, 667 articles were left to review. A total of 634 articles were excluded after reviewing the journal articles' titles and abstracts, leaving a total of 33 full-text articles that were assessed by two independent reviewers (CE and CR) for eligible inclusion.

Of the 33 full-text articles that were assessed, 24 journal articles were excluded. Nineteen journal articles were excluded for failing to focus on the experiences of individual with ASD or members of their family. One journal article was excluded because it did not focus solely on individuals with ASD, but instead included individuals with any intellectual disability. Three journal articles were excluded because they did not use a qualitative method. Finally, one journal article was excluded for not being in a medical setting, instead it focused on students at a school. There were 9 studies included in the qualitative synthesis. A summary of the purpose of the study, demographic information and findings is provided in Appendix B.

Quality of Data

While all nine research articles seemed to carry some deficits in quality, overall the authors were able to clearly state their aims and had outlined their methods in a descriptive and systematic manner (Table 2B). The results included thematic findings that were supplemented by direct quotes from participants. In addition, all but one of the authors used a well-recognized methodology to interpret their data.

Most of the research articles included parents as participants. Only two of the nine included individuals with ASD as the primary participants. In fact, five of the nine research articles failed to include a single participant with ASD. In addition, only one research article actually included adults with ASD. While most did not state why they decided to include only family members, some articles described the difficulty of attempting to capture verbal and written information from individuals with ASD.

Identified Themes

Overall there were two broad categories that were identified throughout these studies- the challenges and socially constructed barriers of the healthcare setting and process; and suggestions and necessary improvements identified by individuals with ASD, and their family members, to make these places and process more patient and family-centered.

Challenges & Deficits of the Healthcare Process

Within this umbrella, there were three overarching themes that wove a common thread through these studies- environmental triggers and heightened sensitivities; difficulties with communication; and time related issues. These were our third order findings obtained from the first and second order findings.

Environmental triggers & Heightened Sensitivities. Both parents and individuals with ASD expressed how difficult it is for individuals with ASD to be bombarded with unfamiliar sights, sounds, and smells. One parent expressed that something as simple “the fact [patients with ASD are] lying down doesn’t help matters because half the time they’re being moved on a gurney. . . . But for these children [with ASD], if they can’t see where they’re going and they’re

looking at a bunch of white lights flicking by, that in itself is going to wind them up” (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016).

In addition, the necessity of having numerous healthcare providers congregating in the child’s room posed a particular challenge to many. One mother expressed her son’s fear and confusion at being confronted with numerous healthcare providers “I think he thought that there was some sort of restraint going to happen and that did have to happen sometimes when he first [was] learning how to accept [the procedure]...(Muskat et al., 2015).”

Difficulties which often led many individuals with ASD to engage in activities that are self-soothing but may be perceived to pose harm to themselves or others “She does get really frustrated because she is nonverbal. She will exhibit behaviors like hitting her head, or throwing something if she’s mad, or, to show her frustration. She gets very frustrated with people in general if they put demands on her’ (Johnson, Bekhet, Robinson, & Rodriguez, 2014).” Something which may require unnecessary procedures such as chemical sedation and use of restraints. Both of which place further burden on both the individual with ASD and their family members.

One parent worried that such a barrier could disadvantage the child “You’re going to create [an] emergency by not putting this stuff in place to help decrease their anxiety or behaviors because if they’re [the child with ASD] in an uncomfortable place, even though they’re not in that much pain, they’re going to escalate to [where] now they’re having behaviors where they’re acting out. We can’t get what we need to get done and we’re going to have to start using general anesthetics for every single autistic kid that comes into the ED, which . . . shouldn’t happen (Burrows, Adams, & Spiers, 2008; Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016).”

Difficulties with Communication. Another barrier identified throughout these studies was how little providers know about communicating with individuals with ASD, particularly if the individual is unable to engage in verbal communication. One child with ASD described his attempt to understand what they [the healthcare providers] were saying to and about him “I could only know a bit of what they were saying. I don’t know much of the grown up words in English, I only know the basic words of English (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016).”

Another area of major concern is the potential to miss symptoms, such as pain or nausea, which reduce the individual’s quality of care or could pose a threat to his or her health. One parent described an incident in which her child’s nausea could have been missed due to a deficit in communication “Every time [nurses were] saying, ‘Have you vomited?’ And he’s saying, ‘No, I haven’t’. [He didn’t tell them that] he’s been feeling nauseous ... I said to [the nurses], ‘... You need to frame your questions differently. Because ... he’ll just tell you what you asked him’ (Muskat et al., 2015).”

Other participants described health care staff as dismissive, judgmental or simply misinformed about the best manner in which to communicate with the child. One parent described their experience in the ED “it was like 1:00 in the morning, and, you know, these staff who just don’t get it, and they just say, “Hold your arm still, little boy,” and treat him and us like we’re bad parents, and “Don’t be a brat. You’re not going to die because your arm’s broken. (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016).”

Several parents described the fact that many healthcare providers simply ignored the individual with ASD ““What would have been helpful: not speaking about [my child] in his room, at the foot of his bed ... assuming that he’s not understanding it’s about him” (Muskat et

al., 2015).” When healthcare providers were able to provide comprehensive and empathetic care, many parents voiced their frustration with the lack of continuity in communication between providers “... as soon as I said [my children] were on the spectrum...they were very attentive, and listened...My challenge came once they sent us back for an X-ray...there wasn’t obviously communication from the front end people [to the next group of providers we would encounter]...I was like ‘Okay, seriously did nobody just tell you what I just told them all. [My child] has autism, good luck getting him to lie down and stay still and whatever you need to do for your X-ray’ (Muskat et al., 2015).”

Time-related issues. In addition to the issues mentioned above, many parents voiced frustration with waiting and transitioning throughout the hospital without any idea about when they would be seen. One parent stated “autism is most obvious when he has to face change or transitions (Muskat et al., 2015).” Another parent described his experience in the ED and how it affected his son “Kids like my son . . . cannot handle that crowded waiting room on a busy night, too much stuff going on, too many other kids crying. Everything down to the fluorescent lighting, like some kids really get affected by that hum (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016).”

Parents also voiced concern about how little time is given to prepare the child with ASD. Something which often leads to unnecessary restraints and sedation. A traumatic experience which often stays with the individual long after the procedure and negatively affects future encounters with providers (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016). One parent described her experience after her child had to be physically restrained ““a very, very traumatic experience for me and for him. . . . It just seemed to me that there had to be a better way to do it. I understand that they’re in a hurry, but this is a little boy (Nicholas,

Zwaigenbaum, Muskat, Craig, Newton, Cohen-Silver, et al., 2016).” Overall, participants believed that allowing the individual with ASD to move at their own pace led to more success than if the individual was rushed (Davignon, Friedlaender, Cronholm, Paciotti, & Levy, 2014).

Identified Suggestions and Necessary Improvements

While there a multitude of suggestions provided by participants, all of these suggestions fell under three categories: Recognizing parents as partners in care; providing an ASD friendly environment and the development of resources to address the unique needs of individuals with ASD; finally, educating providers and creating an opportunity for capacity building was emphasized.

Parents as partners in care. One of the recurring suggestions provided by both individuals with ASD and their parents was one of the most basic- allowing the patient, if possible, and the care provider (parent or guardian) to be partners in the child’s care process and decisions. Often individuals with ASD saw their parent as both their interpreter and advocate for high quality care. When asked about how he described his pain, one individual with ASD stated “Tell my Mom, My mom understands my pain and what I mean” (Ely, Chen-Lim, Carpenter, Wallhauser, & Friedlaender, 2016).

Parents were not only able to act as their child’s interpreter, they provided a baseline for their child “who they are, on their typical day, and also who they are on their best days and their worst days ... So, a child with autism ... may come in looking really ill or really distraught, but that may not be too different from what they usually are. Or people may make assumptions that, oh, it shouldn’t be too different ‘cause they have whatever condition but in fact, it’s a huge change, ‘cause this is a child who interacts differently (Muskat et al., 2015).”

Parents were also able to offer suggestions and implement well-recognized positive behavioral strategies during difficult medical procedures (Muskat et al., 2015). However this is only possible if parents are provided with the necessary information about the procedure and the flexibility to be given sufficient time and resources to implement these strategies “preparation is key. The things that set her off with tantrums is when something unexpected happens. If I haven’t done my job of preparing her (Davignon et al., 2014).”

ASD Friendly Environment & Resource development. Throughout the interviews, focus groups, and surveys parents and participants indicated the necessity of adjusting the environment to make it more ASD friendly. Several family members suggested creating a separate room that was quieter and sensory friendly- such as using warm colors and avoiding fluorescent lights and providing families with fidget toys and iPads (Davignon et al., 2014; Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016).

This became of particular importance when the child became agitated “Some type of change needs to happen [when the child is upset], whether wrapping him up in a warm blanket, or turning those lights off, putting calming music on, bringing in a sensory toy. Something environmentally needs to change (Davignon et al., 2014).”

In addition to physical modifications, the culture of the healthcare system was identified as an important barrier that needed to change. Participants identified the necessity of informing families with individuals with ASD of available resources in the hospital- such as child-life services and the availability of child and youth-oriented activities (Davignon et al., 2014). In addition, the overall admission process was in need of significant improvement. Parents suggested better signage to improve orientation to the unit, information about options and places

for breaks, and areas where snacks could be acquired (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Cohen-Silver, et al., 2016).

Other suggestions provided by individuals with ASD and family members were providing healthcare providers (HCP) with a formal resource that they could turn to when caring for pediatric patients with ASD “to have at their disposal, to help them plan ... and even to understand what are some of the issues for kids on the spectrum (Muskat et al., 2015).” One youth suggested a procedure-based storybook, a common practice among the ASD community when preparing an individual for transitioning or a new experience. Another parent suggested creating a formal resource kit for HCP’s to turn to when they needed to provide care to an individual with ASD “to have at their disposal, to help them plan ... and even to understand what are some of the issues for kids on the spectrum (Muskat et al., 2015).”

Educating Providers. Finally, participants emphasized the value of educating providers and capacity building around providing care to individuals with ASD. Participants emphasized the importance of providing education about ASD during student training, something which they believed was central to improving care, experiences and outcomes for individuals with ASD. One parent described her beliefs about this ““It just makes sense for people to be prepared and not be put in a position where you’re going to be arguing with parents just because you’re ignorant (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Cohen-Silver, et al., 2016).”

While some family members wanted formal members of the staff to be specifically trained and assigned to working with individuals with ASD, other participants emphasized the importance of every staff member being equipped with basic communication and behavior modification skills “Having some education about de-escalation would be very helpful (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Cohen-Silver, et al., 2016).” Overall,

however, the importance of staff members being willing to be flexible, open to communication and willing to build a relationship with individuals with ASD, and their family members, was emphasized as the ideal.

One parent described how valuable it was for her and her son to experience a moment in which she was able to step back from her child's medical care "If the nurse had not been the same, it would have got out of hand, I know as I have been in this situation before, but this time it went like clockwork. The interplay between them was incredible, so elegant. Its an art that for once we could witness as bystanders, without carrying any responsibility (Lindberg, von Post, & Eriksson, 2012)."

Discussion

Individuals with ASD comprise only 1% of our population and have an overall hospitalization rate of 65/100,000, with the age group of individuals between the ages of 10-20 years of age having a hospitalization rate of 620/100,000 (Lokhandwala, Khanna, & West-Strum, 2012). Perhaps because of this, acute care inpatient settings may not perceive an immanent demand to create a standard of care that addresses the specific needs of this population.

Regardless of their admission rates, persons with ASD are 1.25 times more likely to be hospitalized than the general population. Hospitalizations for individuals with ASD have also been found to cost three times more than individuals without ASD- with a diagnosis of Autism having an incremental charge of \$1,637. These increased costs have been associated with longer hospital stays and a greater number of patients with ASD being transferred to other healthcare facilities. While statistical information exists about the increased costs of being a patient with ASD, little research has been done about the specific reasons why these costs exists. Something

which needs further clarification (Lokhandwala, Khanna, & West-Strum, 2012; Wu, Kung, Li, & Tsai, 2015).

Given the current deficits in addressing their unique needs (i.e., patient and family centered care) it may be unsurprising to note that a survey of children, adolescents, and adults with ASD found that 28% of respondents had negative experiences and unwanted outcomes as it related to their ED or hospital medical care. In addition, many healthcare providers have noted that there is an overall deficit in information and resources as it relates to providing medical care to an individual with ASD (McGonigle, Venkat, Beresford, Campbell, & Gabriels, 2014; Nicholas et al., 2016).

Despite these deficits, little research has been done about some of the experiences they, and their family members, face when entering the healthcare field. An oversight that needs to be addressed for numerous reasons, two of the most basic being to: provide patient and family centered care and to update what members of the healthcare field know and understand about the socially constructed barriers that disable this population and their caregivers. A necessity which has been continuously noted by family members, individuals with ASD and healthcare providers (Lindberg, von Post, & Eriksson, 2012; Muskat et al., 2015; Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Cohen-Silver, et al., 2016; Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016).

In an effort to address this, we wanted to highlight what is currently known about providing care to individuals with ASD. We also wanted to know the specific aspects of current acute care that lead to patient and family centered care and create healing environments, both of which are considered the standard for pediatric and patient care practice (Kuo et al., 2012). A healing environment is described as a space that attempts to promote physical, psychological,

and social well-being in a manner that takes into account the individual's unique needs (Swanson & Wojnar, 2004). Many researchers have emphasized the fact that a healing environment allows individuals to be free from cultural oppression and social isolation (Kearns & Gesler, 1998).

Finally, we wanted to identify and describe human-constructed aspects of the healthcare environment that create barriers for the patient and family; increased stress and work-load for the family; and create disabling environments for patients with ASD. Barriers that are caused as a result of physical, cultural, and interpersonal environments being constructed in a manner that causes individuals with ASD to believe that the needs of healthcare providers and patients without ASD are placed above their own.

Challenges & Necessary Improvements: Environmental triggers

One common symptom of ASD is a hyper- or hypo activity to sensory input. This may be manifested as adverse responses to specific sounds and textures (American Psychiatric Association, 2013). In the hospital setting, all patients are bombarded with a variety of sensory information- a multitude of unfamiliar faces, mechanical noises, the rapid pulsing of fluorescent lighting, and a constant hum of activity that gives little reprieve to the senses of the individual with ASD. According to our synthesis, patients and their caregivers are often not prepared or consulted ahead of time so that the environment can be adapted to suit their unique needs. Therefore, it is not surprising that many individuals with ASD may become overwhelmed with sensory input in this setting and at times attempt to cope in a manner that is familiar to them- screaming, engaging in repetitive behaviors and even hitting or biting (Johnson, Bekhet, Robinson, & Rodriguez, 2014).

This synthesis highlights that in some acute care environments, both parents and individuals with ASD perceive a medical culture where little or no environmental support exists for their physical, cognitive, emotional, or spiritual needs. The implicit messages noted from the culmination of patient and caregiver narratives was that they perceive that the suffering they experience, as a result of these human-constructed environments, are not a concern for healthcare providers. Many stating that healthcare providers may believe their suffering is both normal and unavoidable.

It was obvious that these deficits not only affected the quality of their care, but made many of the participants hesitate and carefully weigh the benefits versus risks of seeking medical care. Something which creates barriers for individuals with ASD to have access to appropriate care services (Ballard, Kalb, Vasa, Goldstein, & Wilcox, 2015; Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016).

As previously mentioned, a healing environment is one that attempts to take into account more than an individuals' physical well-being. Kearns and Gessler (1998) emphasized the importance of creating a therapeutic place that attempted to take into account familiar, daily routines of the individual and his or her family. In addition, the importance of giving patients a sense of warmth and identify was identified as a major component of the creation of a healing environment.

As it relates to individuals with ASD, suggestions by both medical personnel, caregivers, and individuals with Autism have included creating universally soothing physical environments that are sensory friendly and provide familiar items such as sensory toys or the use of iPads (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Cohen-Silver, et al., 2016; Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016; Zwaigenbaum et al., 2016).In

addition, a healing environment should address the psychosocial and cognitive needs of the patient and family.

Thus, somatosensory interventions that address the individual's five senses are crucial. Examples given were the use of soothing music and headphones to tune out the immediate environmental noises; visual interventions such as books, photos, art supplies, and videos; tactile interventions such as weighted blankets, heat wraps, massage/touch and brushing; olfactory interventions such as markers and flavored lip balms; and vestibular physical exercise or movement activities such as rocking chairs (McGonigle, Venkat, Beresford, Campbell, & Gabriels, 2014).

Challenges & Necessary Improvements: Impaired Communication & Necessary Training

While individuals with ASD may have impaired methods of communication, it was healthcare professionals who were perceived as lacking the necessary tools and knowledge to establish effective social interactions. Even when caregivers attempted to describe their child's developmental baseline, communication deficit often resulted in subsequent interventions that further disadvantaged the patient and family. Numerous examples were provided about the manner in which nurses and other healthcare providers failed to understand that their typical nonverbal communication methods were not effectively interpreted by persons with ASD, or that the manner in which their question was posed would be taken in a very literal manner by persons with ASD (Davignon, Friedlaender, Cronholm, Paciotti, & Levy, 2014; Muskat et al., 2015).

Unfortunately such oversight may go beyond simply missing subjective input from the patient. Taking into account the physical, psychological, and cognitive deficits these studies have described, there currently exists a cultural environment that implicitly tells these families that

they are not equals to families of children without ASD; they are not partners in the care of their child; and that their diagnosis is the source of the problem and a burden to acute care healthcare systems.

Something which often results in individuals with ASD, and their family members, fearing the healthcare field. It also results in children associating negative experiences with medical care- something that makes their behavior more likely to deteriorate in future encounters. A tragic result that makes it more likely that individuals with ASD will require physical and chemical restraints, have longer hospital stays, and receive a lower quality of medical care (Lindberg et al., 2012; Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Cohen-Silver, et al., 2016; Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016)

Limitations

While this systematic review attempted to include the overall experience of individuals with ASD, and their family, only one of the nine articles actually included participants over the age of 18 in their study. This limitation was further compounded by the fact that five of the nine journal articles did not include the perspective of individuals with ASD. Instead most articles included feedback from the individuals' parents. While most individuals with ASD described their parents as their advocate and interpreter, the necessity of including their own perspective on the experiences they faced in acute-care and in-patient settings cannot be overstated.

Conclusion

Individuals with ASD entering acute care settings are faced with unique challenges that are often dismissed by HCP who may have little exposure or background into the unique needs

of patients with ASD. However, the importance of providing high quality care and taking into account the individuals' unique needs was emphasized by all participants.

For future studies, researchers need to begin using interview processes which are able to capture the unique perspective of individuals with ASD. In addition, beginning to explore the unique needs of adults with ASD is a necessity; particularly when we consider the fact that little research has managed to focus on this population.

Regardless of the research methods utilized, more research is needed to further uncover how socially constructed barriers develop and contribute to the disability and disparities in this population so that relevant interventions, policies, and research can be implemented.

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Appendix A

Search Process for Meta-Synthesis

Table 1A: Search Terms Used

PubMed	("autistic disorder"[MeSH Terms] OR autism[Text Word]) AND "Patient Care"[Mesh] AND ("life change event"[All Fields] OR experience[All Fields] OR experiences[All Fields]) AND ("2007/01/25"[PDat] : "2017/01/21"[PDat] AND English[lang])	61	
	("autistic disorder"[MeSH Terms] OR autism[Text Word] OR Autism Spectrum Disorder) AND "Patients"[Mesh]	36	
	("Quality of Health Care"[Mesh]) AND "Autistic Disorder"[Mesh] AND "Hospitalization"[Mesh]	18	
	("Quality of Health Care"[Mesh] OR quality) AND "Autistic Disorder"[Mesh] AND ("Hospitalization"[Mesh] OR acute care OR inpatient)	40	
	("Autistic Disorder"[Mesh]) OR Autism) AND	74	

	("Hospitalization"[Mesh] OR acute care OR inpatient) AND (viewpoints OR experiences OR events OR behavior)		
	("autistic disorder"[MeSH Terms] OR autism[Text Word]) AND (hospitalized OR acute care) AND (quality of care OR behavior management OR patient compliance)	41	
	("Autistic Disorder"[Mesh]) OR Autism) AND ("Hospitalization"[Mesh] OR acute care) AND (interview OR experiences OR behavior management)	18	
EMBASE			
	'autism'/exp OR autism AND ('patient care'/exp OR 'patient care') AND ('experiences'/exp OR experiences) AND ('asperger syndrome'/de OR 'autism'/de) NOT 'psychiatry'	28	
	'autism'/mj AND 'health care quality'/exp AND 'hospital patient'/exp	13	
	'autism'/mj AND 'patient care'/mj	45	
	'autism'/mj AND 'patient care' AND (2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py) AND 'human'/de	156	
	'autism' AND ('hospital patient' OR 'emergency care' OR 'acute care	29	

	hospital' OR 'acute care surgery') AND (qualitative AND method OR interview OR 'interpersonal communication' OR 'behavior management')		
	'autism' AND ('hospital patient' OR 'emergency care' OR 'acute care hospital' OR 'acute care surgery') AND (qualitative OR interview OR 'interpersonal communication' OR 'behavior management')	32	
PsychInfo			
	AUTISM AND ("patient care" OR "behavior management") AND (hospitalized OR acute care OR medical)	8754	
	Hospitalization AND Autism OR "Autism Spectrum Disorder"	131	
	(hospitalization OR acute care OR emergency care OR inpatient) AND (Autism OR "Autism Spectrum Disorder")	285	
Total		1,061	
Total Duplicates			398
Total w/o Duplicates		663	

Figure 1

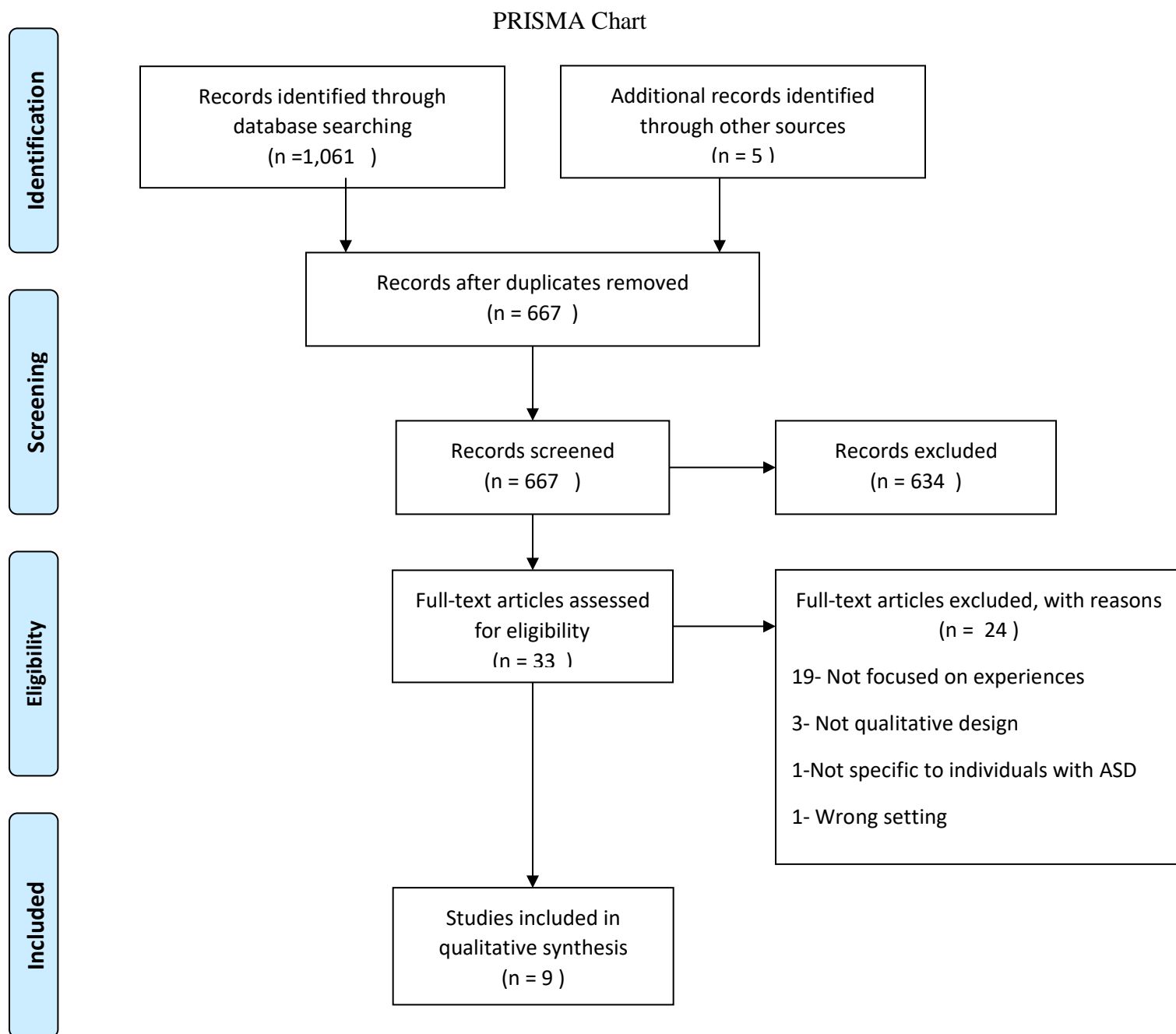


Table 2B.

[illegible]

[illegible]

6. Data Collection & Analysis a. Were the data analysis and procedures systematic? b. Was an audit trail provided? c. Did the researcher search for disconfirming cases?	2	2	2	2	2	2	2	2	2
	NC	NC	NC	NC	NC	NC	NC	NC	NC
	NC	NC	NC	NC	NC	NC	NC	NC	NC
	NC	NC	NC	NC	NC	NC	NC	NC	NC
7. Reflexivity of the account a. Did the researcher self-consciously assess the likely impact of methods used on the data obtained? b. Were sufficient data included in the reports to provide sufficient evidence for readers to assess whether analytical criteria had been met?	NC	NC	NC	1	NC	1	NC	1	1
	2	2	2	2	2	NC	2	2	1

Table 3B

Summary of Articles Included in Systematic Review

Study	Country	Data Collection Method/ & Methodology	Type & Number of Participants (N)	Diagnosis & Age of IWASD*	Explored Experiences
Johnson, Bekhet, Robinson & Rodriguez (2014)	USA	Focus groups/ Narrative Methodology	Parents (5) IWASD: (0)	Diagnosis: Autism: 3 PDD-NOS*: 2 Age of IWASD: 3-5: 3 6-11: 0 11-12: 2	To describe the meaning attributed to challenging behaviors of hospitalized children with ASD and the prevention strategies used by parents and HCPs
Muskat, Riosa, Nicholas, Roberts, Stoddart & Zwaigenbaum. (2015)	Canada	Interviews/ Interpretive description	Parents (22) IWASD (6)	Diagnosis: ASD 17/20 youth categorized as severe on SRS (Social Response Scale) Age of IWASD: Age range: 10-16 Mean age: 11.9	To understand the hospitalization experiences of children and youth with ASD, their families, and their HCPs with the objective of utilizing our findings to improve hospital care for children and youth with ASD
Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, Greenblatt, Roberts & Cohen-Silver (2016)	Canada	Interviews/ Grounded theory approach	Parents (31) IWASD (4)	Diagnosis: ASD: 30 Age range: 3-17 Average Age: 9.9 years	How are ED services accessed and navigated by children with ASD and their families? & How is the ED experienced by these children and their families?
Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Cohen-Silver & Kilmer (2016)	Canada	Focus groups/ Interpretive description	Parents (16) IWASD (0)	ASD	What are the perceived gaps and needs in ED care for children with ASD?' and 'What resources and supports are needed to optimize ED care for children with ASD?
Ely, Chen-Lim, Carpenter,	USA	Interviews/	IWASD: (40)	Diagnosis: Aspergers:14 Autism: 13	To identify barriers to pain assessment in children with ASD and

Wallhauser & Friedlaender (2016)		Qualitative descriptive		<p>PDD-NOS: 13</p> <p>SRS Response Scale Results:</p> <p>Severe impairment: 25</p> <p>Mild to moderate: 10</p> <p>Normal: 4</p> <p>Age range: 6-17</p> <p>Mean Age: 11.73</p>	describe methods to communicate about their experience of pain
Davignon, Friedlaender, Cronholm, Paciotti & Levy (2014)	USA	Interviews/ Modified grounded theory	Parents (20) IWASD (0)	<p>Diagnosis: Autism: 13 ASD: 4 PDD-NOS: 2 Asperger's: 1</p> <p>Nonverbal: 8 Verbal: 12</p> <p>Age range of IWASD: (3-17) 3-7: 11 (55%) 8-17: 9 (45%)</p>	To qualitatively explore parent and provider perceptions of hospital-based procedural care for CWASD* with the intention of using their input to generate hypotheses for future intervention trials
Lindberg, Post & Eriksson (2012)	Sweden	Interviews/ Hermeneutic approach	Total: Parents (12) IWASD (0)	<p>Diagnosis: "Severe" Autistic Disorder</p> <p>Age range of IWASD: 5-16</p>	The aim of this study was to obtain an understanding of what parents of children with severe autism experience in connection with their child's anesthetics in the presence and absence of the perioperative dialogue
Kopecky, Broder-Fingert, Iannuzzi, & Connors (2013)	USA	Survey/ NP	Parents (80) IWASD: 0	<p>Diagnosis: ASD</p> <p>Age range of IWASD: 2-49 Average age: 14.5</p>	To characterize the needs of hospitalized patients with ASD in various categories as a first step to facilitating the inpatient experience for this population and improving their quality of health care.
Stefanatou (2008)	Greece	Interviews/ Descriptive statistics &	IWASD (25)	<p>Diagnosis: PDD</p> <p>Age range: 5-12</p>	To explore the level and nature of the emotional upheaval of hospitalized children diagnosed with PDD prior to hospitalization, related to their stage of development

		content analysis			
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*IWASD: Individual with Autism Spectrum Disorder *HCP: Health Care Provider(s)*CWAD: Child with Autism Spectrum Disorder *PDD-NOS: Pervasive developmental Disorder- Not Otherwise Specified

Table 4B

Derived Themes		
Theme	Second-order constructs	First-order constructs: Direct Quotes
Challenges & Deficits of Healthcare Process		
A. Environmental triggers/heightened sensitivities	Participants expressed difficulties across sensory experiences– touch, sound, taste, smell and sight. Participants acknowledged that hospitalization involves a great deal of touching, which may be especially difficult for some patients. (Muskat et al., 2015)	Parent: “the fact [patients with ASD are] lying down doesn’t help matters because half the time they’re being moved on a gurney. . . . But for these children [with ASD], if they can’t see where they’re going and they’re looking at a bunch of white lights flicking by, that in itself is going to wind them up” (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016)
B. Difficulties with communication	Both groups indicated that providers struggle in communicating with CWASDs, adversely impacting interactions. . . asking parents to clarify a given child's communication needs was described as the most effective way to address this barrier. Parents strongly endorsed use of pictorial and graphic communication aids as well. Although open to learning about such tools, most providers were not aware of them (Davignon et al., 2014)	Parent: “Every time [nurses were] saying, ‘Have you vomited?’ And he’s saying, ‘No, I haven’t’. [He didn’t tell them that] he’s been feeling nauseous . . . I said to [the nurses], ‘... You need to frame your questions differently. Because . . . he’ll just tell you what you asked him’” (Muskat et al., 2015)
C. Time-related Issues	Lengthy wait times in the ED were consistently described	Parent: You’re going to create [an] emergency by not

	<p>as especially challenging for children with ASD . . . Parents described insufficient time and processes to prepare the child with ASD for potential stress in the ED. Despite some children needing time to acclimate to the prospect of a needed procedure, such time allowance often was not possible due to rigid time constraints or urgency of need for the procedure (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016)</p>	<p>putting this stuff in place to help decrease their anxiety or behaviors because if they're in an uncomfortable place, even though they're not in that much pain, they're going to escalate to [where] now they're having behaviors where they're acting out. We can't get what we need to get done and we're going to have to start using general anesthetics for every single autistic kid that comes into the ED, which . . . shouldn't happen. (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016)</p>
Identified Suggestions & Necessary Improvements		
A. Parents as partners in care	<p>Family preparation aids encounter success, but preparatory guidance is variable (Table 2). Participants endorsed family preparation as another key to improving procedure success. (Davignon et al., 2014)</p>	<p>Parent: If I knew the things they needed to accomplish, then I could say, 'Okay, first we should do this or first we should do that', ... that would have helped, because I know what thing to tackle first" (Davignon et al., 2014)</p>
B. ASD friend environment & Resource development	<p>Parents indicated that modifications to the built environment, making it more autism-friendly (e.g., quiet and/or sensory room available, warm colors, no fluorescent lights), would lead to less stressful visits. Participants also recognized that individualized modifications to the environment could be helpful both in avoiding and addressing the child's agitation (Davignon et al., 2014)</p>	<p>Parent: "Sometimes you go to restaurants that have long waits and they give you that page system so that you can disappear until you're going to get closer to the time you might be called. And I just think how wonderful that would be because it would enable you to get your child out of that [ED] environment to somewhere they're comfortable and safe (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Cohen-Silver, et al., 2016)</p>

C. Educating Providers	Improvements in staff knowledge of ASD and competence in caring for patients with ASD through professional development opportunities were described (Muskat et al., 2015)	Parent: “it just makes sense for people to be prepared and not be put in a position where you’re going to be arguing with parents just because you’re ignorant.” (Nicholas, Zwaigenbaum, Muskat, Craig, Newton, Kilmer, et al., 2016)
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