

A PHENOMENOLOGICAL STUDY OF PARENTS OF AUTISTIC CHILDREN'S
EXPERIENCES WITH SAFETY

A DISSERTATION
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BY

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DEDICATION

This research is dedicated to my daughter, Annabeth. She was my inspiration for going back to school to get my PhD, and to try and make the world better for her and others on the autism spectrum. I'm so proud of her and lucky to be her mom.

I also want to dedicate this to the incredible families who live with autism every day, especially the parents who participated in this study. Many of them have helped other families affected by autism over the years. They gave advice, just listened, or offered a shoulder to cry on even when they were struggling themselves. I am fortunate to know them.

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ABSTRACT

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A PHENOMENOLOGICAL STUDY OF PARENTS OF AUTISTIC CHILDREN'S EXPERIENCES WITH SAFETY

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Autism is a complex problem with a significant global burden with increasing prevalence. Autism is a complex disorder with varying presentations. Autistic children are most often cared for by parents who, at the time their child is diagnosed, are overwhelmed and have limited knowledge of autism and the potential safety issues that exist. Safety may not be an immediate consideration while they learn to cope with the diagnosis and what it means for them and their family. It is unknown if healthcare providers are communicating enough about safety issues specific to autism to give these parents appropriate anticipatory guidance during check-ups. A review of the literature reveals limited recommendations for the education of parents of autistic children about how to manage safety concerns specific to autism or what safety issues to anticipate once their child has been diagnosed with autism. During this phenomenological study, parents of autistic children were interviewed. The study explored the safety issues they have experienced with their child and where they obtained information about safety specific to autism. Ricoeur's hermeneutic phenomenology method was used to interpret the data. Two underlying structures that demonstrated the trajectory of the experience were: lost/finding our way and battle-ready/battle weary. The phenomenological themes within

battle weary included: living with fear, living with uncertainty, and living with disappointment. The participants provided recommendations for other parents and healthcare providers to help keep autistic children safe.

This study illustrates the unique perspective of parents of autistic children concerning safety.

TABLE OF CONTENTS

	Page
DEDICATION.....	iii
ACKNOWLEDGMENTS.....	iv
ABSTRACT.....	iv
LIST OF FIGURES.....	ix
Chapter	
I. INTRODUCTION.....	1
Focus of Inquiry.....	1
Background.....	4
Study Purpose	8
Philosophical Orientation	9
Summary.....	11
II. REVIEW OF THE LITERATURE	12
Parenting a Child with Autism	13
Obtaining a Diagnosis.....	13
After the Diagnosis.....	14
Adjusting to the Diagnosis.....	16
Parent Training.....	18
Autism and Safety.....	23
Injuries and Autism.....	25
Autism Specific Safety Issues.....	29
Aggression.....	29
Elopement.....	30
Self-Injury.....	32

Bullying.....	33
Abuse.....	36
Summary.....	39
III. PUBLISHED ARTICLE: CONCURRENT MEDICAL CONDITIONS AND AUTISM SPECTRUM DISORDERS.....	41
IV. PROCEDURE FOR COLLECTION AND TREATMENT OF DATA.....	61
Methodology.....	61
Setting.....	61
Population and Sample.....	62
Recruitment.....	62
Protection of Human Subjects.....	63
Data Collection.....	68
Data Analysis.....	68
V. CHAPTER: MANUSCRIPT SUBMITTED FOR PUBLICATION.....	71
VI. SUMMARY OF STUDY.....	106
REFERENCES.....	110
APPENDICIES.....	133
A. Figure 1 Prisma Diagram.....	133
B. Letters of Support.....	135
C. Recruitment Flyer.....	139
D. Recruitment Script.....	141
E. Eligibility Form.....	143
F. Consent Form.....	145
G. Demographic Form.....	148
H. Interview Guide.....	150
I. CV.....	152
J. CITI Training Pl.....	158
K. Proof Manuscript is in Peer Review.....	161

LIST OF FIGURES

Figure	Page
1. PRISMA DIAGRAM.....	110

CHAPTER I

INTRODUCTION

Focus of Inquiry

Autism is a complex problem with a significant global burden. An epidemiological data review by Baxter et al. (2015) estimated that there were 52 million cases of autism worldwide in 2012 in addition to being the leading cause of disability in children under five. The frequency of autism continues to increase in the United States. Baio et al. (2018) reported that the prevalence of autism was 1 in 59 children in 2014 according to the Autism and Developmental Disabilities Monitoring Network (ADDM). This is an increase from when the Centers for Disease Control and Prevention (CDC) started tracking the prevalence in 2000 when the rate was one in 150 (2016). The etiology of autism is still unclear. The Diagnostic and Statistical Manual of Mental Disorders, 5th Ed (DSM-5) cites a variety of risk factors including environmental and genetic factors (American Psychiatric Association [APA], 2013).

Autism was first identified by Kanner (1943). Once thought to be purely psychological, autism is now considered a medical condition affecting development as well as the neurological system. The DSM-5 (APA, 2013) defines autism as a disorder that has deficits in communication and social interactions that may be associated with repetitive behaviors as well as interests that are pervasive. Revisions to the DSM in 2013 removed autism subtypes and included all types of autism under the blanket term of *autism spectrum disorder* with severity levels based on the level of support required for the person affected (APA, 2013). Autism has a wide variety of presentations that may

include some or all of the symptoms presented in the DSM in varying degrees of severity (Lai, Lombardo, & Baron-Cohen, 2014).

The global burden of autism is staggering. Lavelle et al. (2014) reported children on the autism spectrum had more office visits, used more medications, and special education services compared to those without autism. The same study found that raising children with autism had higher costs, including healthcare, education, therapies, family services, and caregiver time that was estimated to be \$17,081 per child per year compared to those without autism (Lavelle et al., 2014). The cost of these items extrapolated across the 2011 estimated total number of those with autism, ages 3-17, in the United States (673,000 total) was 11.5 billion dollars. Buescher, Cidav, and Knapp (2014) used data to determine the lifetime cost of caring for someone with autism and intellectual disability (ID) at \$2.4 million in the United States and \$2.2 million in the United Kingdom in the year 2013. The monetary cost of caring for someone with autism is one of many reasons why having a child with autism is overwhelming for parents.

Autism has varying presentations. Symptoms that are common include difficulties with attention, reasoning, speech, and social interactions. In addition to communication and social deficits, those affected by autism cannot often recognize danger which puts them at risk for multiple safety issues, including wandering and other injuries (Rice et al., 2016).

Historically, it has been shown there are potential safety concerns for autistic people in every setting and these change depending on the environment they are in (Volkmar & Wiesner, 2004). Shavelle, Strauss, and Pickett (2001) found that the

mortality rate of those with autism was significantly higher compared to death rates in the general population, with suffocation and drowning among the most common causes of death for those with autism. Autistic children have poor judgment and may have poor motor ability (Volkmar & Wiesner, 2004) that makes it difficult for autistic children to extricate themselves from dangerous situations. Impairments that are common in autism result in difficulty navigating one's surroundings (Kalb et al., 2016) and increase the likelihood of life-long safety issues making those affected more unlikely to escape unsafe situations (Sirin & Tekin-Iftar, 2016). Cavalari and Romanczyk (2012a) found that children with autism spectrum disorders were more likely to have risky behavior that increased the potential for injury. As the severity of autism increased, it resulted in more frequent injuries.

Autism spectrum disorders are not easily recognizable. Autism is an “invisible disability”; the behavior of someone on the autism spectrum can be mistaken for intoxication, drug use, or other conditions (Gorlin, McAlpine, Garwick, & Wieling, 2016; Hoogsteen & Woodgate, 2013). The lack of specific identifiable physical attributes in those with autism has led to documented traumatic interactions with first responders and the failure of others to intervene in dangerous situations due to non-recognition of autism. A study by Solomon and Lawlor (2013) described one parent's experience where her young, autistic child was able to visibly elope without anyone stopping him. No one realized there was a safety concern or that the child had autism due to the lack of easily identifiable autism specific attributes; thankfully, the child was found before he was injured.

Autism also affects communication and cognitive processing for some individuals. This can be misinterpreted by first responders. In 2003, police responded to a call about a teenager with a history of developmental disabilities, who had become agitated. The teen was holding a knife and was not able to respond appropriately to commands from the police which ultimately resulted in the teen being fatally wounded (Osborne & Reed, 2008). Joseph Weber, who had autism, was fatally shot in 2016 when the police attempted to stop him for a traffic violation and he did not follow their commands (Pugliese, 2017). In both of these accounts, the non-recognition of impairments caused by autism contributed to the death of these individuals.

At the time their child is diagnosed, parents of autistic children are overwhelmed and have limited knowledge of autism. Safety may not be an immediate consideration while they learn to cope with the diagnosis and what it means for them and their family. They do not yet know all of the potential safety issues associated with autism. The varying presentations of severity that occur within the autism spectrum contribute to many safety concerns in this population. While some safety concerns are specific to individuals, many concerns are common throughout this population. Unfortunately, autism continues to be misunderstood by many, including parents of newly diagnosed children, their caregivers, teachers, and community service providers such as police, first responders, and healthcare professionals.

Background

Many healthcare professionals work with the autism population in various capacities. These providers, especially those in primary care settings, are uniquely

positioned to assist with safety issues specific to autism. Well-child visits include anticipatory guidance for various issues related to age, including safety, which occur as children develop. The literature fails to adequately document safety as an issue in the autism population. Few autism specific safety recommendations to educate parents of children with autism during well-child visits were found in the literature. “A Guide to Safety Counseling in Office Practice” by the Injury Prevention Program of the American Academy of Pediatrics (AAP) (2012) is a key resource for child safety counseling. This guide, however, does not give safety recommendations for special needs populations.

Preventing injuries due to safety issues is essential in the autism population. Numerous injuries could be prevented with safety education and preparation of the parents and caregivers of individuals with autism (Kendrick, Barlow, Hampshire, Stewart-Brown, & Polnay, 2008). There are multiple considerations when teaching parents of children with autism about safety. The knowledge that the developmental “age” of the autistic child may be different from the chronological age is an important consideration when preparing to educate about safety issues (Kutz, Patterson, & Klein, 2012). There is no known literature to indicate if healthcare providers, especially those in primary care settings, are communicating safety issues specific to autism spectrum disorders to give appropriate anticipatory guidance during check-ups.

There are studies that discuss training for parents of children with autism which primarily include behavioral interventions and communication techniques (Beaudoin, Sebire, & Couture, 2014; Meadan, Meyer, Snodgrass, & Halle, 2013; Steiner, Koegel, Koegel, & Ence, 2012; Suppo & Floyd, 2012). Beaudoin, Sebire, and Couture (2014) did

a systemic review of 15 studies that included parent training for children with autism under the age of two. There were various types of interventions noted in these studies. Behavioral interventions intended to support desired behaviors with a reward system were included in two studies (Rocha, Schreibman, & Stahmer, 2007; Steiner, Gengoux, Klin & Chawarska, 2013). Sociopragmatic interventions occur through interactive play with the autistic child which contributes to learning were included in eight studies (Drew et al., 2002; Green et al., 2013; Mahoney & Perales, 2003; Mahoney & Perales, 2005; Oosterling et al., 2010; Schertz & Odom, 2007; Wetherby & Woods, 2006; Wong & Kwan, 2010). Five studies in this review included both behavioral and socialpragmatic interventions (Carter, Messinger, Stone, Celimli, Nahmias, & Yoder, 2011; Gulsrud, Jahromi, & Kasari, 2010; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Rogers et al., 2012; Vismara, Colombi & Rogers, 2009). The majority of the studies were focused on teaching the parents to work on eye contact, communication, attention, motivation, skill acquisition and increasing positive interaction with their autistic children (Beaudoin, 2014). While some of these interventions included reducing undesirable behavior, the review did not specify if any of these behaviors were related to safety concerns and prevention education.

Tonge, Brereton, Kiomall, Mackinnon, and Rinehart (2014) did a randomized control trial where parents were randomized to either an education and counseling group (PEAC)($n = 35$) or education and behavioral modification group (PEBM)($n = 35$). There was also a control group ($n = 35$) who received the usual treatment without either intervention. There were, in total, 107 children represented in the combined parent

groups. Children were measured based on adaptive behavior, autistic symptoms, daily living skills, socialization, and the ability to adjust emotionally as well as in language development. These measurements were assessed before treatment and six months after the interventions were implemented in the intervention groups. The control group was assessed before the study and approximately one year afterward. The PEBM group had both group and individual sessions which talked about autism, communication, socialization, behavioral issues, development, and teaching new skills with some references to managing difficult behavior. The PEAC group received a manual with educational material that was also used for the PEBM group. The PEBM group had the most improvement in communication ($p < 0.01$), daily living skills ($p < 0.05$) and social skills ($p < 0.01$) compared to the control group after adjustment of the mean pretreatment scores. Parents who received direct training and coaching reported better outcomes in their children. In the intervention groups, the greatest benefit was seen overall in those children who had the most significant delays in the communication and socialization before the study. Limitations included being dependent on parent report for the behavioral measures. No specified safety issues were addressed unless the parents included them as part of a problem behavior they wanted to work on for their child. The specific behaviors that were addressed were not included in the article, so it is unknown what the potential safety concerns might have been addressed.

A mixed-methods study by Giarelli, Bloch, Souders, Levy, and Pinto-Martin (2005) discussed a pilot program of parents of children with autism ($n = 31$). Parents were randomized to the treatment or control group with all participants receiving standard

care (two contacts with the autism center one week and six months after the autism diagnosis). The intervention group received two extra contacts with a pediatric nurse practitioner (a one-hour phone call one week after the diagnosis and a home visit three months following the diagnosis of autism). Stress was measured at the beginning of the study and four months later using the Perceived Stress Scale (PSS; Cohen & Williamson, 1988) and the Impact of Event Scale (IES; Zilberg, Weiss, & Horowitz, 1982). There was not a statistically significant difference reported between the two groups on the total stress scores measured on either the PSS or IES. When comparison specific items on the PSS from each group, statistically significant differences were found in the intervention group only on being less upset due to something unexpected ($p = 0.05$) and that accumulated difficulties were not so great they could not be overcome ($p = 0.04$). The small sample size used was a major limitation of this study and could have affected these results. Although there was a recommended format for the parent support, there was nothing to indicate that safety was specifically addressed as part of the intervention or standard care for the parents.

A review of the literature indicated (see Chapter 2) that there are limited recommendations for the education of parents of autistic children as to how to manage safety concerns specific to autism. There was also limited information about the safety issues parents should anticipate when their child has been diagnosed with autism.

Study Purpose

Autism is a disorder that has various presentations and degrees of severity and continues to be misunderstood by many, including parent(s) and healthcare providers.

The variabilities that occur with autism contribute to safety concerns in this population. Sirin and Tekin-Iftar (2016) found that parents of autistic children felt that safety was a paramount concern. Parents of children affected by autism look to healthcare providers as experts and for information about autism and safety.

The purpose of this phenomenological hermeneutical study was to explore the parents of autistic children experiences with keeping their child safe and how they obtained safety information to protect their child. The research questions were:

- 1) What are parents of autistic children's understanding and experiences of child safety?
- 2) What are the parents' experiences of obtaining and using information related to autism and safety from their child's healthcare providers?

Philosophical Orientation

Ricoeur's (1981, 2007) hermeneutic phenomenology is the philosophical underpinning that guided this study. Ricoeur (1981) described phenomenology as a philosophy of interpretation of what "being" means. He stated that hermeneutics is the discovery of the meaning of a problem that is hidden and interpreting it into what the actual experience is like for those who "live" it and exist in that world which is being described. Ricoeur's philosophy of hermeneutics included gaining understanding through interpretation of the text. This interpretation is accomplished through subsequent readings and analysis while recognizing the factual conditions in which the text exists. Ricoeur stated that "the text...is the paradigm of distancing in communication...namely that it is communication in and through distance" (p. 131).

According to Ricoeur (1981, 2007), there are four forms of distancing within a text. First, the meaning of what is being described in writing is externalized from the original discourse. Secondly, there is distance between the writing and the speaker. Ricoeur felt the purpose of the speaker and the import of what is said does not overlap. He felt the word-based meaning, and the psychological connotations were dissimilar. Thirdly, Ricoeur said that since the written text is open to an indeterminate number of viewers over time the social and historical implications of the text are removed. This enables a multitude of unlimited readings. Fourth, in writing the discourse that was spoken no longer exists, only the world it reveals is uncovered through the process of interpretation.

Understanding and explanation are part of the process of interpretation in hermeneutics. The reader can view the text from a structural point of view and look at the text in terms of the relations within it. Also, the reader can view the text from a phenomenological point of view and interpret the non-apparent lived experiences in the text. Ricoeur contended that explanation of the text theoretically could not be reduced only to structural analysis. To understand the text, the reader seeks to understand what is disclosed of the world the text describes beyond its sense of orientation. Ricoeur stated “to explain is to bring out the structure” compared to interpreting which is following “the path of thought opened up by the text” (Ricoeur, 1981, p. 160-1). Both understanding and interpretation are necessary to integrate the overall meaning of a text. Interpretation includes the process of appropriation, which is the self-understanding of the subject through the intention of the text. This occurs concurrently with the inclusion of what is

the meaning of the text and one's self, making the text one's own. During interpretation, Ricoeur indicated the need to consider the sense of the text as something other than what is intended by the author. The possibility of the different readings and interpretations contain some degree of uncertainty or guessing. To limit the different perceptions, Ricoeur stated the text must be considered in its entirety, holistically, which also allows for recognition of the parts without marginalizing them. Interpretation is considered in terms of probability. Texts, as well as human actions, have some specificity and a finite measure of conceivable translations (Ricoeur, 1981; 2007)

Summary

The lack of a sense of danger associated with autism can pose multiple safety concerns for children with autism and their families. In this study, parents of autistic children were interviewed and asked about their issues in keeping their children safe. Parents were also asked where they obtained their safety information and how they utilized that information.

CHAPTER II

REVIEW OF THE LITERATURE

Many difficulties associated with parenting a child with autism are included in this literature review. This review begins with a detailed discussion of autism, followed by the diagnostic process, and the stress such a diagnosis has on the parents of the autistic child. A review of autism and safety from selected published journal articles specific to the autism population are included: autism and comorbidities, aggression, elopement, self-injury bullying, and abuse. This integrated literature review utilized the Whitemore and Knafl (2005) literature review methodology.

A literature search was done using online databases accessed through the medical library in the Texas Medical Center as well as Texas Woman's University. The databases included PubMed, the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medline and OVID. Initial searches included a five-year period (2013-2018) but were extended to a 10 year timeframe (2008-2018) due to scant research about autism and safety. Keywords utilized in the search included autism, special needs or disabilities and each of the following terms individually: safety, injuries, morbidity, mortality, wandering, elopement, first responders, parental guidance, anticipatory guidance, and parents. For those articles found using the term disabilities or special needs, the article was reviewed to see if autism was included within the disabilities addressed in the research as part of the inclusion criteria. Additional inclusion criteria included: written in English; published in a peer-reviewed journal; evaluated safety, injuries or morbidity/mortality relating to participants with autism or developmental or intellectual disabilities

(if not stated as autism specifically) or evaluating training for parents of these children. Safety studies related to medications, clinical drug trials or studies that only assessed the ability to acquire safety skills with applied behavioral analysis (ABA) were excluded. The searches were combined, and duplicate studies were removed. The abstracts of the studies were reviewed to ensure they were related to autism and safety. References to the articles were hand reviewed to ensure that no other possible journal articles were missed. This literature review emphasizes autism and safety including the characteristics associated with autism that are associated with safety issues, the burden of autism for the parents, and autism-specific safety issues that relate to the scope of this research (see Appendix A-Prisma Diagram- Figure 1).

Parenting a Child with Autism

Obtaining the Diagnosis

The process of obtaining the initial diagnosis of autism is often cited as being difficult and challenging by parents of children with autism. In a retrospective study by Zuckerman, Lindly, and Sinche (2015), parents were often reassured by their healthcare providers when they first mentioned concerns about their children. In many cases, providers placated the parents rather than investigating their concerns. The study found this reassurance often resulted in a delayed diagnosis of autism up to a year or more. The faster the provider investigated the parents' concerns, the less delay in obtaining the diagnosis. Similarly, Bloch and Gardner (2007) identified finding a medical professional who could diagnose a child with autism was reported as a burden by many

parents. Overall, parents were frustrated with the length of time it took to get an autism diagnosis (Osborne & Reed, 2008).

In a qualitative study by Carlsson, Miniscalco, Kadesjo, and Lassko (2016), three themes emerged that mirrored parents' experiences during the autism diagnosis process: seeking knowledge, trusting and challenging experts and feeling empowered but alone. The seeking knowledge phase corresponded with the time the parents had identified an area of concern for their child and were referred for further evaluation. In this phase, parents also reported the process was not straightforward. The trusting/challenging experts phase occurred when parents received the autism diagnosis, which was associated with a variety of emotions and responses. The adjustment period that followed the autism diagnosis was referred to as feeling empowered but alone. At this point, parents were empowered with the new information and diagnosis but at the same time, felt alone and unsure how to proceed. Parents said that once their child was diagnosed, it was difficult to get further help for their child and themselves.

After Diagnosis

The time following an autism diagnosis is challenging for parents. Stress is often reported as well as needing time to become accustomed to the diagnosis and the changes this brings for the parents and family. Poslawsky, Naber, Van Daalen, and Van Engeland (2014) did an exploratory study that looked at the parental reaction to their child's autism diagnosis and found that although many parents of autistic children eventually acknowledge the autism diagnosis, those who have children more severely affected were likely to experience recurrent grieving.

There was conflicting information in the research about the number of information parents received about autism at the time of diagnosis. Osborne and Reed (2008) found that many parents in their study felt they did not receive much information when their child was diagnosed, and more help and support were needed. Additionally, Hall and Graff (2010) found that parents felt confused about the etiology of autism. In another study, parents described the amount of information received about autism at the diagnosis as valuable, but some noted it was overwhelming (Carlsson et al., 2016). A qualitative study by Derguy, Michel, M'Bailara, Roux, and Bouvard (2015) found that parents of children with autism felt that information and parental guidance were among their greatest needs. In all of these studies, the parents felt they did not get all of the information they needed about autism at the time their child was diagnosed.

O'Reilly, Karim, and Lester (2015) did a qualitative study of a group of stakeholders, which included autism parents and siblings, about their viewpoint regarding information that was available on autism as well as parental information needs. Although the study identified numerous sources of information about autism, there was some confusion about where the information could be located. In some cases, the research participants indicated the amount of information was overwhelming or the parents too fatigued as caregivers to make sense of it. Some parents involved in the study identified not have access to the internet or being able to read as potential barriers to obtaining information about autism. The formality of the language used in many of the resources was noted as an issue as it made much of the information difficult to read and understand. Many stakeholders questioned whether the resources were trustworthy. This

study found that there was an ongoing public and professional lack of knowledge about autism, which negatively affected the families directly impacted by autism. These families had a continual need for information and providing information solely at the time of diagnosis was believed to be inadequate.

Adjusting to the Diagnosis

The autism diagnosis is life-altering. Many parents noted they felt isolated, struggled with emotions, and making decisions (Carlsson et al., 2016). Parents in a hermeneutic, phenomenological study by Woodgate, Ateah, and Secco (2008) felt isolated from family and friends and felt stigmatized and marginalized in society. Parents of children with autism also described frustration with educational and healthcare systems due to the deficit in autism specific training, knowledge, and resources.

Parenting a child with autism is often exhausting and demanding 24 hours a day, seven days a week. One qualitative study (Altieri & VonKluge, 2009) found that so much time was spent caring for autistic children, that parents often fell out of touch with family and friends and had less support as a result. Some parents reported their autistic child was destructive and impulsive which often caused them to avoid going places with their autistic child. Maintaining a normal family life for siblings was also a concern. While siblings often assisted with caring for their autistic sibling, they also experienced significant stress due to the effects of living with autism. The realization that their autistic child might not have a typical life led to parental concerns such as depression, anxiety, and stress.

Stereotypes about autism that are often portrayed in the media result in stress for parents. Movies such as *Rain Man* (Johnson & Levinson, 1988), for instance, portray autism as mild without a true snapshot of the full spectrum and severity of symptoms. When parents realized that the milder form of autism is not always the reality for their child, they were extremely upset. Since their child's disability is not physical, and not always apparent, parents of children with autism found they needed to educate and inform others about autism repeatedly to explain various notable differences in behavior. Poor communication can also affect the parent child relationship and contributed to the parental stress. Parents also reported communication difficulties with the autistic children who were unable to articulate their needs. Often families described feeling detached from the autistic children and feared they were not meeting the child's needs (Gorlin et al., 2016).

Hall and Graff (2010) conducted a qualitative, pilot study of parents of autistic children and identified the following sources of stress: behavior, development, etiology of autism, autism services, financial burden, familial relationships, and thinking about the future. Parents stated that autism had engrossed their family life so much, they did not have enough time or energy for their other children. Some parents identified a concern about their child's future and worried about what may happen to their child when they were gone.

Research by Burke and Heller (2016) suggested the presence of maladaptive behaviors or poor health in children with autism increases the burden on the caregiver. Kissel and Nelson (2016) found that parents who reported their child exhibited severe

autistic behavior described more distress compared to those whose children develop normally. More severe behaviors resulted in poorer parent/child interactions.

Parent Training

Some research discusses general training for autistic parents. Bearss et al. (2015) reviewed the literature related to parent training for those who have children with autism. They separated the training into two main categories: parent support (which is knowledge-focused) and parent implementation (which is skill-focused). Parent support training was further broken down into care coordination and psychoeducation, which are services that directly helped the parents. Parent implementation was divided into parent-mediated interventions for symptoms (communication, play, and imitation) and parent training for challenging behaviors (such as disruption, feeding, sleep, or toileting).

Suppo and Mayton (2014) conducted a quasi-experimental study of parents who were the primary caretakers of children with autism. Nineteen parents were divided into treatment and control groups. The treatment parents were given an online program with material from the state of Ohio about autism. The modules contained general information about autism and also mentioned bullying, wandering, and how to manage challenging behaviors. The parents were tested pre and post-intervention to determine their scores on knowledge, satisfaction, and application. The treatment group scored higher in the knowledge area and had a significant difference between pre and post intervention scores ($p = 0.039$). Application for the treatment group was measured with a case study. There were no specific safety measurements to determine if any of the information helped with

safety concerns. The level of detail of the topics included in the curriculum was not discussed in the study.

Bearss, Johnson, Handen, Smith, and Scahill (2013) did a pilot study, that examined specified parent training to address autism and included how to prevent disruptive behavior. Sixteen participating families had autistic children between ages three and six years old. Interventions were implemented over six months in 11 “core” (face-to-face) and two optional home visit sessions. The results were measured by the parent rating their child on the Aberrant Behavior Checklist (ABC) and the Home Situations Questionnaire (HSQ) at baseline and weeks 8, 16, and 26. The ABC Irritability subscale and the ABC Hyperactivity subscale scores were reduced and found to be significant ($p < 0.001$, $p < 0.001$ respectively). The training in this program focused on behavior modification, play, and social skills. The program description did not include a discussion of specific safety issues. One limitation of this study was that extremely aggressive children were excluded. It is unknown if the training would have benefited the parents of those children.

Bearss et al. (2015) did a randomized clinical trial as a follow up to the previous pilot. This trial was done over 24 weeks, and compared parents separated into two groups: a group with parent training ($n = 89$) to a group with parent education ($n = 91$) at six academic centers in the United States. There were 180 autistic children total, ages 3-7 years, with existing behavioral issues. The parent training group had 12 core sessions, two optional sessions, two phone calls, and two home visits to assist with behavior. The parent education group had 12 core sessions and one home visit and focused only on

general autism information. The participating parents used the ABC and HSQ to rate the disruptive behavior of their autistic children. The parent training group had a larger improvement in the sub scores on the ABC compared to the parent education group (treatment effect, -3.0, 95% CI, -6.2 to -1.7; $p < .001$; $ES=0.62$). The HSQ scores were also better in the parent training group (treatment effect, -0.7, 95% CI, -1.1 to -0.3; $p < .001$; $ES=0.45$). The training in the intervention group (parent training) was targeted to specifically address ways to reduced behaviors such as aggression, “tantrums,” noncompliance, and self-injury. The major limitation of this study is that the data being gathered was dependent on parent recall and parents were not blinded to the group they were placed in for treatment. The locations the treatments were given were all academic settings with trained staff, so the authors stated more research would be needed to see if the training would be able to be implemented effectively in other settings.

There are many studies that discuss teaching parents to deliver behavioral interventions only for their children with autism. Some studies taught parents behavioral interventions to help them to manage aggressive and challenging behaviors (Machalichek et al., 2016). A study by Vismara, McCormick, Young, Nadhan, and Monlux (2013) used the same type of intervention to assist training parents with communicating with their autistic children with the idea this would help to reduce problem behaviors as well. These studies addressed ways to teach parents to reduce aggressive and challenging behaviors. These are only a portion of safety issues that these families experience as a group.

Suppo and Floyd (2012) did a review of the literature about parent training for families who have children with autism that included 23 studies from 2001-2010. There were a total of 325 children with autism who participated in the studies along with at least one parent. The studies included had parent training interventions that addressed social, communication, and behavioral issues. Interventions were done in facilities, the home or natural environments. Some referenced behavioral issues, but how much was covered in each training program is unknown. Additionally, safety was not mentioned as a topic in the studies included in the review.

Beaudoin, Sebire, and Couture (2014) did a review of the literature about parent training and the effect the training had on their autistic children's development, as well as parent well-being. Fifteen studies were included with a total of 484 children up to age 3. Interventions ranged from behavioral to sociopragmatic (spontaneous play and learning). There were six randomized control trials (Carter et al., 2011; Drew et al., 2002; Kasari et al., 2010; Oosterling et al., 2010; Rogers et al., 2012; Wong & Kwan, 2010), two pre-experimental studies (Mahoney & Perales, 2003; Mahoney & Perales, 2005), two quasi-experimental studies (Gulsrud et al., 2010; Wetherby & Woods, 2006), two mixed methods studies (Schertz & Odom, 2007; Rocha et al., 2007), and three case studies (Green et al., 2013; Steiner et al., 2013; Vismara et al., 2009). The targeted desired behaviors included attention, eye contact, communication, motivation, imitation, and play. Beaudoin et al. (2014) did not indicate that any of the studies reviewed discussed safety.

A descriptive study by Yildirim, Sari, Girli, Ozturh, Ozgonenel, and Rowley (2016) included 100 Turkish mothers of children with autism spectrum disorder (ASD) with and without ID to determine the home safety measures the mothers used for their children and how these safety measures were affected by different demographic variables. Almost 90% said they supervised their children almost constantly, except when someone else was watching their child, or the child was not involved in a potentially risky situation. For example, mothers indicated they might let their guard down when the child was watching television. The study showed significant relationships between the younger age children and increased safety measures in the home ($p < 0.05$), and a lower age of the mothers with more safety measures being taken at home ($p < 0.05$). More safety measures were also implemented if the child was the first-born ($p < 0.05$). The study also examined risk for injury in the children and found that 38.6% were at a higher risk of injury with about 68% who jumped off structures/furniture, and 52.9% wandering into prohibited areas. The lack of a control group, small sample size and the dependency on the accuracy of the information reported by the mothers were limitations. The mothers might not have reported accurate supervision or other safety measures if they feared this would reflect poorly on them. It is not known if the home safety measures list used in the study was tested, or if the tool was valid or reliable.

In all of the parent studies discussed, the length of time since the autism diagnosis was received in each case was not recorded. If the parents in the research had already been coping with an autism diagnosis for a lengthy amount of time, they might have already tried to locate their own resources. These parents may also have experienced

safety issues with their autistic children and made changes based on experience. The research studies did not explore previous autistic child injuries. In some cases, children may have already been injured or had a near miss due to the parents not knowing that autism could put their child at greater risk. In the literature that was reviewed regarding parent training, safety information was not consistently provided nor was there a standard curriculum. When safety information was provided, it did not include all areas that could be affected by autism and was generally incomplete. Yildirim, et al. (2016) did not explore how the mothers learned the safety information they used in their homes or if they had received any autism training before participating in the research. This finding may have yielded important insight into autism and safety.

Autism and Safety

Comorbidities

The presence of comorbidities affects the safety of those with autism. Epilepsy has been shown to be a common comorbidity in the autism population, especially in those children who are treated for injuries (Bilder et al., 2013; Gillberg, Billstedt, Sundh, & Gillberg, 2010; Iannuzzi, Cheng, Broder-Fingert, & Bauman, 2015; Mouridsen, Bronnum-Hansen, Rich & Isager, 2008; Shavelle et al., 2001). In some cases, deaths of those having autism concurrently with epilepsy resulted from status epilepticus, respiratory arrest, anoxia (Bilder et al., 2013; Mouridsen et al., 2008) and aspiration pneumonia (Bilder et al., 2013; Bourke, Nembhard, Wong & Leonard, 2017). Jain et al. (2014) found that children with autism and seizures concurrently had a 40% higher risk of sustaining injuries. Comorbid diagnoses of anxiety (Dempsey, Dempsey, Guffey,

Minard, & Goin-Kochel, 2016; Maddox, Turbanova, & White, 2017; Turcotte, Shea, & Mandell, 2018), ADHD (Jain et al., 2014; Turcotte et al., 2018), and depression (Jain et al., 2014) were also present in many children with autism who were injured.

In some cases, having an ID which may coexist with autism, has been shown to affect mortality. Bourke et al. (2017) conducted a retrospective cohort study of children ($n = 10,593$) with ID born in Western Australia between 1983-2010. During this time, 326 children with ID died. The level of ID was determined in several ways: by a value from the intelligence quotient (IQ) scale or having a disability known to be consistent with ID. Disabilities that were included as having a biomedical cause were: autism with ID, Down syndrome, Fragile X syndrome, maternal alcohol abuse, and post natal injury. Survival rates for those with ID were compared to those without ID at one year, five years, 10, 20, and 25-year survival rates. The study reported children with ID had an overall risk of death that was almost nine times greater than those without ID (HR = 8.7, CI: 7.7, 9.9). There were increased risks that were specific to age groups as well: ages 1-5 years had a six-times higher risk of death (aHR = 6.0, CI: 4.8, 7.6) , ages 6-10 years had a twelve-time increased risk of death (aHR = 12.6, CI: 9.0, 17.7) and ages 11-25 had five times higher risk of death (aHR = 4.9, CI: 3.9, 6.1) compared to those without ID. Children with a known biomedical cause for ID or had severe ID had the highest risk of death across all ages when compared to those without ID. The causes of death in the ID group were appeared to be primarily related to the nervous system, followed by endocrine or metabolic causes, congenital defects, then external causes, and injuries or poisoning compared to those without ID. Accidents were the cause of death in about one of ten of

those with ID. As the degree of ID increased, the likelihood accidents were the cause of death increased to as high as one in three with moderate ID. The study noted that females with ID had a higher risk of death compared to males with ID. This gender difference was recommended for further follow-up.

Injuries and Autism

Several studies reviewed injuries in the autism population. A retrospective study by Guan and Li (2017a) examined the deaths ($N = 1367$) of those with autism between 1999-2014 in the United States with data from the National Vital Statistics System. The average age at the time of death was 36 years old compared to 72 years old in the general public. Approximately 28% ($n = 381$) were due to injury with suffocation/asphyxiation and drowning being the most common causes. Forty percent of the deaths were at home or in a residential facility. The average age for those with autism who died as a result of an injury was 29 years old, and the risk of unintended injury was higher in those under 15 years old. One limitation of this study is that the data reported is dependent on the accuracy of the diagnostic codes assigned for autism, injury, and the external cause codes as well as the accuracy of death certificate data. Additionally, the data used a proportionate mortality analysis as the researchers were unable to calculate standardized mortality ratios due to the lack of data in this population.

A case-control, epidemiologic study by DiGuseppi et al. (2018) compared injuries of children with ASD, ages 30-68 months ($n = 693$) to two control groups, the general population ($n = 883$) and other developmental disorders not associated with ASD ($n = 676$) (language delay, motor delay, hearing deficiencies or sensory integration

problems). The study used data from six states (California, Colorado, Georgia, Maryland, Pennsylvania, and North Carolina). Caregivers were given several questionnaires to determine the cognitive ability and behaviors of their children. The caregivers were also interviewed about safety. The interview included questions about injuries for the children and if the subsequent injuries were treated in the emergency room or required hospitalization. Overall, injuries were highest in the ASD group (32.3%), followed by the general population (30.2%) and developmental disabilities (27.8%). The most serious injuries were again highest in the ASD group (26.6%), followed by the general population (24.7%) and lowest at 23.4% in children with developmental disabilities. A major limitation of this study is that it relied on the accuracy of the information recalled by the caregivers. The injury perceptions of the person being interviewed were also listed as a possible limitation that could have affected the results. If the caregiver did not define what an injury was or perceive injury in the same way as the researchers did, it could have affected what was reported.

A retrospective study by Jain et al. (2014) looked at injury claims data 2001-2009 from a commercial health plan. There were 33,565 children on the autism spectrum (up to 20 years old) compared to 138,867 children who were not autistic. Almost 45% of those with ASD in the sample ($n = 15,023$), had at least one injury compared to those in the study without ASD (31.5%, $n = 43,762$). The study included age as an important factor that influenced the risk of injury in children with autism. Many of the autistic children in the study also had concurrent medical conditions, but further research was recommended to compare the risk of injury with that population (ASD and concurrent conditions) with

varying degrees of autism severity. Further research was also recommended by the authors to compare the risks of injury in children with autism related to different age groups.

McDermott, Zhou, and Mann (2008) conducted a retrospective study of 1,610 children with autism who received Medicaid in South Carolina and were treated for injuries. The study focused on children with autism, 12 months to 17 years old, who had injuries requiring hospitalization or treatment in the emergency room in 2003. Children on the autism spectrum had more significant rates of injuries to the face, neck, and head (RR 1.47, 95% CI 1.13–1.90, $p = 0.004$) (excluding traumatic brain injury). The poisoning rate for children on the spectrum was almost eight times higher compared to those without autism (RR 7.59, 95% CI 3.76-15.30). The relative rate of those with self-injury was statistically significant in the autism children 7.6 times higher than those without autism (RR 7.62, 95% CI 1.65-35.21, $p = 0.009$). One limitation of the study was that self-injury was not further differentiated into suicide versus the self-injurious behavior that is commonly seen with autism. Without more specific information, it was difficult to discern the severity of the injury or if the injuries led to death. This lack of differentiation was due to the external cause codes that were used to bill the visit which did not specify the International Classification of Diseases (ICD) codes for the different circumstances. The study did not include any other injuries treated in outpatient settings, which is another limitation.

Kalb, Vasa, Ballard, Woods, Goldstein and Wilcox (2016) did a retrospective data analysis of 2008 data from the National Emergency Room System (NEDS) database. The

NEDS data came from 1980 emergency rooms in 28 states. A multivariate analysis compared children with ASD ($n = 14,532$) to children with ID ($n = 4118$) and a control group that was non-ASD/non-ID ($n = 6,398,195$). When comparing the ASD and ID groups- the chances of injury were 71% greater in the autism group ($p < 0.001$). In the autism group, the most common causes of injuries were falls and being struck by/against an object. These injury types were also the most common causes of injury in the non-ASD/ ID control group ($p < 0.001$). Emergency visits related to suffocation, poisoning, and self-injury were more likely in the ASD and ID groups ($p < 0.001$). Although the actual number of emergency room visits was lower for the ASD and ID groups compared to the control group, the authors determined that injury-related emergency room visits were 54% more common in children with ASD when compared to children with ID. There were some limitations in this study. The 2008 data was from before the ICD10 diagnosis codes were implemented on October 1, 2015. If the diagnosis codes for autism or the external cause codes identifying injuries were not assigned correctly, this could affect the data reported. Visits with the ICD code 315 (specific delays in development) were excluded from the data ($n = 4628$). These codes could potentially have been assigned to a child with developmental or speech disorder instead of autism, which could have affected the number of study participants. Additionally, children concurrently affected with ASD and ID were excluded ($n = 734$) and anyone with autism under 3 or over 17 years were excluded.

Autism Specific Safety Issues

Aggression

Aggression may be present in some children affected by autism and is often challenging for caregivers and parents. Aggression is defined as threatening behavior (either physical or verbal) or behavior that could cause harm. Managing or anticipating aggressive behaviors can be difficult, especially in the autism population. Aggressive behavior often has an unfavorable impact on the life of a person with ASD or their caregivers and families (Fitzpatrick, Srivorakiat, Wink, Pedapati, & Erickson, 2016).

A qualitative study by Hodgetts, Nichols, and Zwaigenbaum (2013) found parents who reported their autistic child was aggressive also reported feeling isolated due to being afraid to leave home. Leaving home meant leaving an environment that they could control by removing hazards and fragile or dangerous items. These parents often feared for the safety of their children, for others or others' belongings when their children were in unfamiliar environments. It also meant they needed to be on constant alert to keep their child "out of trouble," which made it almost impossible for parents to socialize or get support from friends or family in external settings. Parents of aggressive autistic children also reported excessive fatigue and sleep deprivation due to the need for constant surveillance of their child. In some cases, there were reports of the autistic child physically assaulting another family member. Respite care, which was difficult to find, was even more difficult to obtain for an aggressive autistic child. Professional support and knowledge about autism-related aggression have been reported by parents to be

minimal, especially when it was not observed firsthand. Aggression often resulted in additional costs in home repairs or modifications to make the environment safer.

Kanne and Mazurek (2011) looked at the prevalence of aggression with autism and the associated factors. A retrospective analysis included families of children with autism at multiple sites in North America. Children ($N = 1,380$) were between 4-17 years of age. Parents were given several questionnaires to measure diagnostic information, core symptoms of their child's ASD, and behaviors specific to their child. The symptoms of ASD were converted to a severity score. Fifty-six percent of the sample was found to have some degree of aggression, generally toward caretakers. Thirty-two percent of those had aggressive behaviors toward non-caretakers. Sixty-eight percent had been aggressive to a caretaker at some time in the past and 49% to those who were not caregivers. Aggression towards caretakers and non-caretakers were both found to be statistically significant ($p < 0.001$). Younger age positively contributed to aggression in those with ASD. Impulse control and emotional regulation are thought to be possible contributors, but these were not assessed in this study.

Elopement

Children with autism may leave a safe area if something upsets them or to explore something that interests them (McIllwain & Fournier, 2012). This behavior is referred to as wandering or elopement. Elopement is probably the most publicized safety issue related to autism. A survey by the Interactive Autism Network (Law & Anderson, 2011) found that 49% of autistic children between the ages of four and ten attempt to wander which is four times higher compared to those who are unaffected by autism. Of

those children that successfully elope, about a third are not able to communicate identifying information if they become lost and are unable to understand social cues (Law & Anderson, 2011).

Autistic children and adults can elope from many different settings. Common sites where elopement occurs include homes (Anderson, et al. 2012; Kiely, Migdal, Vettam & Adesman, 2016; Rice et al., 2016; Solomon & Lawlor, 2013), stores (Anderson et al., 2012, Law & Anderson, 2011; Rice et al., 2016), schools (Anderson et al., 2012; Kiely et al., 2016), public places (Kiely et al., 2016) or other open areas, where it is difficult to contain the autistic person (Rice et al., 2016). Rice et al. (2016) reviewed data from the Pathways Study and found children with ID and autism had the most reports of wandering or being lost within the last year, followed by those with autism alone (approximately 24-38%).

Wandering or elopement often leads to other potential safety issues for those with autism, such as drowning. Between 2009-2011, the media reported that 91% (20 of 22) deaths associated with children with autism were those who wandered and later drowned (McIllwain & Fournier, 2012). In 2013, a 14 year-old autistic boy named Avonte Oquendo eloped from his school in New York City after security stopped him and instructed him to go back to his classroom. His remains were found months later by the East River, and his death spurred proposed legislation called The Avonte's Law Act of 2014 (Hilton, 2017).

Parents reported having a child that eloped as a significant burden and 26-40% of those surveyed had taken some preventative measures on their own to prevent it; some

families had installed alarms, metal bars, and locks on doors and windows (Rice et al., 2016). Global Positioning System (GPS) devices have also been considered as an intervention with elopement in those with developmental disabilities such as autism (Hayward, Ransley & Memery, 2016).

Self-Injury

Self-injury behavior (SIB) may be found in some individuals with autism. Parents in a phenomenological study by Gorlin et al. (2016) reported that their autistic children experienced a wide variety of these behaviors such as biting themselves, head banging, hitting themselves or throwing themselves into objects. Children with autism were also found to have patterns of injuries in specific locations when they were related to self-injury. A study by Slingsby, Yatchmink, and Goldberg (2017) compared injuries in autistic children with SIB to those without SIB. In the group with SIB, injuries were common to the forehead, back, feet, hands, thighs that were not as common in the control group without SIB. Self-induced injuries described by participants included: scratching or pinching, cutting, biting, pulling out hair, hurting themselves with sharp objects, burning themselves or seeking aggressive activities in an attempt to injure themselves (Maddox et al., 2017).

In an analytical, cross-sectional study, Akram, Batool, Rafi and Akram (2017) did a cross-sectional survey of children, ages 8-18 years, with ASD ($n = 83$) from a city in Pakistan. Of those participants, 33% were found to have some form of non-suicidal self-injury behavior (NSSI). Of those with NSSI, 47% hit themselves, 38% scratched themselves, 35% pinched themselves, 33% picked scabs, 32% bit themselves, and 30%

were pulling their own hair. Of those ASD children with these behaviors, the age of the child ($p < 0.05$), gender ($p < 0.0001$) and the severity of ASD ($p < 0.0001$) were found to be statistically significant factors that could be indicative of the presence of NSSI. Early intervention and parental counseling were also tracked to see if either made a difference in the presence of NSSI. ASD children who had early intervention for their ASD and whose parents had received counseling were also shown to have a statistically significant decrease in the presence of NSSI (early intervention, $p < 0.0001$; parental counseling, $p < 0.05$). Limitations of this study included the small sample size. The specific details of the early intervention and type of counseling were not included, which could also be a limitation if this study was to be duplicated.

Bullying

Children with ASD have a higher risk of being bullied when compared to their peers. Some of the reasons for this are due to the specific attributes related to autism. Problems with communication, socialization and making friends put these children at risk for being victims (Cappadocia, Weiss, & Pepler, 2012). For some on the autism spectrum, not being able to communicate or identify those bullying them also makes them an easy target. Additionally, some affected by autism are unable to understand social cues (Law & Anderson, 2011) which can make it difficult for them to understand appropriate versus inappropriate types of behavior or to know when to ask for help.

Zablotsky, Bradshaw, Anderson, and Law (2014) did a non-experimental study of 1221 parents of children with autism ages 6-15 in the United States. Parents were asked to complete a 63 item online survey tool called the Bullying and School Experiences of

Children with ASD Survey (Interactive Autism Network, 2011). The majority of the autistic children (63%) had experienced bullying at least once in their lifetime, and 38% reported being bullied within the last month. The study covered a variety of autism spectrum disorders. It was found that within the spectrum, bullying was most common with Asperger's (48.7%), followed by other autism spectrum disorders (24.9%), and then autistic disorder (19.3%). It was found that ASD children who were in full inclusion education settings ($p < 0.001$, Odds Ratio (OR) = 3.23, 95% Confidence Interval (CI): 1.88-5.56) as well as those who spent the majority of the time in inclusive settings ($p < 0.001$, OR = 2.55, 95% CI:1.56-4.16) were more likely to be bullied compared to those children, who were exclusively in special education settings. The limitations of this study included that the findings were based on 1) accuracy of the information from the parents about the autism diagnosis, 2) parents' accurate use of the BSE survey tool and 3) the accuracy of bullying information.

In a cross-sectional, qualitative study five students with ASD were interviewed about their experiences with bullying. All of the students in this sample were able to understand what bullying was, but not why it happened, and all had been affected by bullying to some degree. Due to the lack of understanding of the cause of bullying, some ASD students developed anxiety, which sometimes triggered problem behaviors. What parents and teachers identified as minor bullyings, such as name-calling was not always perceived the same way by the autistic child. Even when the ASD child's peers were tolerant, the ASD child had difficulty befriending or maintaining friendships, which often

resulted in isolation. The small sample size was a limitation, as was the ages of the children who were not clearly stated (Hebron, Humphrey, & Oldfield, 2015).

An exploratory study was done with 192 parents of children on the autism spectrum (Cappadocia et al., 2012). Parents were recruited through snowball sampling and surveyed online. Participants completed a demographic questionnaire, a screening tool about psychological distress called the Kessler 6-Item Psychological Distress Scale (Kessler et al., 2003), a child behavior assessment tool Nisonger Child Behavior Rating Form-Parent Form (Aman, Tasse, Rojahn, & Hammer, 1996), an autism severity tool called Autism-Spectrum Quotient-Adolescent Version (Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006), as well as a tool for measuring bullying and victimization experiences for their children called Promoting Relationships and Eliminating Violence Network Assessment Tool-Parent Version (PREVNet Assessment Working Group, 2008). Seventy-seven percent of parents indicated their child had been bullied within the last month at school. Of those who experienced bullying within the last month, 30% reported having been bullied two or more times per week, 13% once a week, 23% two to three times that month and 11% only once. The total length of time the victimization was going on varied: 54% indicated it had been going on for more than a year, 9% for one year, 20% several months, 2% for two months, and 6% for one week. Overall, the rate of bullying was higher when compared to rates in the general population. In this sample, bullying was mainly verbal or social. Children with ASD who were frequent targets of bullying were rated by the parents as being more anxious, hyperactive, and had higher rates of self-injury behavior. Those targeted by bullies also had baseline

communication difficulties consistent with existing research. The convenience sampling method limits generalizability.

Abuse

Disabled children are at a higher risk for abuse (Maclean et al., 2017; Palusci, Nazer, Greydanus, Athens, & Merrick, 2017). Palusci et al. (2017) found disabilities that affect behavior place individuals at a greater risk of being a victim, especially when those affected are children. Children with disabilities are frequently marginalized which is more prevalent in some circumstances. Disabled children may not be “mainstreamed” and need to attend special education classrooms. These classrooms are generally more isolated, which can lead to more opportunities for different types of abuse such as physical or sexual abuse.

A retrospective study (Maclean et al., 2017) of children born in Western Australia between 1990-2010 was compared to registries for disabilities in that country to identify those with disability ($n = 54,535$). Autism was included as one of the disabilities examined in the study ($n = 2253$). Of those who were identified as disabled, the names and identifying information were then compared to additional databases of mortality or allegations of abuse. The results found that about 25.9% of the abuse allegations (one in four) and 29% of the confirmed cases of abuse involved children with a disability (one in three). There were 8551 children with ID, and 62.6% of those were identified to have a comorbid condition (birth defects, cerebral palsy, autism, conduct disorders, or other behavioral diagnoses.) The types of abuse allegations included neglect, physical abuse, sexual abuse, and emotional abuse. The study identified other risk factors that contributed

to the abuse allegations including young age of parents, parents with mental health or substance abuse issues, or being disadvantaged with less access to resources. Limitations identified included the abuse needing to be identified and reported to accurately reflect the numbers, as well as the timing of reporting.

Children on the autism spectrum are at risk for abuse by their parents. A study by Chan and Lam (2016) recruited parents from special schools that served children with ASD in China ($n = 424$). The parents were measured on the Parent-Child Conflict Tactics Scale (Strauss & Mattingly, 2007) to determine their method of discipline. The subscales of this tool, psychological aggression, corporal punishment, and severe physical abuse were used to measure mental as well as physical abuse. Each item utilized a Likert scale to measure the frequency of each occurrence. Risk factors for these parents were investigated to determine if any had an influence on the severity of the aggression of the parents. There was a correlation between parental psychological aggression and physical assault of the autistic children ($p < 0.001$, $r = 0.49$). When comparing bivariate factors, correlations were found between psychological aggression and the family financial status ($p = 0.026$, $r = 0.11$), discrimination experienced by the family ($p < 0.001$, $r = 0.22$), age of the parent ($p = 0.007$, $r = -0.13$), age of the child ($p = 0.003$, $r = -0.14$), the number of hours the ASD child required caregiving by the parent ($p = 0.046$, $r = 0.10$) and the number of years since the ASD diagnosis ($p = 0.002$, $r = -0.15$). Physical abuse was correlated ($r = 0.11$) with the severity of symptoms ($p = 0.02$), parental stress ($p < 0.001$), and the number of years since diagnosis ($p = 0.01$). Based on the results, recommendations were made for more early interventions for parents to alleviate stress

and develop coping mechanisms. Limitations included the conceptualization of the factors, the parent sample being predominantly mothers, and convenience sample. Another limitation is that the data relied on self-report of the parents of the autistic children. Future research recommendations included outsider perspectives in addition to the parents and including more fathers.

In some instances, deaths of children with autism were caused by parents or family members. A retrospective study by Coorg and Tournay (2012) looked at news articles detailing the incidence of murder of disabled children by a parent, followed by the (attempted/actual) suicide of the parent. There were 21 articles analyzed with 22 disabled children, who were victims between 1982-2010. Fifty-five percent of the children who were victims were autistic. Of the male children who were affected, 62% were autistic. Thirty-eight percent of the parents involved had some mental illness such as depression, psychosis, and bipolar disorder. Seventy-one of the parents did commit suicide after killing their child, and the remaining 29% attempted suicide unsuccessfully. There were different reasons cited for these homicides such as the parent perceived the death of the child as a form of altruism. Another reason was that the disabled child was abused and that resulted in death. The most frequent reasons for the death of the children were gunshot wounds (38%), medication overdose (24%) and carbon monoxide poisoning (14%). The remaining 24% of deaths were a combination of suffocation, stabbing, car crash, fall from bridge, and fire. A large amount of data for this study was taken from non-peer reviewed sources such as news articles which is a limitation of this

research. There is not a specific database for this type of activity related to disabled children.

Those affected by autism are at risk for sexual abuse. A study of disabled students ($N = 37,693$) was conducted across nine public college campuses. Students with ASD ($n = 158$) and other non-ASD disabilities ($n = 7,108$) were given a campus climate survey which asked specific questions about unwanted sexual contact with specific examples given to define unwanted sexual contact. These responses were compared to undergraduate students without any identified disabilities. Students with disabilities (ASD and non-ASD) reported higher incidences of unwanted sexual contact when compared to their non-disabled peers. Limitations of this study concerning this literature review are that the autistic students are on the higher functioning end of the spectrum if they were attending college. The more severe end of the spectrum, where the autism is more pronounced, is generally considered lower functioning. Typically these children do not enter college. Another limitation is that there were greater numbers of women in this sample, which was about 28% of those with ASD. Since ASD is less common in women, it could make extrapolation of the data to males with ASD less generalizable (Brown, Pena, & Rankin, 2015).

Summary

This review of the literature demonstrates the various safety concerns that exist within the autism population. With the prevalence of autism increasing, more families continue to be affected and will need assistance. Autistic children are most often cared for by parents who, at the time their child is diagnosed, have limited knowledge of autism

and the potential safety issues they might encounter. The time following the diagnosis of autism can be overwhelming for parents. Although safety may not be an immediate consideration while parents learn to cope with the autism diagnosis and what that diagnosis means for them and their families, it is an important area of concern requiring further investigation. No research was found to indicate what safety issues parents of autistic children are made aware of at the time of their child's diagnosis. A gap in the literature exists. Some autism parent training is reported in the literature. However, no standardized safety program or curriculum for parents or caregivers of autistic children was found in the research. It is not known where parents obtain safety-specific information about autism. It is also not known if healthcare professionals are aware of this information or what and when to include this in their anticipatory guidance for this population. This gap in the literature is significant. If healthcare professionals are not aware of the issues about safety and autism, they cannot communicate it to parents of children with autism. Without being taught about the variety of safety concerns that apply to the autism population, parents are less able to prepare themselves or modify their home environment preemptively and prevent injuries to their children.

CHAPTER III

Concurrent Medical Conditions and Autism Spectrum Disorders

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Abstract

Long thought to be purely psychological in origin, current research lends credence to the idea that autism has a medical basis. Patients with autism can be among the most challenging patients that a healthcare provider may care for. Often the presenting symptoms of autism make these patients difficult to examine and may also mask underlying concurrent conditions. This article reviews some of the more common conditions found concurrently in the autistic population.

Concurrent Medical Conditions and Autism Spectrum Disorders

Case study:

AB was born at 39 weeks following an uncomplicated pregnancy and routine delivery. Between 12-15 months, her parents noticed she wasn't speaking as much as expected and had a limited vocabulary. They took her to a pediatrician who was not concerned and suggested waiting for reevaluation at the next visit. At the 18-month checkup, AB's family felt something was wrong due to her lack of speech and asked for a referral to a speech therapist. After two visits with the speech therapist, an evaluation with a developmental pediatrician was suggested. Frustrated, her parents asked why she wasn't developing normally. They understood that the speech therapist couldn't officially diagnose AB with anything that was not speech-related, but they were looking for an answer about her delayed speech. What was the therapist suspecting? Autism.

AB's parents found the waiting list for a developmental pediatrician was approximately one year long. Literature stressed the importance of early intervention in potential cases of autism. How could a year-long waiting list be acceptable for evaluation? With persistence, they were able to get into a different developmental pediatrician about a month later. Just before her second birthday, the doctor confirmed the speech therapist's suspicions and diagnosed AB with Pervasive Developmental Disorder-Not Otherwise Specified which is one of the Autism Spectrum Disorders (ASD). The family was given information about behavioral therapy, speech therapy and a list of local providers for

those services. No mention was made about looking for possible concurrent medical issues.

Autism

Autism is difficult to diagnose. Long thought to be psychiatric in origin, current research has indicated autism is a complex medical issue with psychological manifestations (Autism Treatment Trust, 2013). Autism is part of a spectrum of disorders that range from one extreme to the other: Patients can be mildly affected with no apparent disabilities and be barely distinguishable from their peers, or they may be severely affected and need around the clock care. Each patient has his or her own unique presentation. The parents of autistic children will often remind you: “if you have seen one child with autism, you have only seen one child with autism.” The Centers for Disease Control and Prevention (CDC) currently estimates that 1 in 88 children are affected by autism while that number increases in boys to 1 in 54 (2016). According to the CDC (2016), prevalence has almost doubled since 2008 when it was 1 in 150. Manifestations of communication and behavioral issues make these some of the most difficult patients to treat. Providers must be willing to take extra time to look for issues and become familiar with the baseline examination of the patient in order to be able to detect changes in the future. It is imperative to understand patients with autism communicate nonverbally in many cases, so it is important to determine the particular behaviors a child manifests and understand what the patient is trying to communicate. Understanding that many patients with autism have behavioral deterioration in unfamiliar environments is common, particularly when environments are over-stimulating. Special

toys and treats that are friendly to children with autism are essential to have in the office and may facilitate the visit.

Since children with autism cannot communicate normally, illnesses will not manifest with the typical symptoms that would normally be seen in the general population. In addition, these patients cannot usually communicate what their symptoms are or what they are feeling. Examining and treating patients on the autism spectrum involves some detective work. The medical significance of presenting symptoms or behaviors may not be obviously related. Autistic patients often act out by hurting themselves or others because they are in pain or cannot indicate what is bothering them. Parents and direct caregivers can be very useful in describing the patient's baseline regarding what is typical or atypical for their child/ patient in terms of behavior. All organic causes should be ruled out before the assumption is made that an issue is strictly behavioral.

Based on the incidence of autism, there is an increased likelihood healthcare providers will have autistic patients in their practice. Current research estimates that a full time pediatrician will have at least 20-25 patients on the autism spectrum (Carbone, 2013) or 11 patients with ASD per 1,000 in a practice (Will, Barnfather, & Lesley, 2013). As these autistic children age, we can expect that primary care providers will see a corresponding increase in the number of affected adult patients in their practices. Research has indicated most primary care providers do not feel comfortable managing a patient on the autism spectrum especially those who are severely affected (Carbone, 2013). Both nurse practitioners and physicians rated their ability to function as primary care providers for

ASD patients lower than that of other chronically ill patients due to its complexity (Will, Barnfather, & Lesley, 2013).

Until recently, there has been a lack of information available on autism and this has led many experienced primary care providers to feel uncomfortable in caring for patients with autism and their families. This is also true of many older healthcare providers who are teaching and practicing simultaneously. Few have experience with managing or treating autism but are in the position of training new primary care providers on this subject (Major, Peacock, Ruben, Thomas, & Wetizman, 2013). Healthcare providers who lack experience with autism would benefit from a training program designed to care for the autistic patient that incorporates new research in this area. Medical education programs are adding more robust training about autism. It is anticipated the future will show an increased in autism education and providers will be better equipped to deal with the increasing numbers of patients with autism.

Concurrent Medical Conditions

Recently, cutting-edge medical research has demonstrated many medical abnormalities that are associated with autism. Improved awareness of these disorders can increase the medical professional's index of suspicion when evaluating a child with autism. Below are descriptions of several examples of co-morbid medical disorders that can be easily missed in patients with autism.

Sleep disorders: Sleep disorders are a common occurrence in the autistic patient as compared to the non-autistic population. Autistic patients may awaken during the night several times a week and stay awake for extensive periods of time (Bauman, 2010).

Some studies have found an incidence of up to 80% sleep disorders in children with autism (Bauman, 2010; Malow et al., 2012) compared to a lower rate of about 30% for children without autism (Bauman, 2010). Although the exact causes for sleep disorders in the autistic population are unknown, there are many theories that suggest alterations and/or abnormalities in the biology or chemistry of these patients. Others suggest a disorder of melatonin production, dysregulation of the circadian rhythms, or perhaps medical issues such as gastro esophageal reflux disease (GERD) that lead to sleep issues and night time awakenings (Bauman, 2010).

Regardless of the reason or theory for sleep disorders, it is critical that patients on the autism spectrum get enough sleep. Lack of sleep can cause difficulties with attention, training, behaviors or functioning during normal daytime hours and can interfere with learning (Malow et al., 2012). Primary care providers should investigate the possible environmental as well as medical causes of sleep issues and rule out disease processes. If any sleep concerns are identified, the child needs to have a sleep study or be referred to a specialist (e.g. sleep specialist, neurologist) to investigate potential issues such as sleep apnea (Bauman, 2010; Carbone, 2013). Healthcare providers must remember that sleep issues affect not only the autistic patient but also the primary care giver and potentially other household members. Family members who are caring for these patients often have little respite. Frequent sleep issues can have a negative impact on their ability to cope with the stress of being 24/7 caregivers (Malow et al., 2012). When family member sleep deprivation is identified to be an issue, be sure to encourage family members to seek care as needed.

Medications that are available to assist with sleep have sedative side-effects. Any medication for children with autism may affect them differently as compared to non-autistic patients depending on the presence of concurrent medical conditions. For example, children with autism who have mitochondrial dysfunction may have difficulty with gastrointestinal (GI) issues that could interfere with the absorption of medications (Frye & Rossignol, 2011). When ordering medication for these patients, starting with low doses and titrate up slowly will allow one to monitor the child for side effects or other issues. Many of these patients tend to be on over-the-counter supplements that may not be monitored by a provider but still need to be considered for the possibility of drug interactions.

Melatonin has been used frequently for treatment of sleep disorders for autistic and non-autistic patients and demonstrated to be safe (Rossignol & Frye, 2011). A recent meta-analysis pointed out that five randomized, double-blind placebo controlled studies have demonstrated that melatonin, an over the counter supplement, is safe and effective for improving sleep in children with autism (Malow et al., 2012; Rossignol & Frye, 2011). Research indicates melatonin is the only treatment that has been shown to have efficacy for the treatment of sleep problems in children with autism (Rossignol & Frye, 2011). It is also clear that simply improving sleep also improves behavior during the day. Malow and colleagues (2012) treated 24 autistic children ages 3-10 with 1mg doses of melatonin and were titrated based on their responses up to as high as 6mg, although satisfactory results were seen between 1 to 3mg each evening. The study showed the medication caused minimal to no adverse effects with one possible case of gastrointestinal (GI)

upset, but no other issues or alterations in lab results were identified (Malow et al., 2012). Study outcomes revealed better quality sleep as well as improved behavior for these children in the daytime and slightly reduced stress for the parents of the affected children.

Immunologic issues: Multiple allergies are common in autistic patients supporting the theory of an underlying immune system dysfunction in this population (Autism Treatment Trust, 2013). The combination of food and environmental allergies often results in a domino effect on other body systems evidenced by an inflammatory response with elevated serum cytokine and IgE levels (Autism Treatment Trust, 2013). This is believed to affect the neurological system in individuals with autism. Reactions to common food or environmental allergies may vary from local to systemic and manifest in some patients as behavioral or sleep issues (Autism Treatment Trust, 2013). New fields of research investigation have suggested possible connections between autism and autoimmune diseases (Autism Treatment Trust, 2013).

The physical exam of these patients should include assessment of usual signs and symptoms of allergic responses, such as eczema, Dennie's lines, allergic salutes, and/ or swollen boggy nasal mucosa (Cash, 2011). Not all signs of allergies may be apparent or easy to isolate in the autistic patient, so testing for allergies should be considered if suspected. Blood work can be done to test for IgE reactions to the most common allergens. This is useful in detecting sensitivities which may not be obvious and manifest as behavior issues in patients with autism. Skin testing for allergies may be considered. However many autistic patients have sensory processing issues and would likely not tolerate skin testing which could potentially cause itching and local reactions. A workup

by an allergy treatment provider may be beneficial. Current treatment recommendations for allergies include avoiding the allergen (if known). Antihistamines may be given to treat symptoms. Currently, there are no recommendations for treatment of allergies specific to the autistic population in the literature.

Gastro intestinal issues: GI disorders are commonly found in autistic patients. Common concurrent GI disorders that are seen with autism include reflux, colitis/ inflammatory diseases, food intolerances or symptoms of irritable bowel syndrome (Autism Treatment Trust, 2013; Bauman, 2010). Loose stools, undigested food or abdominal distension, are some of the more apparent symptoms that are often noted while other GI issues, such as colonization with abnormal bowel flora, may not be so easily detected without further evaluation (Buie et al., 2010).

Children on the autism spectrum may have a “non-celiac” food sensitivity, which tends to be more common in those patients who have both ASD and allergies (Autism Treatment Trust, 2013). They may also have food intolerances due to sensory issues and may need intensive feeding therapy in order for them to receive a healthy, balanced diet. Many children have a self-limited diet which may result in motility issues. Pica is also a common finding on the autism spectrum and is thought to be related to a mineral deficiency (Olivie, 2012).

Some food elimination diets such as Gluten Free-Casein Free have gained popularity in the autism population and have also shown some improvement with GI symptoms. Current research literature does not support this as a first line intervention (Cash, 2011) but has suggested it may be more effective on a case-by-case basis. Food elimination

diets may alleviate GI symptoms by removing an unknown allergen or item that is not well tolerated. Theories suggest ingesting irritant foods causes inflammation in the gut lining which causes the membranes to leak, releasing particles into the body outside the GI tract (Autism Treatment Trust, 2013; Malow, 2012).

In 2010, Buie et al. recommended that GI or other medical issues be considered when there is a sudden change in behavior without explanation in a patient with ASD.

Assessing the autistic child for GI disorders can be difficult. Children often present with unusual discomfort symptoms which may include grimacing, mouthing or chewing objects, putting pressure on their abdomen, hurting themselves, or being aggressive toward others (Bauman, 2010).

Treatment will depend on the identification of the underlying GI issue. Some treatments that may be considered may be food elimination trials as well as allergy testing to look for possible food sensitivities. Other treatments would follow the standard of care for issues like GERD, constipation or diarrhea (Buie et al., 2010). If a GI issue is suspected and standard treatments have not shown improvement, referral to a gastroenterologist who has experience with autistic patients would be appropriate.

Neurological

Seizures have been shown to be present in up to 35% of patients with autism; about 60% of autistic patients have abnormal electroencephalograms (EEG's) (Bauman, 2010).

Seizures, like autism, have a variety of presentations. Symptoms can range from obvious tonic-clonic seizures to easily missed absence seizures. Without any clear seizure activity, it can be easy to overlook seizures in this population. Screening EEG's are

recommended when seizures are suspected or when there is speech regression (Frye, Butler, Strickland, Castillo & Papanicolaou, 2010; Olivie, 2012).

Autism often involves periods of staring or repetitive movements which can make a diagnosis of seizures difficult. Providers should inquire about symptoms of seizures including periods of staring or eye fluttering, deviated gaze, behavior changes which are followed by excessive fatigue (Bauman, 2010). Screening EEG's in this population have indicated some seizure like changes without evidence of observed seizure activity (Bauman, 2010). Treatment with medications, such as anti-epileptic drugs have often been associated with improvement in behavior and language in this population (Autism Treatment Trust, 2013) and should be considered (Frye et al., 2010). Referral to a neurologist for an EEG should be contemplated, preferably one who is familiar with ASD.

New Areas of Research

One of the newer developments in the science of autism includes the links to mitochondrial disorders. Guilivi et al.(2010) (as cited in Frye & Rossignol, 2011) reported that mitochondrial disorders may be present in the majority of patients with autism. Mitochondrial disorders are theorized to be related to the clinical findings of autism as well as the comorbidities often found within autism spectrum disorders, which could account for the various range of symptoms (Frye & Rossignol, 2011).

Diagnosis of underlying mitochondrial disorders can be difficult since this requires specialized testing. Frye & Rossignol (2011) discusses the presence of elevated lactate as one factor indicating underlying mitochondrial disorder, and research is continuing to

identify other biomarkers. Other means of testing for mitochondrial disease include muscle biopsy, buccal swabs, and serum testing for mitochondrial DNA abnormalities (Frye & Rossignol, 2011). The laboratories equipped to do these tests are not common and advanced planning is often required to package and ship the specimens for testing. Since this is a highly specialized field, referral to or consultation with a provider who is familiar with mitochondrial disorder would be best for patients who need further evaluation.

Return to case study:

AB's parents followed up with the pediatrician with the diagnosis from the developmental pediatrician in hand. The pediatrician also gave information about early childhood intervention programs in their community in addition to what the developmental pediatrician recommended: speech, occupational therapy, and behavioral therapy. AB's parents researched autism and became connected with some other parents of children with autism through local support groups. It was very frustrating that there was not a consistent, agreed upon treatment plan for autism at that time. Locating doctors who were knowledgeable about the treatment of autism proved to be an even more difficult task. With the over-abundance of theories and misleading information available, AB's parents wanted to find interventions that were evidence-based. Fortunately, they located a neurologist who had just moved to their community who treated autism.

The neurologist did a thorough evaluation, ordered a 24-hour electroencephalogram (EEG) and blood tests. The EEG results showed abnormal activity over the speech areas of AB's brain, which the neurologist explained could be a prelude to seizures and

recommended an anti-seizure medication. He explained that even though the seizures were not fully apparent yet, they could become may be more apparent at a later point. The neurologist indicated the anti-seizure medication could treat the potential seizure activity and also was shown to help speech development when those areas of the brain were affected and advised starting Trileptal.

After starting this medication, AB's speech showed remarkable improvement. There was a lot of echolalia, but both the family and therapists were thrilled. They felt they had more to work with and would be able to shape her speech over time. Her parents felt the neurologist was the first doctor who looked at the reasons behind why AB had autism and identified some other medical concerns as well which they could treat. The serum lab work repeated on several occasions came back with a consistently high level of lactate which the neurologist felt was a metabolic issue and needed further investigation.

Genetics tests later showed an underlying mitochondrial disorder confirmed by blood tests and buccal swabs which are currently being treated as well.

Six years later, AB has shown remarkable improvement and continues to see this neurologist. She can speak in words and sometimes in phrases and sentences to make her needs known. Thanks to the thoroughness and persistence of the neurologist, AB has improved exponentially. Had he not considered medical causes for what has long been considered merely a psychiatric issue, AB's progress would be very different. I am thankful for this every day because AB is my daughter.

The Role of the Nurse in Caring for Children With Autism

A thorough nursing assessment of children with autism and their needs is recommended in any healthcare setting. In addition to the normal items included in a nursing assessment, Scarpinato et al. (2010) discuss other important areas to be addressed in the baseline assessment, such as developmental level of the patient, any hypersensitivities the patient may have, activities that may cause overstimulation or upset the patient, what usually works best for the patient in similar situations, and the best way to communicate with the patient. Parents and family remain the best sources of information about what works best and what does not work (Johnson, Bekhet, Robinson, & Rodriguez, 2013). Kopecky, BroderFingert, Iannuzzi, and Connors (2013) suggest a parent/guardian survey that can be completed on admission to assist healthcare providers in determining the child's needs, including expressive communication, receptive communications, what will/will not be tolerated, how to interpret behaviors the patient may display, how to calm the patient, sleep issues, supervision, and safety issues. Communication is different for each child with autism. Some children may use a picture schedule or visual schedule and others may use a mobile device, such as an electronic tablet with communication software. Careful use of language is necessary as well. Scarpinato et al. (2010) related the importance of keeping communication short and in simpler terms. Because children with autism often have difficulty generalizing, they may only know one word or term to describe something. For example, if they know "belly" as the term for their stomach, if "stomach" or another similar term is used, they will likely not understand it. Children with autism also have issues reading facial expressions and other non-verbal

communications; thus, these methods of communicating are not recommended (Scarpinato et al., 2010). Children who cannot communicate effectively often have aggressive outbursts that are misinterpreted (Kopecky et al., 2013). However, there may be medical causes for these behaviors, such as pain, that should not be overlooked. Nurses should initiate a discussion with caregivers or family to help facilitate the use of familiar terms and determine the most effective methods of communication for each child. Safety is an important consideration as well. Healthcare providers may think of safety issues for children with autism only as when they act out or have behavioral issues. These behavioral issues can include agitation to more aggressive behaviors, such as kicking and hitting, which may be directed at family or healthcare providers, but can also include self-injury (Johnson et al., 2013). In some instances, when children are upset, allowing them to calm down may be the best approach (Kopecky et al., 2013). Wandering is a common problem in the autism population. Wandering and/or eloping from the inpatient environment is a concern that necessitates careful supervision (Kopecky et al., 2013). Nurses should work with family members to ensure that children who are at risk for elopement are carefully monitored. Behavioral therapy (applied behavioral analysis) can be effective. This therapy consists of a system of reinforcing good behaviors and extinction of undesirable behaviors using a reward system and reinforcement (Johnson et al., 2013). Rewards and reinforcement vary from child to child and can include praise, TV time, puzzles, games, favorite toys, or edibles (Johnson et al., 2013). Timing of rewards is just as important as giving the rewards themselves. Parents (and behavioral therapists) will give rewards often to help continually reinforce when the

child is acting appropriately (Johnson et al., 2013). Continuing with consistent reinforcement of desired behaviors is important. If they plan to use reinforcement, nurses should discuss the reinforcement with the behavioral therapist or family to ensure they are following the behavioral plan correctly. Johnson and colleagues (2013) state that distracting children with preferred toys or activities can help to calm them, and reducing environmental stimulation is key. This stimulation is most often noise-related, but it can be anything in the healthcare environment. Limiting the amount of unnecessary medical interventions is also helpful (Scarpinato et al., 2010). Tasks should be broken down into smaller steps, which can help make them less overwhelming. However, they may require a longer amount of time to complete (Johnson et al., 2013; Kopecky et al., 2013). Being flexible is one of the best things a nurse can do. Children with autism are so much alike in some ways and so very different in other ways. What may work for one child may be upsetting to another. Flexibility often means being willing to try to accomplish something in different ways rather than the way it is usually done. Taking extra time to learn about these children and their needs will help facilitate their care. Nurses can also assist the family by creating and maintaining a list of community resources. These resources can be used as a starting point for families to help them begin evaluation for services that can be accessed while waiting for a formal diagnosis. This list should include information about local Early Intervention Programs, a crucial piece of information for families. Children can be evaluated without a diagnosis, and if they meet the conditions for early intervention, they can often start receiving services long before they can see a specialist.

Conclusion:

Healthcare providers should be aware of the concurrent medical conditions that occur with autism. Children with autism do not have typical presentations for medical illnesses; careful assessment and attention should be paid to the subtlest differences that occur. The list of differential diagnoses in this population should be considerably longer, and new issues should not be merely dismissed as behavioral. Since waiting lists for specialists may be very long, it is important for primary care providers to start an initial work up, and if possible, in conjunction with a specialist. Recommendations include maintaining a list of current providers who treat patients with autism both within and outside the community. As time goes on and the population of those on the autism spectrum grows, it is only a matter of time until a patient on the autism spectrum is encountered all nursing practice.

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CHAPTER IV

PROCEDURE FOR THE COLLECTION AND TREATMENT OF DATA

Methodology

This phenomenological, qualitative study explored the parents of autistic children's experiences with safety. The recruitment sites were facilities located in the Houston, Texas metropolitan area that are utilized by autistic children and their parents. Snowball sampling was used to recruit beyond the facilities serving families with autistic children. Data was collected during semi-structured interviews with parents who self-identified as parents of autistic children and later analyzed hermeneutically. The following sections will give more detail in the various areas utilized during this research.

Setting

The recruitment settings for this study were sites that are utilized by families with autism, such as therapy offices, clinics, and special needs children's gymnasiums. The researcher obtained a letter of support from each participating business that serves the autism population and was willing to assist with recruitment. The researcher obtained three letters of support for recruitment sites (see Appendix B). One recruitment site was a special need children's gymnasium. There are no known age restrictions for this facility, and it served children on the autism spectrum. The census was approximately 30-40 children per day. Another recruitment site was a facility that does behavioral therapy for children with autism, which served up to 30 autistic children (ages 2-13) per day. The third recruitment site was a private school for children with autism in the Houston area. It served approximately 15 children, ages 7 to 16 years old.

Population and Sample

The population for this study was parents of children with autism in the United States. The face-to-face contacts were in the Houston area but due to snowball sampling, included participants outside of the Houston area and the state of Texas. Inclusion criteria were 1) parents who self-reported they have a child with autism; 2) age 18 years or over and, 3) English speaking to complete the consent and interview process. Exclusions were under-aged parents of children with autism and those who were non-English speaking. There were no exclusions based on the degree of severity of autism.

Recruitment

The recruitment was done via snowball sampling. Snowball sampling is used to reach populations that are considered difficult to contact or isolated (Sadler, Lee, Lim & Fullerton, 2010). The parents of children with autism are often isolated or hard to reach because of the autism diagnosis (Kutz et al., 2012), which makes this method appropriate for recruitment. Parents often avoid going out in public due to the unpredictable behavior of their autistic child and not being able to control the environment outside of the home (Hodgetts et al., 2013).

The primary recruitment was done by posting the recruitment flyers in each setting (see Appendix C). Employees and consumers were encouraged to share this information with any potential participants via word of mouth or sharing the flyer via email, Facebook, etc. The recruitment flyer was intended to notify possible participants of the study (parents of children with autism). The flyer included a brief, general description of the study purpose: to learn about the experiences of parents of autistic

children with safety and where parents obtained their safety information. It contained the timeframe for the study (Fall 2018-Winter 2019) and also included contact information for the researcher. The recruitment script (see Appendix D) was used to guide the researcher in the recruitment process. It identifies the researcher as both a Ph.D. student and parent of a child with autism.

The eligibility form for potential participants (see Appendix E) identified possible study participants. It asked the parent to identify if they had a child with autism and if they could read or write English. The parent was also asked if they would like to participate in a one-time only focus group at a designated day/time. Alternatively, they were asked if they wished to do a face-to-face interview or a phone interview.

Protection of Human Subjects

The PI obtained initial permission for the study in July 2017 from the Texas Woman's University Institutional Review Board (IRB) on the Houston campus. The IRB approval was updated in the summer of 2018. Each potential participant went through an informed consent process. The researcher explained: the purpose of the study; the study process; the time commitment; the risks and benefits of participation; how confidentiality would be maintained; the choice to participate or not voluntarily; the right to stop answering questions/ participating at any time; how the data would be collected; and they would receive a gift card for participation.

The consent form (see Appendix F) was reviewed with potential participants during the consent process. The consent form explained the study purpose and provided a brief description of the study procedures. The consent form detailed the potential risks of

participating in the study as well as the benefits. The researcher's contact information was provided if there were questions as well as the contact information for the Texas Woman's University Office of Research. The participants also indicated if they would like to receive the results of the study.

Specific risks were discussed with each participant. The first risk was related to becoming tired or upset during the interview process. The participants were made aware they could choose to stop answering questions at any point in time and end the interview or request breaks. If the participant needed to request additional help to deal with any upsetting feelings that might arise in the course of the interview, they were advised that the researcher would provide them with a list of available resources in a convenient geographic area. At the time of the study completion, none of the participants asked for a list of resources.

Another possible risk was the identification of child abuse or neglect during the interview process. Study participants were informed if they disclosed any child abuse or neglect during the interview process, the researcher was required to report it to Child Protective Services. They were also informed they were not required to answer any questions or incriminate themselves at any time. Participants were advised they could choose not to answer any of the questions and end the interview at any time.

Loss of confidentiality was discussed. Participants were informed that confidentiality would be protected to the extent it was allowed by law. If the participant chose to participate in a focus group for their interview or the validation meeting, they were informed they were not required to disclose their name. If they chose the private

interview, the location of the interview was agreed on by the participant and the researcher. Interviews were recorded by the PI. The tapes, recorders, paperwork and recorded interview, were kept in a double-locked cabinet in the researcher's home office until uploaded to DropBox. (DropBox is an online, password-protected information storage system. The researcher was the only person who has the password for DropBox.) Once the digital tapes were uploaded into DropBox, they were deleted from the digital recorders. All files in DropBox were secured in a password-protected file within DropBox. Only the researcher, her advisor and the person who transcribed the interview heard the tapes or read the transcribed interviews. (Transcription services were used for some interviews). The real names of the study participants were not added to the transcripts: only codes were used for identification. At a later point, a fictitious name was added that does not match any actual names of anyone involved in the study for writing purposes. The digital tapes and any documentation completed by the participants will be shredded or destroyed by 9/1/2019 after the study is finished. The de-identified transcripts will be kept for possible use in a later study. The study results will be reported in scientific magazines or journals. Publications will not include any identifying information.

Participants were informed that the researcher would try to prevent any problem that could occur due to this research. They were reminded they should let the researcher know if they had any issues and the researcher would try to help them. Study participants were informed that Texas Woman's University does not provide medical services or financial assistance for injuries that might happen as a result of taking part in the

research. Participants were given a chance to ask any questions or clarifications at the end of the consent process. Participants were informed again that they could choose to drop out of the study at any time.

Data Collection

A demographic information form (see Appendix G) was used to gather basic demographic information about the participants, including name, age, diagnosis of the child with autism, when they were diagnosed, and if the parents had any prior experience with autism before the child's diagnosis. Also, the form asked if there was a preferred method of contact about where they would like the study results sent. Participants were sent a reminder before the focus group/ interview only when indicated they would like one.

An interview guide (see Appendix H) with semi-structured interview questions was used to guide the discussion of the safety experiences of the parents with their autistic children. Additional prompts, which were also in the guide, were used if needed. These prompts were intended to facilitate gathering the most information about the experiences of the parents and where they obtained their safety information about autism.

Procedure for Recruitment:

The PI went to the potential recruitment sites and spoke with the management/ owner to discuss the study and gain approval to recruit at their site. Once approval was obtained, the PI got a letter of permission to recruit participants and hang flyers for the study in the location(s) permitted by the facilities. While on site, the PI would approach

parents who have a child on the autism spectrum (if possible) and introduce themselves and explain the general overview of the study.

Parents who were interested in participating and met the inclusion criteria, went through the informed consent process with the PI. The informed consent process included: explaining the study in greater detail; the risks/ benefits of the study; how personal information was protected; how data was gathered (via interview/ focus group); if they asked for a reminder, when to expect one; the opportunity to have a copy of study once published; and the \$25 gift card incentive after completion of focus group/ interview.

Once verbal consent was obtained, the parent signed and dated two copies of the consent form. The parent received one copy of the signed consent, and the PI kept the other. The PI kept the hard copies of documents secured at all times and locked in a file cabinet until the paperwork was either uploaded to Drop Box or shredded at the end of the study. Once informed consent was given, the parent also completed the demographic form and set up a date/time for an interview or participation in a focus group if they were unable to complete the interview at the time of recruitment. If the parent could not attend a focus group or complete the interview when approached, they were asked how and when they wished to do the interview. Options that were discussed included online meetings (such as Skype or Zoom), phone meetings, or a one-to-one interview in the setting of their choice at mutually agreed upon time.

Procedure for Data Collection

The PI entered participants in a contact list to send reminders before focus group or interview (if applicable) one week and 48 hours before. Reminders were sent via the preferred method identified by the participant (email/ text/ call). On the designated day and time, the PI interviewed the participant by whichever method they chose (in person/ skype, focus group). All interviews were audio recorded by the PI with two digital recorders. The digital recorders were placed at two different locations in the interview room on opposite sides of group/ participant to capture the best sound of all participants. Once the participants completed the interview/ focus group, the PI sent \$25 gift card to the participant.

The PI downloaded the recorded information for analysis after the data collection was completed and uploaded into Dropbox from the audio recorders. The PI or a certified transcription company transcribed the information from the interviews into Word documents. All information was secured when not being analyzed in locked files and secured in a locked computer and a locked file within Drop Box. Lastly, the PI analyzed the transcripts and interpreted the data from the interviews according to the Ricoeur's hermeneutic phenomenology.

Data Analysis

The interviews were transcribed Word documents that were analyzed. The data analysis was done with hermeneutic phenomenology. Following transcription to Word documents, a naïve reading was done. This involved making notes and initial impressions directly on the Word documents when reading the text from the interviews. The PI

looked for items or words that stood out to gain a deeper understanding. Once all transcripts had the initial reading completed, the text was analyzed structurally to look for recurrent ideas. The data analysis included structural analysis to identify specific constructs within the text that were identified during the interpretation. These structures encompassed a juxtaposition of themes. All specific information from recurrent themes etc. were related back to the text to understand the overall meaning of what it means to exist in the participant's world. This was interpreted to give us the phenomenological understanding of the viewpoint of the participants. Since Ricoeur's phenomenology was used for the philosophic foundation of this research, which includes the concept of will. Ricoeur (1981) felt will determines how one intentionally responds to the circumstances surrounding him or her.

The PI summarized the information in the analysis. All participants were given the opportunity to validate the analysis, but only four chose to meet with the PI for validation. Following the validation meeting, additional revisions to the analysis were made. Data from the interviews and validation meetings were included in the dissertation findings.

Trustworthiness

Lincoln and Guba (1985) discuss various methods for maintaining rigor in research. To maintain creditability, the researcher planned to have prolonged engagement with the recruitment sites to build trust among staff and potential study participants (Lincoln & Guba, 1985). As previously mentioned, research that includes triangulation by using both individual interviews and focus groups also strengthens the creditability of

the findings (Lambert & Loiselle, 2008). Having the participants validate the results assisted in maintaining creditability (Lincoln & Guba, 1985).

The data was analyzed to create a detailed description of the experience, which will aid in the transferability of the research (Lincoln & Guba, 1985). To maintain confirmability, the researcher kept a trail of the research progress through journaling to explain the various steps taken and thought processes behind them (Lincoln & Guba, 1985). The PI has been journaling throughout the research process to allow for capturing thoughts, and the procedures followed.

CHAPTER V

CHAPTERS SUBMITTED FOR PUBLICATION

A Paper to Be Submitted for Publication in the

Journal for Advanced Nursing

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ABSTRACT

BATTLE WEARY/ BATTLE READY: A PHENOMENOLOGICAL STUDY OF PARENTS OF AUTISTIC CHILDREN'S EXPERIENCES WITH SAFETY

Aim: This study explored the concept of safety through the experiences of the parents caring for their autistic children.

Design: Hermeneutic phenomenology.

Methods: Fifteen participants who self-reported they were parents of children with autism were recruited via snowball sampling. Data were collected from September 2017 to December 2018 in audio-taped interviews using semi-structured questions. Validation interviews were held with four participants.

Results: Two underlying structures that demonstrated the trajectory of the experience were: lost/finding our way and battle-ready/battle weary. The phenomenological themes within battle weary included: living with fear, living with uncertainty, and living with disappointment. The participants provided recommendations for other parents and healthcare providers to help keep autistic children safe.

Conclusion: This study illustrates the unique perspective of parents of autistic children concerning safety.

Impact: The majority of parents in this sample reported they faced substantial issues with safety for their child. Study results demonstrated that parents received little to no information about safety from healthcare professionals. Parents of autistic children and healthcare providers need to be educated about safety issues to prevent injuries and death.

Keywords: Autism, Safety, Parents

A Phenomenological Study of Parents of Autistic Children's Experiences with Safety

Autism spectrum disorders have increased in the United States, and are currently estimated at one in 40 children (Kogan et al. 2018) and is a disability noted commonly in childhood. This prevalence is a significant increase from the data collected in the year 2000 which estimated one in 150 children were autistic (Centers for Disease Control and Prevention [CDC], 2016). Impairments in communication, socialization, and decreased awareness of the surrounding environment are common in this population (CDC, 2016), which increases the risk of safety issues occurring. The presentations and severity of autism range from mild to severe along the spectrum and differ within a population (Constantino & Charman, 2017).

Background

Researchers have indicated that autism is associated with safety issues such as injuries and death. Higher rates of injury exist in the autism population compared to the general population (DiGuseppi et al., 2018; Jain et al., 2014; Kalb et al., 2016). Guan and Li (2017a) completed a retrospective study of 1,367 deaths of people with autism. Data obtained from the National Vital Statistics Survey in the United States (1999-2014) indicated the mean age of death in the autism sample was 36 years old compared to 72 years old for those without autism, and 27.9% of deaths resulted from injuries. In those under 15 years of age, 79.4% of those deaths resulted from unintentional suffocation, asphyxiation, and drowning.

The presence of comorbidities was reported to be a factor in the safety of those with autism (Bourke, Nembhard, Wong & Leonard, 2017; Dempsey, Dempsey, Guffey, Minard, & Goin-Kochel, 2016; Iannuzzi, Cheng, Broder-Fingert & Bauman, 2015; Maddox, Turbanova, &

White, 2017; Turcotte et al., 2018). Aggressive tendencies were present in some autistic individuals and often resulted in injuries (Fitzpatrick, Srivorakiat, Wink, Pedapati, & Erickson, 2016; Hodgetts, Nichols, & Zwaigenbaum, 2013; Kanne & Mazurek, 2011; Mazurek, Kanne, & Wodka, 2013). Furthermore, impairments in communication and socialization made individuals on the autism spectrum targets for bullying (Cappadocia, Weiss, & Pepler, 2012; Zablotzky, Bradshaw, Anderson, & Law, 2014).

Elopement, or wandering, is also a concern for those on autism spectrum due to the impairments that often coexist. Wandering was acknowledged as a critical issue among individuals with autism (Anderson et al., 2012; Kiely, Migdal, Vettam & Adesman, 2016; McIllwain & Fournier, 2012; Rice et al., 2016; Solomon & Lawlor, 2013). One study (Guan & Li, 2017b) found that wandering often preceded drowning. Self-injury behavior, which included biting, hitting, pinching or scratching, was a familiar finding in research (Gorlin et al., 2016; Slingsby, Yatchmink, & Goldberg, 2017; Akram, Batool, Rafi, & Akram, 2017). Also, the presence of disability places those affected with autism at higher risk for abuse or neglect (Maclean et al., 2017; Palusci, Nazer, Greydanus, Athens, & Merrick, 2017). Researchers indicated that familial abuse of individuals with autism exists (Chan & Lam, 2016) and could lead to the death of the disabled person (Coorg & Tournay, 2012).

Research that discusses education for parents who have children with autism exists (Bearss, Burrell, Stewart, & Scahill, 2015; Bearss, Johnson, Handen, Smith, & Scahill, 2013; Beaudoin, Sebire, & Couture, 2014; Machalichek et al., 2016; Suppo & Floyd, 2012; Suppo & Mayton, 2014; Vismara, McCormick, Young, Nadhan, & Monlux, 2013). These studies focused on different methods for educating parents and preventing challenging behaviors such as

aggressive tendencies. None of the studies indicated if safety concerns that are common with autism were addressed.

Having autism predisposes those affected to more safety concerns, injuries, and death. The research that exists about safety education specific to autism is limited. As the number of families affected by autism increases, more education will be needed to prevent injuries and death. It is unknown what information parents who have children with autism have received about safety and what their experiences are keeping their children safe.

Study

Aim

The first aim of this study was to explore the concept of safety within the autism population through the experiences of the parents caring for their autistic children. The second aim was to elicit safety recommendations from the parents of autistic children.

Design

Ricoeur's hermeneutic phenomenology (1981, 2007) was the qualitative methodology used for this study. Ricoeur (1981) described phenomenology as a philosophy of interpretation of "experience" and hermeneutics as the process of interpreting a text to find the underlying meaning of an experience. Ricoeur stated structures would be realized through analysis and demonstrate underlying themes that exist in the experience. These structures support the phenomena that describe what it means to exist in the world of the participants being studied.

Recruitment and Sample

A sample of parents who have autistic children was recruited via snowball sampling. Recruitment flyers were distributed at three locations in a large metropolitan area in the

Southwestern United States that served children with autism: a private autism school, an applied behavioral analysis therapy center, and a gym that served special needs children.

Inclusion criteria required participants who (a) were at least 18 years old; (b) self-reported they had a child with an autism spectrum disorder and (c) comprehended the English language in order to complete the study documents. Fifteen parents (12 mothers and 3 fathers) completed the study, and 17 autistic children were discussed (see Table 1).

Data Collection

Data were collected through audio-taped interviews. Eight participants chose to interview over the phone, five participants chose to interview in their homes, and two participants met with the Primary Investigator (PI) in a community setting. The interview questions were semi-structured (see Table 2). Interviews were approximately 45-90 minutes in length. Parents were given a \$25 gift card for participation.

Ethical Considerations

Institutional Review Board (IRB) approval was obtained before the initiation of this study. Informed consent was completed, and participants were advised they could end the interview at any time. Participants were informed that when the results were disseminated, a pseudonym would be used for writing purposes. During the focus group, participants were advised not to share identifying information to maintain their privacy.

Data Analysis

All interviews were transcribed into Word documents and analyzed via Ricoeur's (1981, 2007) hermeneutic phenomenology. First, a naïve reading was performed, and initial notes were documented including superficial impressions of words and feelings. Through subsequent readings, the underlying structures demonstrating essential key meanings of the text were

identified. According to Ricoeur (1981), structures are correlations within the text that may exist in a dichotomy but may not be explicitly stated. Once the structures were determined, the deeper, phenomenological meanings hidden within the transcripts were revealed. The structures and phenomenological themes were analyzed to determine if they adequately described the experiences of parents of children with autism. The results were validated with focus groups with four participants, via conference call.

Audit Trail

Throughout the research, the PI maintained an audit trail in an electronic format. After each interview and subsequent analysis, the meaning of the data matured. At first, the naïve readings of the transcripts revealed superficial impressions of the text. Repeated readings and analyses of the data revealed a deeper insight, which disclosed a greater understanding of the experience.

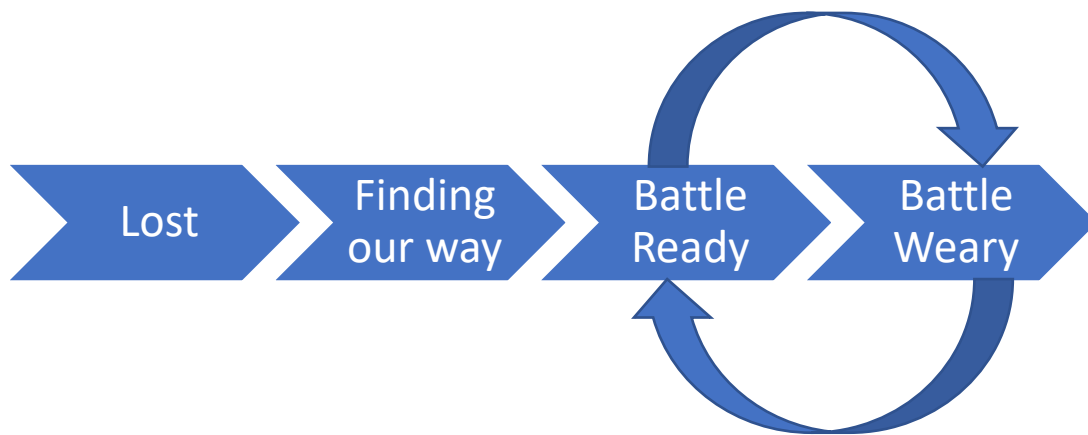
Rigour

To address creditability, the researcher maintained prolonged engagement with the recruitment sites which facilitated trust between the PI, staff, and parents who were potential participants (Lincoln & Guba, 1985). Triangulation of data was achieved through the combination of the focus group data and one on one interviews, which also added to the creditability of the results (Lambert & Loiselle, 2008). The depth of the phenomenological experiences discerned by this study aided in the transferability. The validation meeting emphasized the confirmability of the findings (Lincoln & Guba, 1985).

Findings

Two main structural elements surfaced during the analysis of the text that described the trajectory of the parents' experience with autism and safety: (a) lost/finding our way and (b) battle ready/battle weary (see Figure 1).

Figure 1



Lost/finding our way. The parents in this study described a progression of unusual behaviors in their child that started before the autism diagnosis and failed to resolve over time. Several parents expressed frustration and did not understand what was happening. The combination of these feelings was the beginning of the parents feeling “lost” as they struggled with how to help their child. Parents stated they knew a problem existed but were unsure what it was. Some described it as intuition or a “gut feeling”. (Note: Pseudonyms were used to maintain privacy.) Karen said: *“It was just this nagging feeling...it just didn’t go away.”*

Parents realized their child was not acting like other children and felt helpless. Jack said: *“I mean, all of a sudden, we were like this is not normal... We saw our son with other kids, and it was like night and day.”* The unusual behaviors that many of the children displayed resulted in

safety concerns. Debbie said *"We didn't know what was going on. She would bang her head into the concrete, and I couldn't get her to stop."*

Seeking advice from medical providers about their concerns often frustrated parents, since many providers failed to recognize their child had a problem. Ann indicated her pediatrician did not recognize her concerns, stating: *"My pediatrician didn't even see that he had an issue."* Susan said before the autism diagnosis, she had visited the pediatrician to get help because she was concerned: *"Things went downhill. He wasn't sleeping at night, banging his head constantly, was non-verbal. I didn't know what to do. The pediatrician says, "Why don't you get him in school? Maybe he needs to go to preschool." And I'm thinking there's something else wrong with my kid."*

Parents reached out to support systems that included their families or friends for validation of their concerns. Support was inconsistent, and frequently the parents themselves were doubted. Several parents reported they were made to feel like they had an issue, not their child. Karen reached out for help but felt like her concerns were ignored: *"Even my friends, even my husband, was like no that's not what it is...you're just being paranoid."* This lack of support from family resulted in many parents feeling abandoned.

When their child was diagnosed with autism, a few parents verbalized relief at finally having an answer to explain what was happening while others described how devastating receiving the diagnosis was. Most parents had limited knowledge about autism before the diagnosis and were not sure what to expect. A few parents stated they only got packets of information when their child was diagnosed and felt that support was lacking which resulted in feeling alone. Joe said: *"I just remember leaving the place... a little stunned...you don't know what you don't know other than getting a couple of packets...you're on your own."* Similarly,

Jack indicated he was at a loss for what to do after his son was diagnosed, stating: *"I don't know how to handle this."*

Parents often found their children's behaviors distressing and feared for their safety as they realized that autism changed how their family functioned. Daily activities were difficult and at times impossible, and some parents found they could not leave the house. Sarah described feeling isolated; her home became a jail because she was afraid to take her child out in public: *"You're stuck in your house. It's almost like (being) a prisoner. I can't take him out."*

The families had their lives turned upside down by the autism diagnosis as Linda described: *"It was devastating to our family. It's a roller coaster. It just rocks your family."* Life changed dramatically as they attempted to accommodate the changes that having a child with autism required. Leslie said: *"I don't even know what's normal anymore."* These parents had little knowledge about how to care for someone with autism and did not get the answers they needed from healthcare providers. Most parents fought to find help on their own.

Over time, the parents began to "find their way" as they tried to meet their autistic child's needs. Susan said she educated herself, while other parents used social media to reach out to online support groups. Terri found some Facebook autism parent support groups helpful, acknowledging: *"I was able to get ideas from other moms who had kids that were older."* Ann said: *"My husband basically Googled and researched autism."* Conferences and libraries were useful for some parents, and a few parents reported having some prior experience with autism.

Most parents learned by experience and discovered what worked best for their child. Leslie said she tried different things: *"A lot of it was trial and error and me just adapting different things to keep him safe... You kind of do what works for you based on your child's*

needs.” Some parents learned by doing thing “hands on”. Terri said: “I participated in therapy. I learned a lot just working with him.”

Some parents located local support groups but found going to the meetings difficult. Susan said: *“There’s always somebody worse than your son, or there’s always somebody better than your son...but that’s where we collaborated...and that’s where I learned a lot. It wasn’t from any healthcare professionals.”* Parents and families learned to find their way as they learned the different needs of their autistic child (see Table 3).

Battle Ready/Battle Weary. Parents described fighting a war on many different fronts. They described battling with schools for their child to have access to educational resources. Fighting with insurance companies to get services covered was common when services were not covered. It resulted in significant financial strain. Frequently parents felt as though they were fighting the mistaken perceptions of others who did not understand their child’s autistic behaviors.

Many parents realized the autism-related behaviors were posing a safety issue and sought ways to prevent their child from being harmed. As if preparing for battle, parents made modifications to their homes to keep their child from being injured or from wandering away. Alterations were made to daily routines or the environment depending on the individual safety needs of the child. Karen said: *“Do what you need to do to modify your home...make things safe.”*

Parents described how difficult it was to relax due to vigilantly supervising their autistic children and balance competing demands. Ann described how this affected her whole family: *“We were on high alert, constantly.”* Getting others to understand their point of view proved difficult. Betty said: *“It’s always been a battle to make sure they are taken care of...it’s a*

fight...or battle to make people understand what you're dealing with." Being in a persistent battle mode or state of battle readiness developed due to perpetually advocating for and protecting their autistic child. For many parents, this hypervigilance became a continuous fight or flight mode.

The need to constantly fight for their child and maintain some semblance of normalcy in their lives resulted in relentless stress. The hypervigilance and constant crisis mode that accompanied caring for their autistic child left many parents feeling drained. They tried to keep their lives in balance, but were often pulled in many different directions. Over time, this lifestyle was tiring both physically and emotionally for them. Parents stated the pressure they were under was usually unrecognized and living with autism twenty-four hours a day, seven days a week was exhausting. When talking about her experiences raising her autistic child, Susan said: *"I've been through hell and back."* Betty indicated she felt like the parents' experiences are overlooked: *"A parent can suffer just as much as the child is suffering. It's mentally and emotionally exhausting. It's always the parent gets the brunt of everything... Sometimes they just need to understand...and not be dismissed as you're crazy."* Leslie talked about depression and grieving as the reality of her situation set in: *"I think I was depressed. It was overwhelming; I didn't know what to do. I just wanted to crawl off in a ball in a hole."*

Some parents stated it was easier to avoid going out altogether. Leaving home meant leaving a safer environment that they could reasonably control. Some parents withdrew from any unnecessary activities outside of the home, which resulted in further isolation. Jane described how they had to lock the door to keep their son safe: *"We couldn't go out in public...he was just running off. I couldn't even open the door to say hi to somebody...he would just go into the street. This door (front door) was locked for many years."* The isolation experienced by many of

these parents wore them down and affected their ability to acquire and maintain much-needed support. Parents reported they had difficulty socializing or even leaving the house. Leslie indicated how doing everyday things became extremely hard: *"It's an everyday struggle. Taking a trip to the grocery store can really turn somebody's life upside down. Just doing daily things is difficult."* (see Table 4).

Phenomenological Interpretation

Three phenomenological themes were realized that explained the experience of being battle weary: (a) living with fear; (b) living with uncertainty, and (c) feeling misunderstood. Resilience was a fourth phenomenological theme that supported the experience of being battle ready.

Living with fear. Fear was a multifaceted theme that affected the lives of these families. Being unable to control the environment outside of their home or being unable to control their child made the parents afraid to leave their home. Sarah said: "We really can't get out to do a whole lot because I'm scared to take him out." Some parents described being fearful of going to someone else's home because they had to constantly supervise their child and were afraid of what their child might do in an unfamiliar environment. Ann said: "You're still on alert....*especially* when you go to *friend's* houses. My son will just go in their pantry and get what he wants. If he wants to go lay down in someone's bed, he'll just go get in a bed." These barriers to socialization resulted in additional isolation and decreased support for the parents and the family.

Parents were afraid their autistic child would be injured or killed. Many said their child lacked a sense of danger, which often put them in hazardous situations. Terri said: *"My daughter did elope when she was younger. It was so scary. She would just kind of bolt...and just didn't*

have any understanding of danger.” The parents shared stories about their child being in a perilous situation where they could have been injured or killed. Karen said: *“I couldn’t find him...I called 911...I was crying ... my son had climbed into the car...it was summer time, and we had the child locks on so... he wouldn’t be able to open it from the inside.”* These situations only exacerbated the parents’ fears about safety. Near misses, such as the one Karen described, resulted in an intensified the need to be “on alert” and fear of what could happen if there was a next time. Linda indicated she was worried about what could happen to her child if she failed to anticipate risks to her child’s safety: *“What do I do? I have to figure something out on my own...and with safety it’s not the luxury of figuring it out if something doesn’t work...because you may not get a second chance. There’s no room for error.”*

Several parents mentioned being worried about the future of their child and what the long-term outcomes would be. Other parents were concerned about who would care for their child when they were unable to and what would happen to their child when they were gone. Sarah said: *“You know what gets scarier as they get older... he’s always going to be our third wheel...I knew eventually...I’m not going to be here forever, and somebody is going to have to take care of my child.”* (see Table 5).

Living with uncertainty. Uncertainty resonated in all of the shared experiences. Parents described feeling uncertain about what life would look like and how long the behaviors or hardships would last. Karen said: *“When it starts happening, then you start questioning, is mine the only kid that does this? Or is there something unstable with him? Or this is not a phase? And is this going to happen his entire life?”* Hannah described it as: *“that overall feeling of you are never quite the same...”*

Sometimes the uncertainty was related to not knowing what progress their child might make or what the end result might be. Often there was uncertainty about access to therapies to meet their child's needs. When parents were unable to access the different therapies their child needed, this made the hope for their child's progress uncertain. The end goal for many of these parents was to help their children with autism transition to some degree of independence or life on their own in the community, but others were not sure if this was possible.

Feeling misunderstood. Many parents expressed feeling misunderstood by others, which often resulted in other feelings such as disappointment or feeling unsupported. Others who did not understand the autistic child's disability often judged these parents. Without having distinguishing physical features, children with autism are assumed to be misbehaving, especially in public settings. In regards to advice Susan was given about her son, she stated:

The hardest thing you're going to have is the fact that...you cannot see his disability, and it's not like he's in a wheelchair or uses crutches. When you can't see it, it's harder for the parents because it looks like you're being a bad parent because these kids act up.

Some parents reported their child's healthcare provider did not understand autism, which made it difficult to get the care and the support they needed. Sarah said she would visit the doctor because she felt like something was wrong with her child but could not understand why they did not see what she did, stating: *'It's hard when I go to the doctor, and I can't exactly explain his symptoms...I feel like things get overlooked...I don't know how they can't see what I'm seeing either.'* The majority of parents felt disappointed at the lack of empathy from many healthcare professionals. Joe indicated he felt a lack of support after his son was diagnosed: *"Don't send parents home with a newfound autism diagnosis, and just pat them on the back and say "Good luck."* Some parents felt that family members were unable to comprehend what they

were going through and were disappointed by their reactions and lack of support. Susan said she was scrutinized by her family when she mentioned her concerns about her child while Leslie found that her parents and in-laws did not understand what she was going through (see Table 6).

Resilience. Throughout the interviews, it was obvious that these parents had tremendous resilience. The parents were committed to doing whatever was needed to help their child. They did research, made modifications to their homes, and were determined to find answers. Susan stated *“I spend thousands of dollars, missed hours of work, but I didn’t give up...even when people told me not to.”* The concept of being strong for their child and their families resonated among participants. The parents focused on doing what was needed, rather than being mired in self-pity. Jane stated: *“I have to be strong. What can I do instead of crying? I have to be strong. What can I do next to help him? Crying isn’t going to get me anywhere.”*

Some parents were committed to helping other parents who have children with autism. Other parents acted as autism advocates to spread awareness in their communities. Terri said: *“You have these possibilities to learn from other parents...being able to educate other parents...yourself and your own experiences and then being able to help bring awareness to the community at large.”*

Discussion

Recommendations for autism parents. Parents who have an autistic child should be educated that sensory elements (i.e., light, sound, motion, and other people) in the environment may upset their children. If noise upsets an autistic child, for example, noise-cancelling headphones may reduce stimuli that may trigger unsafe behaviors.

When autistic children become overwhelmed, they have “meltdowns” which are often misinterpreted as tantrums. During these “meltdowns”, autistic children could unintentionally

injure themselves or others. Parents need education about ways to safely restrain or calm their autistic child during situations where injury may be a concern.

Modifying the home environment for safety is necessary, based on the child's needs. This includes: putting locks/alarms on doors and windows, putting stop signs on doors that go outside, covering electrical outlets and hiding potentially dangerous objects to prevent injuries. Visual monitors to continually observe children when they are in a different rooms such as bedrooms, can assist with supervision.

Wandering, or eloping, was one of the main concerns identified. In addition to securing doors and windows, using identification (ID) tags/ bracelets or wearable GPS devices are helpful in the event a child elopes. Having another adult to help monitor the child when going out in public is another safety measure. Tell neighbors the child should not be outside alone so the neighbors can intervene if they see the child outside. Since wandering is often followed by drowning in this population, parents recommend putting the autistic child in swimming lessons. Being vigilant with supervision around water and when the child is in an unfamiliar environment is essential. Some parents recommended devices such as strollers or wrist "leashes" to physically prevent the child from wandering away in public. Use fences with locked gates to prevent wandering at home.

All of the parents stated a lack of sense of danger in their autistic children was present. This resulted in safety issues, such as not looking before crossing the street or unbuckling safety restraints in moving vehicles. Teach autistic children about appropriate/ inappropriate behaviors to help the child identify if they are being bullied, or victimized. Parents who have newly diagnosed autistic children need to be educated they may encounter these safety issues and proactively put a plan in place.

The participants in this study stressed that autism parents should remember to prioritize their own care. Parents should seek help for themselves if needed, such as: networking with other autism parents, join support groups, and getting professional help.

Parent recommendations for healthcare providers. The parents in this study wanted more support from their healthcare providers following the autism diagnosis. Frequent face-to-face visits or phone calls can be done, which will offer more communication, follow up and support for these families. These visits or calls should be spread out over time to allow parents a chance to formulate questions and absorb new information about autism and safety. For example, following an autism diagnosis parents should be contacted by their healthcare provider (or their support staff) within one week. Follow up calls/visits should be made at least monthly for the first six months and the need for more frequent follow up can be reassessed on an individual basis. If providers do not have answers to the parents' questions, they should be knowledgeable about local and national resources where this information can be obtained. Sharing contact information of an experienced autism parent who is willing to talk to new parents on the autism journey would be helpful. Encourage parents to join autism support groups.

Participants in this study wanted to feel that their concerns were addressed and that they were not alone. Parents recommended that healthcare providers be honest, even when the conversations are difficult. Provide individualized information specific to a child's needs whenever possible. Show empathy and take time to listen. Parents with developmental questions should be scheduled with longer visits to allow enough time to address concerns. Parents recommended that healthcare providers learn more about autism in general, and realize that the needs of each autistic child is different. Additionally, parents suggested that separate waiting rooms with less stimulation would be beneficial for autistic individuals with sensory concerns.

The previous recommendations for autism parents should be incorporated in patient care when patients are newly diagnosed with autism, when safety issues persist, and reviewed during healthcare visits. Healthcare providers can share this information with parents who have autistic children when the child is newly diagnosed and reinforced as needed during future visits. Preparing the parents of children with autism and discussing safety issues in advance, will hopefully reduce possible injuries or death.

Implications for research. The topic of safety and autism has not been fully explored. Future research should consider: (a) the development and implementation of autism specific safety education programs for parents who have children newly diagnosed with autism, (b) implementation of standardized safety educational programs for parents who have autistic children with recurrent safety issues, (c) the implementation of autism specific safety education programs for healthcare professionals who care for autistic individuals and (d) a longitudinal study following implementation of autism safety programs to determine if the intervention reduces the prevalence of injuries in this population.

Summary

To the authors' knowledge, this is the first comprehensive, qualitative review of parents of autistic children's experiences keeping their children safe. The parents in this study discussed a myriad of safety issues they had experienced (see Table 7). This information is consistent with the literature that safety is a concern for those with autism and their families (Cavalari & Romancyak, 2012a; Cavalari & Romancyak, 2012b; Kalb et al., 2016; Sirin & Tekin-Iftar, 2016; Solomon & Lawlor, 2013). The literature indicated that parents receive inconsistent amounts of information about autism in general at the time their child is diagnosed (Carlsson et al., 2016; Derguy, Michel, M'Bailara, Roux, & Bouvard, 2015; Hall & Graff, 2010; O'Reilly et al., 2015).

From the interviews in this research, we know that the parents in this sample received very little information about autism. This is consistent with the literature. Most parents in this sample stated they did not receive information about autism specific safety issues at the time their child was diagnosed.

No prior studies were located that discuss if parents are given safety information at the time their child is diagnosed with autism. When safety information was received by a few parents in this sample at the time of diagnosis, it was generally related to a singular topic and did not reflect the spectrum of possible safety issues that may be encountered or how to prepare for these events. Most of the parents in this study learned about autism specific safety issues by experiencing them first hand. They found reaching out to other parents to be helpful when solving safety concerns.

This study addresses a gap in the literature and demonstrates that parents who have children with autism are not adequately prepared to deal with the safety concerns they may encounter. Safety information specific to autism should be included when a child is diagnosed and would enable parents to be proactive about safety. The various education programs found for parents who have children with autism are not standardized and it is not known to what extent safety concerns are addressed (Beaudoin et al., 2014; Meadan, Meyer, Snodgrass, & Halle, 2013; Steiner, Koegel, Koegel, & Ence, 2012; Suppo & Floyd, 2012; Tonge, Brereton, Kiomall, Mackinnon, & Rinehart, 2014). To our knowledge, current autism specific safety recommendations to educate these parents at well-child visits do not exist. The PI believes theoretical saturation was approached due to the similar themes identified in the structures and phenomena despite the various ages and severity of the autistic children discussed by participants.

A standardized, comprehensive autism-specific safety program should be developed for parents, who have autistic children and should include the participant recommendations. This program should include a review of the potential safety concerns that parents may encounter related to autism with possible solutions. This autism specific safety information should be given to parents when their child is diagnosed and be reviewed periodically by healthcare providers at well child checks and whenever safety is a concern. All healthcare providers who have the potential to work with autistic individuals should be knowledgeable about autism and receive a comprehensive review of the condition itself to deliver individualized care more effectively, including safety concerns. In addition, this review should include the recommendations from the study participants for healthcare providers to guide interactions with these families.

Limitations

This study is dependent on recall. Data was not being able to be collected at a time more proximal to the experiences discussed. The length of time between the different events and the interviews varied for each participant, which could affect the recall of information about the individual experiences. While some parents had young children who were diagnosed with autism within the last few years, several had autistic children who were young adults and diagnosed many years ago.

Conclusion

The data indicated the unique journey of parents who have a child with autism. After diagnosis, these parents had to adjust to a new normal and learn about the complexities of autism, realizing a myriad of experiences and emotions. Many had a series of trials and errors while they attempted to keep their children safe. Without adequate support from their healthcare providers, most of these parents sought help from other autism parents or found resources on

their own. The data indicated the parents in this study received little to no autism specific safety information at the time their child was diagnosed. Many of these parents felt that the healthcare providers they had encountered were generally not knowledgeable about autism or autism-related safety issues. More information about autism and related safety concerns needs to be added to education programs for healthcare providers. Parents of newly diagnosed autistic children, must be educated as well about autism and safety. If both of these occur, we can hope to see a decrease in the number of autism related injuries and deaths over time.

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Table 1**Demographics & If Received Safety Info Related to Autism**

Parent Gender	State	# ASD Children (Gender)	Dx of Child ***	Age Child	Safety Info at Dx?	Safety Info Other HCP?
F	New York	1 (F)	Autism/ PDD-NOS	16	No	State Medicaid-after parent identified issue
F	Pennsylvania	1(M)	Autism Spectrum Disorder	7	Crisis Phone #	No
F	Texas	1(M)	Autism	10	Unsure	No
M	Texas	1(M)	Asperger's	20	No	No
F	Texas	1(M)	Autism	11	Unsure	No
M	Texas	1(M)	Autism	6	Brochure-Wandering	No
F	Texas	1(M)	Autism Spectrum Disorder	23	No	No
F	Texas	1(M)	Autism	7	No	Some-Therapists
F	Texas	2(1M, 1F)	Asperger's Asperger's	31, 27	No	No
F	Texas	2(1M, 1F)	Autism Autism	9,7	No	Some-Therapists
F	Texas	1(M)	Severe Autism	15	No	Autism School
F	Pennsylvania	1(M)	Autism	13	No	No
M	Texas	1(M)	High functioning Autism	12	No	No
F	Pennsylvania	1(M)	Autism	16	No	Autism School
F	New Jersey	1(M)	Autism/ Asperger's	15	No	No

*** Note: Some diagnoses will be prior to changes in DSM-5; Dx reported by participating parent.

Table 2

Interview Guide

Interview Guide
Tell me about your child.
Tell me about an experience that stands out about your child's safety
What information about safety did you receive when your child was diagnosed?
What information about safety did you receive at other times from your child's healthcare provider?
What information did you need that you did not have?
What advice about safety do you have for parents who have a child diagnosed with autism?
What would you like medical professionals to know about autism and safety?

Table 3

Lost/ Finding Our Way

Lost	Finding Our Way
Susan: I didn't know what to do, I didn't know how to communicate with him.	Terri: I definitely kind of had to learn as I went with him...I learned a lot just doing ...I participated in the therapy...I learned a lot just working with him with them...and kind of figured out some things
Paul Like half the time we had no idea what was going on with him.	Ann: it wasn't from a doctor that we got any information about autism in the beginning...it was all from the internet.
Jane: I was lost...I was lost.	Susan: I educated myself. Nobody handed me anything, or no one told me what to expect – even the neurologist that diagnosed him, that sent me to ask my pediatrician at my school district. Not even the school system.
Betty: It was hard for us to decipher sometimes what was setting her off.	Joe: You learn as you go.
Sarah: It was one of those moments where...you break out in tears. What am I going to do?	Leslie: But a lot of it was trial and error and me just adapting different ways to keep him safe such as not taking him at all... it's really trial and error, I think. You kind of do what works for you based on your child's needs. Because I don't think every child with autism is the same.

Table 4
Battle Ready/Battle Weary

Battle Ready	Battle Weary
Hannah: You know you kind of sleep with one eye open.	Betty: Ultimately a parent can suffer just as much as the child is suffering...mentally because it's mentally and emotionally exhausting....It's always the parent gets the brunt of everything that happens...and sometimes they just need to understand...and not be dismissed as you're crazy.
Paul: I have had to fight for a bunch of crap for him since he was like 3 years old Jack: I have fights with insurance all the time.	Ann: The amount of stress on autistic parents...I don't think people realize ...they really don't Terri: You're in the grieving process... trying to ...figure out, ok what do we do now?...It causes yourself to feel... like you're the only one...experiencing these things...and you're a lot more likely to struggle with anxiety and depression
Jane: I was always on alert.... I couldn't relax at all	Leslie: It was horrible. It was like literally – even though things were so bad at home at the time ...and just everyday life, like it was like somebody ripped our heart out of our chest. It was horrible.
Leslie: So, I would go out there like five times before bed to make sure everything was locked and he couldn't get to the pool.	

Table 5
Living With Fear

Living with Fear
Joe: he is still struggling to remember I need to look both ways for crossing the street...or navigating a parking lot...it doesn't matter whether he darts out or not. When you're hit by a car, you're hit by a car.
Leslie: We heard the door open one night and it was cold, there was snow on the ground...we found him outside.
Betty: my grandmother called me, she said do you (your daughter) is over here? I was kind of like what are you talking about? So, then I got up in a panic looking for her....and she had gotten out of the house.
Terri: What do we do if something happens to one or both of us? ...What happens if there's a car wreck and there's a first responder...my son...he's not going to be able to answer questions.

Table 6

Feeling Misunderstood

By Others

Ann said : They can get away so quickly...so when people say "Oh they should have been watching their child"

that makes me so angry because we do watch them...they're so smart

Mary said: It was a nightmare just going to the store...then the screaming and the people not understanding...

you, the situation, what's going on... so the stress starts building.

By Healthcare Providers

Karen: When I would take him to checkups and stuff...they would ignore him for the most part and just talk to me...it was harder to get them to pay attention...and more that they would just want to hold him down...let's just get this done, you know?... My son cut his foot on a lightbulb...glass...and I had to take him to an urgent care where...I don't know that they even knew...anything with autism. It was very traumatic for him...They were trying to get it done as quick as possible but they said ...it would hurt him more to numb it...let's just get this over with ...just hold him down, it was awful...my son was screaming and screaming...in pain and just fear you know? It makes me tear up just thinking about it

Jack: We went to the pediatrician...she didn't know how to handle autism.

By Family

Jane: My mom is mad. She doesn't understand. Why isn't he in church? You're Catholic. He has to go to church.

Mom, you don't understand. The bells, the noise...I have tried it. He in tears...She's mad.

Betty-The grandparents don't understand (they say)... "why don't you just whoop them and maybe they'll act right?"

Table 7
Safety Issues Identified (# children identified by participants out of total of 17)

Physical	Risk of Being Victim	Lack of Sense of Danger
Sensory Issues (13)	Higher risk of being victim (9)	Lack of sense of danger/ doesn't understand consequences (14)
Meltdowns (8)	No stranger danger (8)	Elopement/ Wandering (13)
Aggression (7)	Can't differentiate appropriate/ inappropriate interactions (6)	Water safety/ drawn to water (9)
Self-injury (7)	Bullying (4)	Street/ parking lot safety (7)
Unintentional Injury (6) (climbing/ falls)	Developmental age not equal to chronological age (3)	Inappropriate use/ play with objects (5) (ex. putting fork in outlet; playing with knives)
Nutrition/ feeding issues (6)	Bathroom safety (no companion bathroom & child unable to go alone) (3)	Seatbelt unbuckling in car (3)
Sleep issues/ deprivation (6)	Internet Safety (3)	Doesn't wear protective equipment (2) Ex. bike helmet
Fine/ gross motor issues (4)	Invisible disability (2)	
Abnormal/ decreased response to pain (3)		

CHAPTER VI

SUMMARY OF THE STUDY

Through my own personal experiences, I found I was unprepared to deal with autism and the safety implications that resulted from this diagnosis. While collaborating with personal contacts, parents who had children with autism, I found they had similar experiences. I wondered if this was a unique issue limited to the area I lived in, or if this was a more universal problem. It seemed that many news stations often reported drownings and wandering in the autism population, yet I noticed that the topic of safety was not addressed during visits with healthcare professionals during my child's care. I was inspired to do this study to determine if this was a local problem or one of greater concern.

Autism data has indicated that this condition is more prevalent now than since it has first been reported. The impairments that are accompanied by an autism diagnosis make safety a concern for this population. Despite this, many parents who have children newly diagnosed with autism and healthcare providers are not knowledgeable about the variety of safety issues that can accompany an autism diagnosis. The purpose of this hermeneutic phenomenological study was to explore the parents who have autistic children's experiences with autism and keeping their autistic children safe. To my knowledge, these experiences have not been not fully understood or explained in the literature prior to this study. The experiences these parents shared identified a spectrum of safety issues that are not always apparent to those who do not have experience with autism. Additionally, the parents in this study made recommendations for educating other

parents who have children with autism and the healthcare professionals who care for them about specific safety issues.

An extensive literature review uncovered multiple safety issues associated with autism, but no specific recommendations to educate parents of these children at healthcare visits about the spectrum of safety concerns. Without specific recommendations, the PI decided to investigate this further and determine what the experiences of parents are who have children with autism are related to safety. These parents had complicated, multilayered emotional experiences that started before the official autism diagnosis, and continued afterward, and will likely continue for the remainder of their lifespan.

Utilizing snowball sampling, the researcher engaged three organizations who serve individuals with autism to allow recruitment of potential study participants. A total of 15 participants who self-identified as parents of children with autism agreed to join the study. The parents ranged in age from their thirties to fifties and either had one or two children affected by autism. Seventeen children in all were discussed, fourteen boys and three girls, which reflects the normal prevalence patterns of autism being higher in males than females. The autistic children ranged in age from early childhood to young adults.

Participants were interviewed with semi-structured questions and these interviews were audio-recorded. The data collection process included the recordings along with any notes made at the time of the interviews. The data transcribed from the interviews was analyzed and two structures and four phenomena supporting the experiences of the parents who have children with autism who participated in this study.

The findings of this study were analyzed and reported through the lens of Ricoeur's hermeneutic phenomenology (1981, 2007). Phenomenology, according to Ricoeur, is the study of what interpreting "being" or "existing" in the world signifies while hermeneutics divulges the meaning of a problem for the population being studied. Ricoeur's method provided a systematic process of data analysis that revealed both the phenomenology and hermeneutics of the experiences of these parents through sequential analyses of the text. The intent of using this method was to explain the lived experience and distinct perspective, of parents who have autistic children with keeping their children safe. A variety of individual experiences existed but overall demonstrated common themes within the structures and phenomena. Lost/finding our way and battle weary/battle ready were the structures that were identified which described the experiences of these parents as they discovered their child had an issue and then moved toward finding ways to help them while struggling through the different steps of the process. The phenomena of living with fear, living with uncertainty, and feeling misunderstood supported the experience of the parents being battle weary and delved into the specific facets of the different types of occurrences that took a toll on the parents over time. The phenomena of resilience in these parents demonstrated the structure of battle ready. The context for these structures and phenomena were the experiences of the parents who had autistic children. The parents' lives were shaped by their struggles living with autism around the clock, and particularly with attempting to keep their children safe.

The findings demonstrate the complex experiences of parents raising children with autism and keeping their children safe. Their experiences are impacted by multiple

interrelated factors, each one impacting the others with synergistic effects from the time their child first displayed autistic behaviors onward. For the parents participating in this study, the concept of safety was a difficult one to achieve especially when their children were newly diagnosed and without guidance.

The implications of this study affect nursing and all healthcare professionals that work with autistic children and their families. Prior to this research, there was no knowledge about what information parents who have children diagnosed with autism receive at the time their child is diagnosed. In this sample, parents who have children with autism received inconsistent information at the time their child is diagnosed with autism about safety issues related to autism. These parents also needed more support and guidance from healthcare professionals and found this was lacking. Healthcare providers and parents alike who work with autistic children need to be able to understand potential safety issues related to autism so they can educate others.

Future research should consider: (a) repeating this study with a larger national sample, (b) development of guidelines for autism specific safety education, (c) implementation of autisms specific safety education programs for parents who have children newly diagnosed with autism, (d) implementation of educational programs for parents who have autistic children and healthcare professionals who care for autistic children about comprehensive safety information specific to autism and (e) a post implementation longitudinal study to determine if the safety programs were able to reduce the prevalence of injuries in this population.

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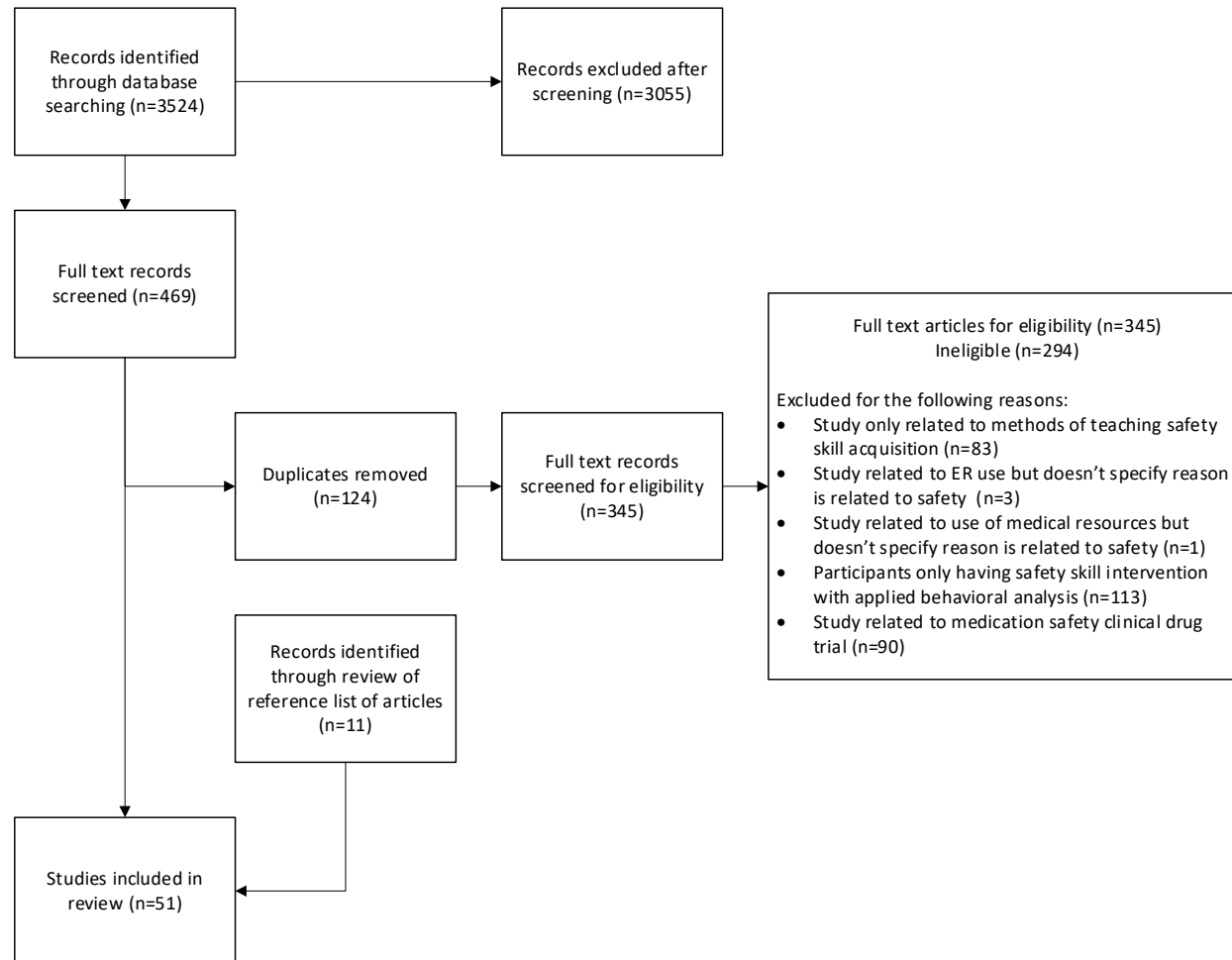
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APPENDIX A

Prisma Diagram

Figure 1 PRISMA DIAGRAM



APPENDIX B
LETTERS OF SUPPORT



September 28, 2018

To Whom It May Concern,

Texas Autism Academy has given permission for Tania Celia to display her Autism Research Study, Autism and Safety flyer on our campus.

You may contact Cary Mollinedo at 281-771-5348 if you have any questions.

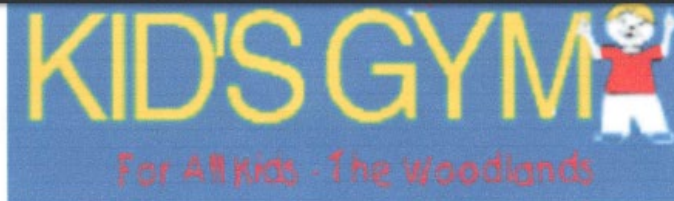
Thank you,

Cary Mollinedo

Director- Texas Autism Academy

www.carymollinedo@asdhope.com





To whom it may concern:

We agree and give permission to Mrs. Tania Celia to post and share flyer/s and or any resources to our business and personal Facebook page anytime.

Business Facebook: we rock the spectrum the woodlands

Personal Facebook: AnaJose Escolero

Thanks;

Ana and Jose Escolero

Owners and operators of We Rock the Spectrum The Woodlands

387 C Sawdust Rd.

The Woodlands, TX. 77380

Phone: 832-246-8566

Email: info@werockthespectrumthewoodlands.com

Web: www.werockthespectrumthewoodlands.com

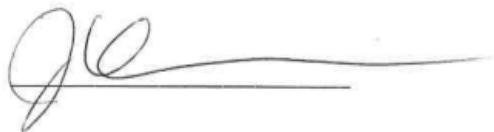
Ana M Escolero

Texas Woman's University
Institutional Review Board
6700 Fannin
Houston, TX
May 31, 2017

To Whom It May Concern:


I, Jessica Cordova, the owner of Autism House give permission for Tania Celia to hang/ display recruitment flyers for her research study at my location at 8911 West Lane, Magnolia, TX 77354.

Sincerely,


A handwritten signature in dark ink, appearing to read 'JC', followed by a long horizontal line extending to the right.

APPENDIX C

Recruitment Flyer



Autism Research Study
Autism and Safety
September 2018-March 2019



You are invited to participate in a research study interviewing parents who have children with autism to learn about their experiences with safety.

As the parent of a child with autism, I want to learn what other parents in a similar situation are experiencing & where they get their safety information from.

This information will be used to develop best practices about safety and autism.

Participants can choose to participate in 1 –on-1 interviews or can elect to attend a focus group.



Location, dates & times of focus groups: To be determined.

Participants who complete the study will receive a gift card.

For more information, contact: Tania Celia

tcelia@twu.edu

832-257-3819



APPENDIX D

Recruitment Script

Recruitment Script for Potential Participants

Hello, my name is Tania Celia. I am a Family Nurse Practitioner, a PhD student at Texas Woman's University in Houston and the parent of a child with autism. I believe that many parents & caregivers of children with autism are not aware of the many possible safety issues that exist when their child has been diagnosed with autism. For this reason, I am studying if parents of children with autism have safety concerns & if so where they get information related to autism and safety. I am recruiting participants to join this study. This research will help us to learn how to assist parents and providers caring for children with autism.

Your decision to participate in this study is completely voluntary. If you agree, you will be asked to complete form gathering demographic and contact information. Then you will be asked to participate in an interview (alone or in a focus group). You will be asked questions about your child and any safety concerns that you have had due to their autism. You will also be asked about where you received information about autism and safety. After you complete the study, you will be offered a \$25 gift card. You can participate in an additional session to validate the results of the research if you wish at a later point.

Please indicate if you would like to participate below:

☐ 1. Yes ☐ 2. No

APPENDIX E

Eligibility Form

Eligibility Form for Potential Participants

Instructions: All potential participants must be screened for meeting eligibility criteria in order to participate in this study. Please mark yes or no to the following questions. (The potential participant must reply yes to all questions).

This person:

Criteria	Yes	No
1. Are you the parent of a child diagnosed with autism?		
2. If you cannot do interview at one of the designated dates/ times do you have a phone to complete the interview at the time you prefer?		
3. Are you able to read, write & speak English?		

Must reply "YES" to all questions to participate.

APPENDIX F
CONSENT FORM

TEXAS WOMAN'S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title: Parents of autistic children's experiences with safety

Investigator: Tania Celia tcelia@twu.edu 832-257-3819
Advisor: Wyona Freysteinson.....wfreysteinson@twu.edu

Explanation and Purpose of the Research

You have been asked to participate in this study because you are the parent of a child with autism. You are being asked to participate in a research study for Ms. Celia's dissertation at Texas Woman's University. The purpose of this research is to determine the parents of autistic children's experiences with safety related to autism.

Description of Procedures

In order to be a participant in this study, you must be at least 18 years of age or older and be the parent of a child with autism. As a participant in this study you will be asked to spend one hour to two hours of your time in interviews with the researcher. You will be given the option of attending a one-hour focus group where several parents will participate in an interview together or a one-hour private interview. If you decide on a private interview, you and the researcher will decide together on a private location where and when the interview will happen. The researcher will ask you questions about your experiences with autism and how it has affected the safety of your child. The interview will be audio recorded and then written down so that the researcher can be accurate when studying what you have said.

If you desire, you can attend an additional one-hour validation meeting at a later date to review the results of the research but this is not a requirement of participation.

Potential Risks

The researcher will ask you questions about your child's autism diagnosis and where you received safety information related to autism. The researcher will also ask you questions about how autism has affected the safety of your child and any changes you have made to accommodate any identified safety concerns. A possible risk in this study is discomfort with the questions you are asked. If you become tired or upset you may take breaks as needed. You may also stop answering questions at any time and end the interview. If you feel you need to talk to a professional about your discomfort, the researcher can provide you with a list of resources.

A possible risk is identification of child abuse or neglect. If you disclose that you are abusing or neglecting your child, the researcher will be required to report it. If you feel you may incriminate yourself you may also stop answering questions at any time and end the interview.

Another risk in this study is loss of confidentiality. Confidentiality will be protected to the extent that is allowed by law. The interview will be held at a location that you and the researcher have agreed upon. You can participate in either a group or private setting or over the phone. If you participate in a group you are not required to disclose your name. The tapes and the written interview will be stored in a locked cabinet in the researcher's office. Only the researcher, her advisor, and the person who writes down the interview

Approved by the
Texas Woman's University
Institutional Review Board
Approved: July 20, 2018
Modifications Approved:
September 17, 2018

Initials
Page 1 of 2

will hear the tapes or read the written interview. A professional transcription service may be used, however, they will not know the identity of the voices they hear. The researcher will not disclose the identity of any of the study participants to the professional transcriptionist. If the researcher needs to clarify something in the transcription, you may be contacted to determine the meaning for a period of no longer than 1 year after the study.

The digital tapes will be erased and the identifiable written documentation will be shredded when the study is finished up to a maximum period of 5 years. The transcriptions will be assigned fake names for writing purposes and will be saved for possible future reference.

The results of the study will be reported in scientific magazines or journals but your name or any other identifying information will not be included. There is a potential risk of loss of confidentiality in all email, downloading, electronic meetings and internet transactions.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. Following the completion of the study you will receive a \$25 gift card for your participation. If you would like to know the results of this study we will e-mail or mail them to you depending on your preference. *

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at 713-794-2480 or via e-mail at IRB@twu.edu.

Signature of Participant

Date

*If you would like to know the results of this study tell us where you want them to be sent:

Email: _____

or

Address: _____

Approved by the
Texas Woman's University
Institutional Review Board
Approved: July 20, 2018
Modifications Approved:
September 17, 2018

Page 2 of 2

APPENDIX G
DEMOGRAPHIC FORM

Demographic Information Form

1. Name of parent participating in study: _____
2. Age of parent participating in study: _____
3. Marital status of parent participating in study: (Circle one) Married/ Single/ Widowed/ Divorced
4. Job status of parent participating in study: (Circle one) employed / unemployed
5. Are you the primary caretaker of the child with autism? Yes/ No (Circle one)
6. Age of child with autism: _____
7. Diagnosis of child: _____
8. Gender of child with autism: _____
9. Approximate year/ date child was diagnosed: _____
10. Location (City/ State) where living when diagnosed? _____
11. Has the city/ state where you live changed since your child was diagnosed? Yes/ No (Circle one)
12. Any prior experience with autism prior to the diagnosis of your child? Yes/ No (Circle one)
13. Birth order of child with autism? (ex. First born) _____
14. Number of adults at home that care for child with autism? _____
15. Email address: _____
16. Phone number: _____
17. Preferred method of contact for participation or copies of results when published?

18. Would you like a reminder text/ email prior to attending the focus group? If yes, what is your preferred method of contact? _____

APPENDIX H
INTERVIEW GUIDE

Interview Questions:

- Tell me about an experience that stands out about your child's safety.
 - What was the situation? What happened?
 - Were you prepared for the situation?
 - What did you know that helped you deal with the situation?
 - How did you learn what you needed to help you deal with the situation?
 - Who provided the information? When? How did you use it?
- What information about safety did you receive when your child was diagnosed? How did you use it?
- What information did you receive about safety at other times from your child's health care provider? How did you use it?
- What information did you need that you did not have? How did not having it affect your experience of keeping your child safe?
- What advice do you have about safety for parents who have a child diagnosed with autism?
- What would have been helpful to know about safety once your child was diagnosed with autism?
- What would you like medical professionals to know about autism and safety?
- What kind of recommendations for other parents of autistic children should be given?

APPENDIX I

CV for Principle Investigator

Curriculum Vitae

Tania Celia, RN, MSN, FNP

9521 Chasewood Blvd.
Conroe, TX 77304
936-463-3419
tania@family5tx.com

Date of initial faculty appointment at SHSU: September 1, 2018

Academic rank: Visiting Assistant Professor

Education

Date (year)	Degree	Major/ Field of Study	Institution/ Location
In Progress	PhD	Nursing	Texas Woman's University
1999	MSN	Family Nurse Practitioner	Widener University
1993	BS	Nursing	Rutgers University

Dissertation Title

A Phenomenological Study of Parents of Autistic Children's Experiences with Safety

Professional Certification/Licensure

Dates (year)	Organization	Title of Certification
12/14/04-present	Texas Board of Nursing	Family Nurse Practitioner License
11/2000-present	American Academy of Nurse Practitioners	Family Nurse Practitioner Certification
4/9/18- 4/2020	American Heart Association	BLS
4/9/18- 4/2020	American Heart Association	ACLS

Professional Teaching Experience

Dates (month/year)	Position	Institution/Location
9/2018-present	Visiting Assistant Professor/ MSN Coordinator	Sam Houston State University Conroe, TX
1/2018-6/2018	Lecturer/ Clinical Faculty	Sam Houston State University Conroe, TX
8/2017-12/2017	Nursing Lab Resource	Sam Houston State University Conroe, TX & Huntsville, TX
8/2012-4/2017	Clinical Educator	Take Care Health Clinics/ WAG Healthcare Clinics Houston, TX & Deerfield, IL
8/2015- 5/2015	Clinical Adjunct BNS Program	Texas Woman's University Houston, TX
8/2006- 8/2007	Assistant Professor	NHMCCD-Montgomery (Now Lone Star College) Conroe, TX

Other Professional Work Experience

Dates (month/year)	Position	Institution/Location
6/2017-present	Nurse Practitioner Volunteer	Tomagwa Healthcare Ministries Tomball, TX
5/2008-2012	Nurse Practitioner	Take Care Health Clinics/ WAG Healthcare Clinics Houston, TX & Deerfield, IL
3/2007- 1/2009	PRN Nurse Shock Trauma ICU	Memorial Hermann Houston, TX
2/2005-4/2007	Nurse Practitioner	ECI-Memorial Northwest Emergency Physicians Group Houston, TX
3/2004-8/2004	Nurse Practitioner	Emcare-Tidal Emergency Physicians Group Neptune, NJ
8/2002-8/2004	Registered Nurse- ER	ShoreCare (Meridian Healthcare) Neptune, NJ
8/2001-8/2002	Nurse Practitioner	Woodbury Surgical Associates Mobile Wound Management Woodbury, NJ
8/2000-8/2001	Nurse Practitioner	Kessler Memorial Hospital-South Jersey Wound Care Center Hammononton, NJ
8/2000-8/2002	Registered Nurse	InteliStaf Bala Cynwyd, PA
8/1997-8/2000	Registered Nurse-Surgical ICU	Hospital of the University of PA Philadelphia, PA
8/1996-8/1997	Registered Nurse-Angiography	Hospital of the University of PA Philadelphia, PA
8/1995-5/1995	Registered Nurse-CTICU	Hospital of the University of PA Philadelphia, PA
5/1993-8/1995	Registered Nurse	R Adams Cowley Shock Trauma Center at University of Maryland Baltimore, MD

Honors and Awards

Dates (year)	Description of Award
2015	John Winston Carter Memorial Scholarship
2012	Visiting Nurses Association Foundation Scholarship
2011	Visiting Nurses Association Foundation Scholarship
2015	Selected to attend Academy of Emerging Leaders in Patient Safety: The Telluride Experience

Teaching

Sam Houston State University

Pre-Licensure

Course Number	Title
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NURS 3320	Pathophysiology for Nursing (Spring 2018)
NURS 3321	Pharmacology for Nursing (Spring 2018)
NURS 3620	Adult Health 1 Clinical (Spring 2018)
NURS 3631	Nursing Fundamentals Clinical & Lab (Fall 2018)
NURS 4030	Community Nursing Lab (Fall 2018)

Texas Woman's University

Pre-Licensure

Course Number	Title
N4045	Adult Health Competencies II Clinical

Scholarly Activities

Research

Current Projects

Date Started	Role	Title of Project
2016-present	Graduate Research Assistant	Mirror Tool Development Research Team MICAS –TWU w/Dr. Freysteinson
2017-present	Graduate Research Assistant	Women Veteran Study- MST-TWU w/Dr. Freysteinson
2017-present	PI	A Phenomenological Study of Parents of Autistic Children's Experiences with Safety

Previous Projects

Dates	Role	Title of Project
2015-6	Graduate Research Assistant	The Amputee Experience of Viewing Self in a Mirror

Refereed Publications

Journal Articles

Authors	Year	Title	Journal
Freysteinson, W., Mellot, S., Celia, T., Du, J., Goff, M., Plescher, T., & Allam, Z.	2018	Body image perceptions of women veterans with military sexual trauma.	Issues in Mental Health Nursing
Freysteinson, Douglas, Melton, Thomas, Sebastian-Deutsch, Bowyer, Reeves, Celia	2017	A Study of the Amputee Experience of Viewing Self in the Mirror	Rehabilitation Nursing

Celia, Freysteinson, Frye	2016	Concurrent Medical Conditions in Autism Spectrum Disorders	Pediatric Nursing
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Professional Presentations

National

Date	Authors	Title	Podium/Poster/ Panel Member	Meeting/Group Presented	Location of Meeting
10/20 15	Freysteinson, Douglas, Melton, Thomas, Deutsch, Bowyer, Reeves, Celia	The Amputee Experience of Viewing Self in a Mirror	Poster	ACRM 92 nd Annual Conference Progress in Rehabilitation Research	Dallas, TX
2013	Celia & Warner	Domestic Violence: What Providers Should Know	Poster	Retail Clinician Congress	Las Vegas, NV

Professional/Community Service

Sam Houston State University

School of Nursing

Date	Role	Committee/ Task Force
9/2018 - present	Member	Curriculum Committee
1/2018-6/2018	Secretary	Lab Committee
8/2017-12/2017	Member	Lab Committee

Membership in Professional Organization

International

Date	Name of Organization
2016-Present	Sigma Theta Tau Beta Beta Chapter

National

Date	Name of Organization
2010-present	American Academy of Nurse Practitioners

State

Date	Name of Organization
2017-present	Southern Nurse Research Society
2017-present	Texas Nurse Practitioners

Local

Date	Name of Organization
2018	North Harris Montgomery Advanced Practice Nurse Society

Professional Development

Date	Title of Program	Sponsoring Organization	Location
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September 2018	Innovative Teaching Techniques Workshop	SHSU	Huntsville, TX
September 2018	New Deans/ Directors/ Coordinators Orientation	Texas Board of Nursing	Austin, TX
August 2018	PACE Teaching & Learning Conference	SHSU	Huntsville, TX
June 2018	AANP National Conference	American Academy of Nurse Practitioners	Denver, CO
December 2017	Dissertation Boot Camp	Pioneer Center for Excellence at Texas Woman's University	Denton, TX
April 2017	29 th Annual Scientific Sessions	Eastern Nursing Research Society	Pittsburgh, PA
June 2016	AANP National Conference	American Academy of Nurse Practitioners	San Antonio, TX
June 2017	PriMed Conference	PriMed	Houston, TX
Before 2017	On request		

APPENDIX J

CITI

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COMPLETION REPORT - PART 1 OF 2 COURSEWORK REQUIREMENTS*

* NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- **Name:** Tania Celia (ID: 3954901)
- **Institution Affiliation:** Texas Woman's University (ID: 1959)
- **Institution Email:** tcelia@twu.edu
- **Institution Unit:** Nursing
- **Curriculum Group:** Biomedical Responsible Conduct of Research
- **Course Learner Group:** Same as Curriculum Group
- **Stage:** Stage 1 - RCR
- **Description:** This course is for investigators, staff and students with an interest or focus in Biomedical Research. This course contains text, embedded case studies AND quizzes.
- **Record ID:** 28427173
- **Completion Date:** 31-Aug-2018
- **Expiration Date:** 30-Aug-2023
- **Minimum Passing:** 80
- **Reported Score*:** 93

REQUIRED AND ELECTIVE MODULES ONLY	DATE COMPLETED	SCORE
Research Misconduct (RCR-Basic) (ID: 16604)	30-Aug-2018	5/5 (100%)
Data Management (RCR-Basic) (ID: 16600)	30-Aug-2018	5/5 (100%)
Authorship (RCR-Basic) (ID: 16597)	30-Aug-2018	5/5 (100%)
Peer Review (RCR-Basic) (ID: 16603)	30-Aug-2018	5/5 (100%)
Mentoring (RCR-Basic) (ID: 16602)	30-Aug-2018	5/5 (100%)
Using Animal Subjects in Research (RCR-Basic) (ID: 13301)	30-Aug-2018	4/5 (80%)
Conflicts of Interest (RCR-Basic) (ID: 16599)	30-Aug-2018	5/5 (100%)
Collaborative Research (RCR-Basic) (ID: 16598)	31-Aug-2018	5/5 (100%)
Research Involving Human Subjects (RCR-Basic) (ID: 13566)	31-Aug-2018	3/5 (60%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

Verify at: www.citiprogram.org/verify/?k22e883c8-4b97-49b0-ac21-fef8e1438863-28427173

Collaborative Institutional Training Initiative (CITI Program)

Email: support@citiprogram.org

Phone: 888-529-5929

Web: <https://www.citiprogram.org>

COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COMPLETION REPORT - PART 2 OF 2 COURSEWORK TRANSCRIPT**

** NOTE: Scores on this Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.

- **Name:** Tania Celia (ID: 3954901)
- **Institution Affiliation:** Texas Woman's University (ID: 1959)
- **Institution Email:** tcelia@twu.edu
- **Institution Unit:** Nursing
- **Curriculum Group:** Biomedical Responsible Conduct of Research
- **Course Learner Group:** Same as Curriculum Group
- **Stage:** Stage 1 - RCR
- **Description:** This course is for investigators, staff and students with an interest or focus in Biomedical Research. This course contains text, embedded case studies AND quizzes.
- **Record ID:** 28427173
- **Report Date:** 31-Aug-2018
- **Current Score**:** 93

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES	MOST RECENT	SCORE
Using Animal Subjects in Research (RCR-Basic) (ID: 13301)	30-Aug-2018	4/5 (80%)
Research Involving Human Subjects (RCR-Basic) (ID: 13500)	31-Aug-2018	3/5 (60%)
Authorship (RCR-Basic) (ID: 16597)	30-Aug-2018	5/5 (100%)
Collaborative Research (RCR-Basic) (ID: 16598)	31-Aug-2018	5/5 (100%)
Conflicts of Interest (RCR-Basic) (ID: 16599)	30-Aug-2018	5/5 (100%)
Data Management (RCR-Basic) (ID: 16600)	30-Aug-2018	5/5 (100%)
Mentoring (RCR-Basic) (ID: 16602)	30-Aug-2018	5/5 (100%)
Peer Review (RCR-Basic) (ID: 16603)	30-Aug-2018	5/5 (100%)
Research Misconduct (RCR-Basic) (ID: 16604)	30-Aug-2018	5/5 (100%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

Verify at: www.citiprogram.org/verify/?k22e883c8-4b97-49b0-ac21-feb8e1438863-28427173

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APPENDIX K

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Submitted Manuscripts

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STATUS	ID	TITLE	CREATED	SUBMITTED
<ul style="list-style-type: none"> Undergoing Review 	JAN-2019-0239	BATTLE WEARY/ BATTLE READY: A PHENOMENOLOGICAL STUDY OF PARENTS OF AUTISTIC CHILDREN'S EXPERIENCES WITH SAFETY	05-Mar-2019	05-Mar-2019
View Submission				

