



Severe Childhood Autism: The Family Lived Experience

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This research examined the experiences of families living with a child with severe autism. There is limited literature on the experiences of families when a child has severe autism as distinct from milder autism and includes the voices of multiple family members. Van Manen's phenomenological approach was used for data collection and analysis. This approach allowed for the use of innovative data sources, including unstructured individual and family interviews, observations, and family lifelines (a pictorial, temporal picture with comments of the families lives). This study included 29 interviews with 22 participants from 11 families. All data were creatively triangulated and interpreted. Six essential themes were identified. First, families experienced autism as mysterious and complex because it is an invisible and unpredictable condition with diagnostic challenges. Second, families described severe autism behaviors that often caused self-injury, harm to others and damaged homes. Third, profound communication deficits resulted in isolation between the family and child. Fourth, families discussed the unrelenting stress from lack of sleep, managing the child's developmental delays, coordinating and financing services, and concern for the child's future. Fifth, families described consequences of isolation from friends, school, the public, and health providers. Sixth, families portrayed their need for compassionate support and formed 'hybrid families' (nuclear, extended families and friends) to gain support. Study results can be utilized to educate nurses/other providers about the unique needs of families with children with severe autism and could influence health care policies to improve the care for families caring for children with severe autism.

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Background

Autism is the most prevalent developmental disability in the United States, affecting approximately 1 in 68 children (Center for Disease Control (CDC), 2014). Autism is a broad-spectrum neurodevelopmental disability characterized by impairments in social communication and repetitive behaviors or interests, both in varying degrees (American Psychiatric Association (APA), 2013). An example is a child who exhibits limited ability to communicate with others and repetitive behaviors such as hand flapping and/or spinning in circles.

The variability in presentation of autism cannot be underestimated as manifestations can range from mild to very severe. In the past the milder forms of autism were referred to as Asperger's or pervasive developmental disorder-not otherwise specified (PDD-NOS), but currently all degrees of autism are referred to as "autism spectrum disorder" or ASD (APA, 2013; Autism Speaks, 2015). For the remainder of this paper, however, because the focus is only the severe portion of the spectrum, ASD will be referred to simply as "autism."

Approximately one-third of the children with autism are considered to have "severe autism" with significant functional challenges. However this estimate is based on IQ (<70) rather than the child's daily challenges because no functional assessment tool specific to autism has been available (CDC,

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Table 1 Autism Functional Challenge Questionnaire

Questions and comments used to assess functional challenges/severity of the child with autism. Developed in collaboration with Michael Reiff, MD (February 2015)

Question	Comment
1. Was there an original diagnosis and severity given? Are there any related conditions such as speech/language and/or intellectual delays?	Usually there are speech and intellectual delays in severe autism, but not always. It is important to assess how “severe” the family perceives the autism is vs. the actual diagnosis e.g., what is severe autism to one family may not be severe autism to another family.
2. Are you aware of any autism testing that has been done: Vineland (functional) and/or IQ?	The children with more severe autism are difficult to test so many may not have had testing and/or families may not remember.
3. How would you describe your child's communication patterns e.g. words, words together, sentences, any reciprocal communication?	In severe autism there may be some words, but little to no reciprocal communication.
4. How would you describe your child's autism-related behaviors?	Usually there are significant behaviors that may limit participating in a regular classroom.
5. Can your child accomplish self-care?	Usually there are limited self-care functions such as brushing teeth, bathing, dressing, or feeding self.
6. Is 24 hr. Supervision needed at home?	In severe cases of autism, 24-hour supervision is needed.
7. What type of school does your child attend and what health care-related supports does your child receive both at school and home?	Often the child with more significant challenges will be in full- or part-time autism school (unless not available in their geographic area), a special education class, or receive special services within a regular class, e.g., para-professional time, physical therapy, occupational therapy, speech, adaptive classes
8. What are three functional challenges your child experiences at home and how does this affect your family?	It is important to focus on functional challenges the child experiences within the family versus focusing only on symptoms.

World Health Organization (2001). ICF: International Classification of Functioning, Disability and Health, WHO Library Cataloguing-in-Publication Data, p. 18.
Reiff, M.I., & Feldman, H.M. (2014). Diagnostic and statistical manual of mental disorders: The solution or the problem?. *Journal of Developmental and Behavioral Pediatrics*, 35(1), 68–70. 10.1097/DBP.0000000000000017.

2014). Additionally autism severity is difficult to assess because it is subjective and basic autism testing is challenging when children are nonverbal and uncooperative. The American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; 5th ed.) defines severe autism (level 3) as children who require substantial support (e.g., 24-hour care), have severe deficits in social communication (e.g., little to no speech), and manifest inflexible repetitive behaviors that are severely limiting (e.g., hand flapping, twirling in circles) (APA, 2013). However this rating also relies more on a list of symptoms than how the child functions in daily life (Reiff & Feldman, 2014).

There has been an effort to clarify autism severity based on a more holistic approach that focuses on the child’s daily needs within the context of the family instead of solely on symptoms (Bölte et al., 2014; Gardiner & Iarocci, 2015; Reiff & Feldman, 2014). For example it might be more beneficial to assess autism severity by asking, “What are the daily challenges your child faces and how does this affect your family?” rather than focusing on IQ or a list of autism-related behaviors.

At the time of this study, because there was no tool to assess autism functional severity and few of the children in

the study had been given a formal severity diagnosis, the researchers developed the Autism Functional Challenge Questionnaire, which was used for inclusion criterion (Table 1). The questionnaire was developed in collaboration with the medical director of a large urban autism clinic who also reviewed each case individually to assure that the child was qualified as having significant functional challenges or “severe autism.”

There has been some exploration in qualitative studies about the experience of families when a child has autism. In many of these studies, however, the severity of the child with autism is not identified (Desai, Divan, Wertz, & Patel, 2012; Dupont, 2009; Farrugia, 2009; Kent, 2011; Lutz, Patterson, & Klein, 2012; Mulligan, MacCulloch, Good, & Nicholas, 2012; Phelps, Hodgson, McCammon, & Lamson, 2009; Safe, Joosten, & Molineux, 2012). In some studies the children are identified as having milder forms of autism such as borderline developmental issues, PPDNOS, or Asperger’s (Bultas & Pohlman, 2014; Dupont, 2009; Hoogsteen & Woodgate, 2013; Kent, 2011; Larson, 2010; Lendenmann, 2010), or the children have a variety of disabilities (Bilgin & Kucuk, 2010; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Only one study of those reviewed included solely children with “severe autism” (Werner DeGrace, 2004).

Additionally, many of the phenomenological studies rely on the response of one family member, usually the mother to portray the family experience (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Larson, 2010; Lutz et al., 2012; Safe et al., 2012). Though fathers are sometimes included in the dialog, extended family members or others considered as family have not been included in the studies reviewed.

This study explored the lived experience of the family when a child has severe autism. During recruitment the parent, usually the mother, was asked to identify who they considered to be family. The mothers included various family members in the nuclear family, but often also included extended family members and friends. Though originally a surprise to the researchers, this was consistent with the definition of family by Poston et al. (2003), "People who think of themselves [as] part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis" (p. 319).

This study was based on the premise that it is possible to identify a family lived experience versus that of the individual lived experience. Anderson and Tomlinson (1992) argued that a paradigm shift was needed to provide a theoretical basis for research and practice to discuss the collective family experience, which is often altered by serious illness. They introduced the concept of shared meaning of family experiences. Daly also supported the position that families are groups that construct individual and shared meaning that should be studied using phenomenology (Daly, 1992). Chesla's research program using interpretive phenomenology to study the family living with chronic illness is an example of the construct of the family lived experience (Chesla, 1995; Chesla, 2005; Chesla & Chun, 2005; Gudmundsdottir & Chesla, 2006).

The aim or purpose of this research was to interpret the meaning of the lived experience of families who live with a child who has severe autism. This research simultaneously both narrowed and broadened the focus of previous research studies. It narrowed the focus in that only families of children with severe autism were included in this study and broadened the focus by including all members identified as family and the family unit when possible. A phenomenological approach was used to ask the study question: *What is the lived experience of the family living with a child who has severe autism?*

Literature Review

Since the 1950s, following the dismantling of institutions for children with disabilities, most long-term care has been provided at home by the family. The family has become the primary care provider for children with developmental disabilities such as autism, throughout their lifetime (Cummins, 2001).

The literature on the lived experiences of families caring for a child with autism at home has focused on the stress of these families. Experiences of family stress include: stigma

(Dupont, 2009; Farrugia, 2009; Hoogsteen & Woodgate, 2013; Lutz et al., 2012; Safe et al., 2012), autism-related behaviors (Bultas & Pohlman, 2014; Desai et al., 2012; Larson, 2010; Lendenmann, 2010; Lutz et al., 2012), challenges of providing direct care (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Dupont, 2009; Larson, 2010; Mulligan et al., 2012; Safe et al., 2012), social isolation (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Larson, 2010; Luong, Yoder, & Canham, 2009; Lutz et al., 2012; Phelps et al., 2009; Safe et al., 2012; Schaaf et al., 2011), and altered family dynamics (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Dupont, 2009; Farrugia, 2009; Kent, 2011; Phelps et al., 2009; Schaaf et al., 2011; Werner DeGrace, 2004). A number of studies have also reported the positive outcomes that emerge from the experience of living with a child with autism (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Kent, 2011; Lendenmann, 2010; Luong et al., 2009; Phelps et al., 2009; Safe et al., 2012).

One aspect the families perceived as stressful was the stigma or disgrace that they experienced due to the invisible nature of autism and the child's atypical behaviors. Families often felt stigma or shame that they were "bad parents" when the child had tantrums that were misunderstood as poor behavior by the public (Dupont, 2009; Farrugia, 2009; Hoogsteen & Woodgate, 2013; Lutz et al., 2012; Safe et al., 2012).

Autism-related behavior as a source of family stress has been discussed in several studies (Bultas & Pohlman, 2014; Desai et al., 2012; Larson, 2010; Lendenmann, 2010; Lutz et al., 2012). Persistent behaviors associated with autism include crying, lack of sleep, and general agitation (Desai et al., 2012; Lendenmann, 2010; Lutz et al., 2012). Tantrums are most common and self-injurious behaviors are least commonly reported (Lendenmann, 2010). Families spend an exorbitant amount of time dealing with the child's "meltdowns" or tantrum behavior leaving little break time for family members (Larson, 2010). Although these behaviors are referenced, in general they have not been clearly defined in the literature.

Providing direct care has been another source of family stress (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Desai et al., 2012; Dupont, 2009; Kent, 2011; Larson, 2010; Lutz et al., 2012; Mulligan et al., 2012; Phelps et al., 2009; Safe et al., 2012). Coordinating care is difficult, including balancing the many health care and educational services needed by the child (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Mulligan et al., 2012; Safe et al., 2012). Parents often found it challenging to locate these services and experienced long waiting periods to receive care (Bultas & Pohlman, 2014; Mulligan et al., 2012; Safe et al., 2012). The high cost of care for a child with autism has been noted (Lutz et al., 2012; Phelps et al., 2009; Safe et al., 2012). Concern for the future care of the child when caregivers are no longer alive was also identified as a source of stress (Desai et al., 2012; Kent, 2011; Phelps et al., 2009).

Isolation is another form of stress faced by many families of children with autism as they often feel isolated from extended family who do not fully understand their situation (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Safe et al., 2012), or from friends and the public who do not understand the child's behaviors (Luong et al., 2009; Phelps et al., 2009; Safe et al., 2012). Many families avoid situations outside the home that were uncomfortable for the child and family (Larson, 2010; Lutz et al., 2012; Schaaf et al., 2011).

Challenging family dynamics have been anxiety provoking, specifically the lack of family time spent together as a family (Dupont, 2009; Farrugia, 2009; Kent, 2011; Phelps et al., 2009; Schaaf et al., 2011; Werner DeGrace, 2004). In the study that solely included children with severe autism, it was noted that several families felt "robbed as a family" because their life revolved around autism (Werner DeGrace, 2004, p. 545). Siblings suffered because the family often focused their attention on the child with autism rather than the siblings (Kent, 2011; Phelps et al., 2009; Werner DeGrace, 2004). This resulted in an altered family dynamic where the younger siblings would care for the older child with autism (Kent, 2011). Marital relationships were affected by caring for their child with autism (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Kent, 2011; Phelps et al., 2009). Marital conflicts reported included the father's objection to the time mothers spent caring for the child (Bilgin & Kucuk, 2010) and differences in parenting approaches (Kent, 2011; Phelps et al., 2009).

Several studies discussed positive outcomes related to the experience of raising a child with autism. Families reported that life caring for the child with autism promoted family cohesion (Bilgin & Kucuk, 2010; Kent, 2011; Lendenmann, 2010; Luong et al., 2009; Phelps et al., 2009). Living and learning about autism often resulted in the family uniting to champion for the needs of children with autism (Lendenmann, 2010; Luong et al., 2009). Personal growth includes increased empathy/compassion and less judgment of others (Bultas & Pohlman, 2014; Kent, 2011; Phelps et al., 2009). Personal growth also includes an acceptance of living with the child and an appreciation for the child's unique characteristics (Lendenmann, 2010; Safe et al., 2012).

Design and Method

Max van Manen's philosophical and methodological approach to phenomenology was the basis of this study. Van Manen (2014) describes his approach as hermeneutic phenomenology in which pre-reflexive and reflective experiences are described by those who encounter them and are interpreted for the meaning embedded in these experiences. Ultimately his phenomenological approach focuses on the universal meaning or "essence" of the phenomenon that is conveyed by essential themes based on the particulars of the lived experience (van Manen, 1997; van Manen, 2014).

The goal of phenomenology, according to van Manen, is to identify a phenomenon or situation, in this study, families living with a child with severe autism, and render meaning to

this phenomenon. This phenomenological approach was selected for this study because collection of detailed phenomenological interview text and observation results in a description with depth and richness (Pals, 2006; van Manen, 1997; van Manen, 2014). This nuanced data is essential to understand the complex experiences of families of children living with a chronic condition such as severe autism. This approach is also congruent with the use of various types of data collection methods used in this study, including individual and family interviews, observation with field notes, and family lifelines. This approach allows for the assimilation and interpretation of the data sources to portray the lived experience that van Manen describes.

Data Collection Recruitment

Inclusion criteria were: 1) family members were identified by one parent (who was the primary care giver). Families could include individuals who may or may not be biologically related, but must have ongoing consistent contact and provide care for the child with autism; 2) autism rating of "severe," was evaluated by the researcher by asking the parent to respond to questions on the Autism Functional Challenge Questionnaire and confirmed by consultation; 3) the child with autism was living at home and was 4–13 years old; (4) siblings were at least 6 years of age; and 5) participants were English speaking.

The age for the child with autism was chosen to roughly correlate with school-age for homogeneity of the sample. In addition, school-age children would have been diagnosed with autism and the family would have spent a significant amount of time living with the child. The age for siblings (6 years and above) was selected because those children would be able to articulate their experiences and be capable of providing assent to participate in the study.

Recruitment posters were placed in two urban clinics: one was an autism clinic at a large urban university, and the other was the office of a pediatric psychiatrist located in a large urban public hospital. The poster was also placed in the research studies page of the local Autism Society electronic newsletter. Families interested in participating in the study e-mailed the researcher. Families were called to determine eligibility based on inclusion criteria to participate in the study and to arrange for an interview in their home.

IRB approval for the study was obtained in December 2014. Data collection occurred from February–June 2015. All participants provided written consent/assent prior to any data collection.

Sample

Twenty-two individual family members from 11 families participated in the study. Six families participated in family group interviews (one family had two family group interviews) comprising 29 total interviews from 19 home visits.

Almost half of the mothers (5 out of 11) identified members outside the immediate family and home—such as grandparents, an aunt, or a friend—as part of their “family.” Participants included: 11 mothers, 4 fathers, 4 grandmothers, 1 aunt, 1 sibling, and 1 friend. A summary of the families who participated in the study is found in [Table 2](#). Demographic characteristics of the 11 families who participated in the study are found in [Table 3](#). Demographics of the 22 individual family participants are described in [Table 4](#). Demographic data on the children with autism are listed in [Table 5](#).

The sample size of eleven families was used in order to achieve richness in the family interview data. This sample size is also consistent with the recommended number of participants (6–10) for a phenomenological study ([Sandelowski, 1995](#)). It was decided that including as many individual family members as possible within those selected families would increase the understanding of the experience of living with a child with autism. Although the qualitative database was large it served the purposes for this study.

Data Sources

Five types of data were utilized in this study: demographic questionnaires, unstructured phenomenological interviews, family/home observations, field notes, and family lifelines.

A demographic questionnaire was used to assess the basic information about the child and family. Information collected about the child included detailed information about their health and healthcare services that were utilized. Family demographic information included family members’ level of education and occupation. This questionnaire was given prior to the interview.

Unstructured phenomenological interviews were conducted with each of the 22 family members as well as with six families who were interviewed as a family unit. The basic question, “What is your experience as a family living with a child with autism?” was used to begin conversation and elicit information about the family experience. Additional questions were asked to clarify information. Throughout the interview, the focus was the family versus the individual experience though there was overlap between the two. The average length of the individual interview was 90 minutes; the average length of time of the family unit interview was 60 minutes and all interviews occurred exclusively in the families’ homes. Each interview was audio-recorded then transcribed verbatim into written text. All interviews were checked for accuracy against the tapes.

Observations were another method for data collection. Observations were conducted in participants’ homes during each individual and family group interviews. Observations included the home environment, the behavior of the child with autism if present, types of interactions between family members, and specifically interactions between the family and child with autism, if the child was present.

Extensive field notes were recorded after each interview, observation and throughout the research process. They included three types of memos: 1) analytic memos were recorded when the researcher interpreted important points during data collection that were incorporated into the analysis e.g., specific observations of the home environment; 2) personal memos were recorded about the subjective experience e.g., feelings such as witnessing children with significant communication challenges in their home; and 3) methodological memos were recorded to document all meetings and discussions among the researchers.

Family lifelines were the fourth form of data collection. The family lifeline was adapted by the primary investigator from the lifeline method described by [Gramling and Carr \(2004\)](#). A lifeline is a visual method used to illustrate a family’s life experiences using a timeline that links events: it may include words, dates, or pictures. The participant was given a regular sized paper (8 ½ by 11 inches) that had a horizontal line printed across the bottom. The left of the line was labeled “Birth of Child,” on the right was printed “Now.” Written on the top of the paper was: “Please draw a picture that describes your family life experiences from before the time your child with special health care needs was born to the present moment. You may draw high points and low points, use pictures and symbols, names and dates—anything that gives a picture of your family’s experience.” The participant was given colored pencils for use.

Data Analysis

As noted, [van Manen’s \(2014\)](#) interpretive approach was used for data analysis in this study. This is a form of hermeneutic analysis in which experiences are interpreted by the researcher to identify essential themes or meanings. The basic phenomenological analysis is reduction, which aims at the insight into the meaning structures (essential themes) of pre-reflexive and reflected experiences.

Treatment of Data

Microsoft Word was chosen to manage the data because it provided an organized, hands-on, approach to data management that allowed the researchers to utilize an iterative analysis to formulate essential themes.

To facilitate identification, each family was assigned a unique color-coded number, each individual within the family and the family interviews was given a letter, and each comment was numbered, with a ‘C’ preceding it. For example, 7AC71 is family #7, A is mother, C71 is comment # 71. Thus the focus of the analysis was always on the family experience which was made easier to identify due to the family-coded color.

Each family member unit and corresponding family unit was analyzed independently. The individual family member interviews were analyzed first with an emphasis on their experience as a member of the family rather than their individual experience. The family interviews were then analyzed. Thus the focus of the analysis was always on the family experience.

Table 2 Summary of Family Interviews

Members identified as family	Family members interviewed	Number of individual interviews and number of family interviews	Family living outside the home	Number of home visits
Mother Friend MGM Aunt Son *	Mom Friend MGM Aunt	4 Individual Interviews 2 Family Interviews: • Mom + Friend • Mom, MGM + Aunt	MGM Aunt	3
Mother Father Daughter *	Mother Father	2 individual interviews 1 family interview: • Mom + Dad	None	2
Mother Father Son *	Mother	1 individual interview No family interview	None	1
Mother MGM Son *	Mother MGM	2 individual interviews 1 family interview: • Mother + MGM	MGM	2
Mother Father PGM PGF Son *	Mother Father PGM	3 individual interviews No family Interview	PGM PGF	3
Mother Father Son * Son Son	Mother	1 individual interview No family interviews	None	1
Mother Father Daughter * Daughter * Friend Friend	Mother Father	2 individual interviews 1 family interview: • Mother + Father	Friend Friend	2
Mother Daughter #1 Daughter #2 Son *	Mother Daughter #1	2 individual interviews 1 family interview: • Mother + Daughter	None	1
Mother Father MGM MGF Son *	Mother MGM	2 individual interviews No Family Interviews	Father MGM MGF	2
Mother Father MGM Son *	Mother Father	2 individual interviews 1 family interview: • Mother + Father	None	1
Mother Father Daughter Son *	Mother	1 individual interview No Family Interviews	None	1

* Denotes child with autism.

Table 3 Demographic Characteristics of Family (N = 11)

Variable	Frequency	Percentage
Current relationship status		
Married	7	64%
Separated or divorced	4	36%
Primary care provider		
Mother	9	82%
Mother + Father	1	9%
Mother + Grandmother	1	9%
Children with autism		
Only one child with autism	10	91%
Two children with autism	1	9%
Siblings in family		
None	7	64%
Older	2	18%
Younger	2	18%

A selective approach was used to analyze the interview text in which the text was read several times and statements or phrases that were revealing about the experience were highlighted. As this process continued, themes began to emerge and possible commonalities were gathered. With further review, thematic statements from the text were identified from these commonalities.

This was followed by linguistic transformation, or expanding the meaning of the evolving themes by documenting a summary note about the possible theme. This process was repeated for every interview including the family unit interview that eventually led to identifying themes within and across families, facilitated by the color coding, that ultimately resulted in the essential themes or meaning of the family of living with a child with autism.

As part of the interpretive process family observations and the family lifelines were triangulated during the analysis, which helped to formulate the essential themes. The family observations resulted in information about interactions between family members and the home environment. Particularly rich were the observations of the child with autism who was observed in 8 out of the 11 families. The extensive field notes were integrated into the formation of essential themes.

The family lifelines were also color-coded and interpreted in a similar fashion to the interviews. The family lifelines were evaluated in a two-step process: the first step included analyzing the written information on the lifelines. For example if the family wrote “grieving” on the lifeline this would be added to the evolving theme. The second step included interpreting the entire Family Lifeline for themes or meaning. Like the observations, the lifelines were instrumental in building the composite essential themes that represented the essence of a family living with a child with severe autism.

Two members of the research team were involved in the analysis and when there were questions about the meaning of the analysis or essential theme, there was discussion until

Table 4 Demographic Characteristics of Individual Family Participants (N = 22)

Variable	Frequency	%
Relationship to Child**		
Mother	11	50%
Father	4	18%
Grandmother	4	18%
Aunt	1	4%
Friend	1	4%
Sibling	1	4%
Gender		
Male	4	18%
Female	18	82%
Age range		
20–30	2	9%
31–40	7	32%
41–50	7	32%
51–60	2	9%
61–75	4	18%
Race		
White European American	15	68%
African American	3	14%
Southeast Asian	1	4%
Multi-racial	3	14%
Religion		
Practicing Christian	12	54%
Non-practicing Christian	5	23%
No affiliation	3	14%
Agnostic	2	9%
Highest level of education		
High school degree	3	14%
One–two years of college	8	36%
Four year college	7	32%
Graduate degree	4	18%

** Percentage may not equal 100 due to rounding to nearest integer.

consensus was reached. The two researchers discussed themes that emerged in a collaborative manner and would converse about which theme appeared most appropriate in light of the interviews, observations and family lifelines. This insured validity or truthfulness as the actual data were reviewed and interpreted by both researchers. In addition, a third member of the research team, a family therapist and expert in family research, led a process of reflexivity through engaging dialog with the researchers about personal experiences they found challenging, such as observing the difficulties that the families encountered.

Rigor or Appraisal of the Phenomenological Study

Van Manen proposes four criteria for evaluative appraisal of phenomenological studies: orientation, strength, richness, and depth (van Manen, 1997). The first criterion is that the text needs to be centered by the researcher’s pedagogic orientation or stance. In this study the focus is pediatric health care with an aim to better understand the experience of families of children with a severe condition such as autism in order to ultimately provide

Table 5 Demographic Characteristics of Child With Severe Autism (N = 12)

Variable	Frequency	%
Gender		
Male	9	75%
Female	3	25%
Age range (mean 8 years)		
4–5	3	25%
6–7	5	41%
8–9	0	0
10–11	2	17%
12–13	2	17%
Age at diagnosis (mean 2.25 years)		
<1 Year	0	0
1–2 Years	8	67%
3–4 Years	4	33%
Time since diagnosis (mean 5 years) **		
2–4 Years	4	33%
5–7 Years	5	43%
8–10 Years	3	25%
Verbal communication		
No words	2	47%
Few words, no sentences	8	66%
Very limited sentences	2	47%
Activities of daily living *		
Requires 24 hour supervision	12	
Cannot complete dress self	7	
Not fully toilet trained	5	
Type of school attending		
Autism school	5	42%
Public school with services	6	50%
Home school	1	8%

* Total does not equal 12 due to multiple listings.

** Percentage may not equal 100 due to rounding to nearest integer.

better health care to these families. Pediatric health and care for families is a core interest of the discipline of nursing and the topic was chosen because of the researchers' orientation in caring for families of children with chronic health needs.

The second criterion is that the research text needs to be strong and based in the researcher's educational experience, with the most rigorous interpretation of the phenomenon. Two of the four researchers have had extensive experience working in pediatrics for over 25 years with families of children with chronic illness. The other two researchers have had extensive experience working with families in practice and qualitative research. The extensive professional background of the investigators gave insight into family experience that assisted with the final interpretation of the phenomenon.

The third criterion is that the text must be rich. Van Manen (1997) states that, "A rich and thick description is concrete, exploring a phenomenon in all its experiential ramifications" (van Manen, p. 152) with anecdotes that capture the experience. In this study all of the five data sources helped to illuminate the experience of families living

with severe autism. There were approximately 45 hours of interview tape, 1,500 pages of individual and family interview text from 19 home visits. In addition, there were 20 page of observational field notes and 13 family lifelines.

The fourth criterion for rigor is that the text must be deep: meaning is incorporated beyond what is actually experienced. In this study the meaning of the family lived experience evolved by reviewing and synthesizing all of the data and developing essential themes. In this way essential themes were not merely a recounting of that which was said in the interviews or drawn in the family lifelines, but rather an assimilation and interpretation of the "essence" of the experience of the family living with a child who has severe autism, reflecting van Manen's methodological process.

Results

In this study six essential themes with several subthemes were identified (Table 6).

Family Perception of the Mystery and Complexity of Severe Autism

The first theme identified was that families viewed autism as a mysterious and complex condition. The public's inaccurate stereotypes about autism and the inherent nature of autism added to this mystery. In fact, in one family lifeline the words, "Unsolved Mysteries" was boldly written.

Several families explained that they believe that the public has a stereotype about autism as a mild condition because they are familiar with only milder forms of autism (e.g. Asperger's), or they see movies that portray characters with autism as highly intelligent. Both of these stereotypes were in stark contrast to the family's experience of autism. As a sibling noted:

My view of what autism looks like started to change completely. It's not like the movies: *Temple Grandin* and *Rain Man*. They can use a toilet and express themselves and earn respect from huge groups of people...They're not the face of autism. Not in my life. Autism is much more painful and degrading and trying and frustrating. Autism isn't genius, it's not "different ability." It hurts.

(41BLLC51)

Families also described the stereotype held by others that disabilities are physical, e.g., disabled children would use a wheel chair. Because autism is not a visible physical disability, their child's behavior was misunderstood as "bad behavior" instead of a manifestation of autism. Families subsequently felt shame and constantly needed to educate others about autism.

The mysterious nature of autism also included the abrupt changes that occurred day to day and over time such as the child suddenly losing the ability to talk, typically at about 2 years of age. One grandmother said, "As time went on, one day he was talking...and I remember his dad saying, 'He said "juice," 'He said "juice"last night.' And the next day...he never talked again" (43BC3). This change

may be more striking in severe autism because of the nonverbal nature whereas in milder autism there is usually some verbal ability.

Adding to the uncertainty, the etiology of autism remains unknown and the child faces many diagnostic challenges. The child's behavioral and communication challenges made the child's participation in standardized autism testing almost impossible. In addition the children often faced long wait lists for autism testing; one mother was outraged that there was approximately an 8-month wait list in the state to obtain formal autism assessment.

Dealing with Severe Behavior Challenges

The next essential theme described how the family dealt with the severe behavioral issues of their child. The families shared that, as the child grew, behaviors became more difficult to manage. They discussed a range of significant autism-related behaviors that they encountered each day which included self-injurious behaviors e.g., head banging, biting their own fingers and arms, throwing themselves into furniture, punching themselves in the head, and picking at their own skin, resulting in open lesions.

Most commonly discussed were meltdowns or tantrums, severe sleep issues, and elopement. In reference to sleep, almost all of the children had sleep issues that kept families awake and alert at night. Two families, however, noted that their child did not sleep from birth until about age 4 (39CC32; 41BLL48). One of these mothers noted:

It was really hard. I ate candy bars, I drank coffee in the middle of the night, and then sometimes he would surprise me and fall asleep, and since I'd had coffee, I'd have to take Nyquil to try to get to sleep so I could be sleeping when he was sleeping. The synergistic effects of Nyquil, coffee, Nyquil, coffee could not have been good for my body. I was just exhausted all the time.

(41AC28)

Families reported how they dealt with elopement of their child. Several families had installed metal bars, alarms, and multiple locks on doors and windows to prevent the child from escaping and running away. Most families often felt safer at home rather than outside the home because of their familiarity with their home's safety features and fear of the chances of the child's running away when in public.

Severe behaviors also included aggression to others, such as pinching, hitting, scratching, biting, head butting, and throwing toys or items. This resulted, among other casualties, in welts and bruises, a teacher's broken nose, and a mother's black eye. One mother said:

He hits and kicks. He's bit us before. He gets physically aggressive with us... For instance, [dad] just took him to see relatives and on the way home on the plane he was attacking dad the whole time. [Dad] comes home and he's got scratches down his

face and a bloody nose, he's bitten up, because [son] was freaking out on him."

(36AC51 +52)

Another mother explained her son's morning routine, "He'll sit on my head or he'll kick my head if I'm sleeping...and if I don't [get up] within 5 seconds, it's *whap*." (16C49).

Some behaviors caused destruction to their homes and damage to furnishings, such as holes punched in walls, food thrown at walls, feces smeared on furniture, books ripped apart, and light fixtures dismantled. One mother described:

He just obsesses about an entire roll of toilet paper and he'll unroll the whole thing and put it in the toilet.... He likes to stick things in the drain. He used to flush things down the toilet.... He has a tendency to eat toothpaste... to the point where he's eaten it and then gone into his room and thrown it all up.

(34AC24 + 25)

Because of this several families created a "minimalist" design to decorating which included few accessories and simple furnishings to decrease the risk of destruction.

As the primary investigator, I observed severe autism-related behavior, home destruction, and austere home decoration through the home visits, which were documented in field notes. I was able to meet several of the children with autism (8 out of 11). I made particular note of one child who shuffled as the child walked across the room and used only groaning sounds for communication. During the interview of her mom, the child pinched my face very hard. The mother's repeated apologies highlighted her own experience of stigma/shame. I observed several homes that had holes in the walls caused by the child with autism throwing toys or other objects. I also observed several homes that were austere, with few to no home decorations to avert home destruction by the child.

Dealing With Significant Communication Challenges

In addition to behavioral challenges, families experienced a significant lack of verbal and nonverbal communication with their child. All of the children had profound communication deficits. A few children were nonverbal and a few could use simple sentences, but the majority had only a few words in their vocabulary and none of the children could carry on meaningful reciprocal conversation. For many there was a delay of several years (e.g., 7–9 years) before they recognized a parent by calling her "mom" and some still had never said it. As one grandmother recounted of her teenage grandson, "No, he doesn't say 'Mom.' It breaks my heart. If he would only say 'Mom,' I would be so happy for my daughter, but he doesn't" (34BC36).

In addition, many of the children with severe autism do not show affection like hugging, but rather used nonverbal

Table 6 Essential Themes and Subthemes

Essential themes	Subthemes
Mystery and complexity of severe autism	Stereotype and stigma <ul style="list-style-type: none"> • Autism is considered a mild disorder • Invisibility of autism • Constantly teaching others Unpredictability of behaviors and communication Diagnosis challenges <ul style="list-style-type: none"> • Unknown etiology • Testing delay • Testing challenges
Dealing with severe behavior challenges	Child size Specific behaviors <ul style="list-style-type: none"> • Meltdowns • Repetitive behaviors and strict routine • Sleep issues • Elopement • Destruction and altered home environment Aggression to others <ul style="list-style-type: none"> • Family members + Those outside of family self-injurious behaviors
Dealing with significant communication challenges	Communication patterns Solitary or parallel play What is child thinking? Altered connection <ul style="list-style-type: none"> • Verbal connection • Non-verbal connection • Delayed connection
Experiencing severe stress	Constant nature of stress Roller coaster experience Child's delayed development Teaching activities of daily living Coordinating services Cost Concern for child's future
Living with severe isolation	Friends <ul style="list-style-type: none"> • Obstacles to meeting with friends • Friends without children with autism • Friends with children with milder autism School <ul style="list-style-type: none"> • Lack of inclusion + Low expectations • Confrontations
A strong dependence on family	Public Medical health care providers Hybrid families: nuclear, extended family and friends Compassion <ul style="list-style-type: none"> • For the child + For each other • Increase over time

communication such as a head tilt, fist bump or rough play. This grandmother also said:

He seems to be into fist bumps now. Every time I see him, I'll say, 'Give Grandma a hug!' He'll put his head down, and it's kind of close to your head, and that's as good as you're going to get; that's a hug!"
(34BC28 + 29)

The lack of communication from the child left families wondering what the child was thinking. The family members worried that they would not be able to help their child if he or she became ill because of the child's inability to communicate basic needs. It was not uncommon that the child could not communicate a toothache or earache which in some cases resulted in severe unresolved pain and medical complications.

Because of the profoundly altered communication, the families often felt disconnected or isolated from their child. One mother said:

I feel like I haven't had the opportunity to enjoy him as a child. When a baby's born, every mom wants to cuddle with a baby and nurture the baby.... We'll try to play with him and he doesn't engage, so after a while we get tired and frustrated and say, 'Okay, I finally give up.'
(44A57+59)

During the home visit I observed the communication of several of the children with autism as they interacted with their family members. The child with autism usually had little to no interaction with others and often played alone. One child was precipitously perched on a high couch while I was there and avoided any direct touch from the parents. Another child stood still and repeatedly twirled a ribbon in circles while the family attempted to hug him, while another child aggressively pursued a younger brother and threw toys at the wall. I saw several of the children tilt their head to the side toward the family member in lieu of a hug.

Experiencing Severe Stress

Families discussed the severe and unrelenting stress they experienced because of the child's severe behavioral issues and altered communication. This was evident both in the interviews and the family lifelines. A good illustration of this stress was one father who told me, "I'm glad that someone is doing this kind of research. Certainly it's been a challenge. If you've talked to my wife at all, you've heard that it's been a challenge!" (44BC1) He then placed his head into his hands and began to weep, which was often the case with fathers. This observation of overwhelming emotion was common among all the males interviewed as well as many other family member participants.

Many families described their lives as an unpredictable "roller coaster" because of the daily challenges they experienced caring for their child. One example of the ups

and downs of their daily experience was the lack of sleep described by all families because of the child's erratic sleep schedules and the need to maintain vigilance watching the child through the night. One mother exclaimed: "How do I take care of myself? How do I just get breaks?... I'm to the point where I'm breaking. I can't continue 24/7. I can't do it!"(16C95).

Another mother commented on the dissimilar lives their families led when compared to other families they knew:

They are children... I'm a mom; but that's where the similarities between me and my children and my friends and their children stops. Beyond that, the way we eat is different, the way we drive is different, the way we dress is different, the way we invite people over is different, the way we decorate is different. The way we shop is different. The way we travel is different. Everything is different.

(39AC38)

Many families shared the frustrations of caring for an older child who acted like an infant because of their delayed development, e.g., they needed to bring a diaper bag on outings. One father described that he and his wife were not able to relax as their child has grown, but rather needed to remain watchful. He said, "I imagine for most people that starts happening at a particular age, that it gets less time-consuming, but that has never happened with us. It's just going to stay. She's 6 and it's always going to be 6" (10CC2).

Families also shared the constant need to reinforce good behavior all day, every day in an effort to model self-care and positive social skills. This involved constantly reminding and patterning behaviors for the child. One aunt recounted, "It's lesson, lesson, lesson" (7BC30).

As the families held the responsibility of primary care provider for the child, they coordinated countless health care providers, which resulted in additional stress. Beginning with the time of diagnosis there was little help in identifying and coordinating services by healthcare providers. The best help came from specialty autism centers, but the centers were often inaccessible because they were generally located in urban areas and families often lived far from them. They reported their frustration about the shortage of autism-related health care services like behavioral therapy, physical therapy (PT), occupational therapy (OT), and speech therapy, each with long waiting lists.

Families recounted the trials of simple visits to the doctor. For these families one trip to a clinic could be exhausting because of the long wait times, child behaviors, and needing to hold the child down to help keep the child calm. As one mother said,

This is a life-altering experience. It's traumatic every time we go into a clinic or a hospital – or even a place where they're not going to be poked or

touched, just the psychologist. This is an event. Like, can I just talk to you over the phone and you can bill for that? Do I really have to be within touching distance?

(39CC43)

The families described the high cost of autism care and the steep out-of-pocket expenses they incurred due to inadequate health care coverage. Some family members held several jobs to make ends meet and several needed to weigh health care coverage in their employment options to procure the best medical insurance coverage.

The stress was constant and the families lived in the present moment, and did not discuss plans for the near future. Although specific plans for the future care of the child were not discussed, a concern echoed by many family members was, "What will happen to my child if I die?" which reflected their concern about who would care for their child if not them.

Overwhelming stress was observed in the home visits as evidenced by the majority of the participants who wept openly during the interview. In addition, anxiety was palpable as family participants often tried to juggle speaking with me while caring for their child, although most had someone helping to care for the child during the interview.

The family lifelines also revealed the extreme degree of distress the family experienced. Although the lifelines were originally printed on standard letter size paper (8 ½ by 11 inches), half of the families printed copies of the lifeline and taped two or three together to obtain more writing space. Family stress was sometimes portrayed in a graph-like representation illustrating the "ups and downs" (Figure 1). In this lifeline, the stress that the family had experienced is evident, particularly when the child was 12–13 years old, during early adolescence. Again, while it might be expected that there would be a general improvement over time, instead there were constant peaks and valleys that continue throughout the child's life. Figure 2 also illustrates the constant anxiety the families experienced; this family lifeline was so chaotic that it was difficult to read.

Families with children who had the most severe functional challenges demonstrated stress on the family lifeline evident from birth (Figure 2). Alternatively, some families experienced a relatively calm period during infancy followed by stress when their child had a sudden onset of symptoms at about 2 years of age. These lifelines showed a different picture with relative calm then anxiety that followed (Figure 3).

Living With Severe Isolation

The fifth theme identified was the extreme isolation related to the child's severe behavioral issues and profound communication challenges. The families discussed not being able to physically leave home because of the child's needs. They described not having the ability to meet with friends

because of their busy schedules and lack of proper childcare. They did not want to socialize with friends who had children who were neuro-typical because they had little in common. Families yearned to meet other parents who had a child as severely affected with autism as their own, although this was a rare occurrence.

Frustration and isolation from school staff was common as their child was often marginalized and taught menial tasks, such as folding towels or drawing, rather than learning educational content like other school children. Families referred to this as “baby sitting” versus “real school.” Several families described having altercations with school staff as they advocated for services, with the child ultimately being “kicked out” of the school system. During one family interview, the mother described their school situation: “That’s when the principal came down that day and told me, and I quote, ‘Get the hell out of my school!’...And then we never went back” (10AC48).

Families were further isolated from the public when their child had behaviors that were misunderstood. One mother recounted a typical experience:

This is what happens at the grocery store. Someone will say: ‘What the hell is wrong with your child?’ or ‘Get it under control; get *him* out of here! Why do you bring *that* in public?’... The loud speaker will be turned on and someone says: ‘What’s going on? Maybe if you can’t get this under control you should leave!’ We have left. Sometimes even with a grocery cart full of groceries—we’ve left. (10AC28+ 29)

There was also isolation from health care providers including, but not limited to gossip about the child’s behavior by nursing staff at the hospital, dismissing the diagnosis of autism by a physician, and general lack of patience by health care providers in clinic. These were the very people families

depended on and they felt dismissed mainly due to the health provider’s lack of knowledge about severe autism.

As previously discussed, families felt isolated from their child relating to the child’s developmental delay and lack of communication. Some families described being ‘heartbroken’ by the fact that they did not know if the child realized that they were not just a child care provider, but rather a dedicated family member called “mom,” “dad,” “sister,” etc. As one mother said,

When I used to work a lot, it seemed like he didn’t even miss me when I was gone. He was 4 when he started to get separation anxiety.... It’s different to have a little kid that doesn’t seem like they care if you’re around or not.... And it’s like, I know you like me, but does it matter if it’s me or if it’s somebody else? It matters because I’m around you more, but is it because I’m mom? You’re not requesting mom. (43AC83 + 43AC84)

A Strong Dependence on Family and Compassion for Each Other

The last essential theme identified in this research was a strong reliance on hybrid families and compassion learned for others. In an effort to find the necessary physical and emotional support, families cobbled together hybrid families who often consisted of nuclear and extended families, and friends. This was a hybrid support system that seemed to help the families as they navigated through the difficulties associated with severe autism. One mother described the importance of friends:

Our family here is largely people that we just extremely love like family. There’s not a blood connection, but there’s a heart connection, so they are our family. So my best friend... she’s my sister! Yeah, and then I have another friend She’s my other

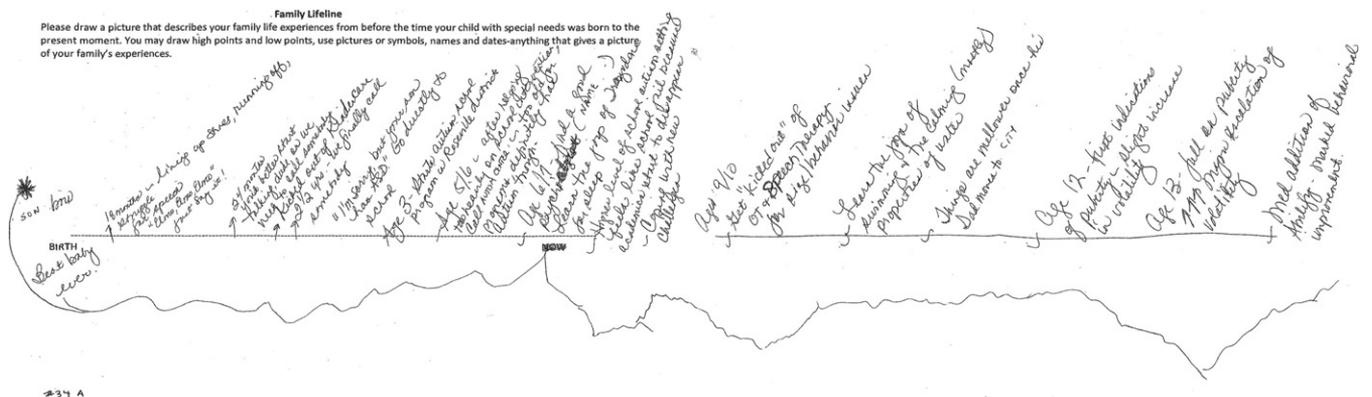


Figure 1 Graph lifeline.

say I only got one little egg and it's cracked. My one little egg and it's cracked. I love him!

(7DC8)

Two family lifelines portrayed family compassion that evolved over time. One example of this is seen in [Figure 4](#). The mother describes their family experience in a progression of the words: “Surface love> Chaos> Stress> Peacefulness again> inner love” with “inner love” being closest to the present time (45LLC67). She described that the family had learned love from caring for the child with autism.

In the second family lifeline ([Figure 2](#)), the mother noted early in their family lifeline: “Grieving... Naive, Didn't know the first thing about love—true love...” Later the mother writes, “Grieving... Joy from sorrow is strongest.” At the end of the family lifeline denoting the present time, she draws hearts and writes: “Grieving, joyful, hopeful... Love wins” (39ALL100).

Discussion

Findings from this study contribute new knowledge that provides unique insight into the experiences of families of children with severe autism. This research included children with only severe autism versus other disabilities or milder forms of autism. It also gave a voice to the family experience from the perspective of multiple family members, including those outside the nuclear family, and the family as a unit versus the parent as the only source of data. The triangulation of several data sources—individual interviews, family interviews, observations and the family lifelines—was also innovative and helped to paint a broad picture of the family lived experience.

The effort to only include children with severe autism was initially a challenge of this study because only one child originally had been given the formal diagnosis of “severe autism” (possibly due in part to the various challenges to severity categorization mentioned previously). Because of this and the lack of a comprehensive assessment tool to assess severity, we developed the Autism Functional Challenge Questionnaire to assess autism severity for inclusion criteria. Including only children with significant functional challenges provided a homogeneity to the family experience since all were all dealing with children who had considerable functional challenges.

The inclusion of family members outside the nuclear family also involved a challenge in the research process and was an iterative process. At the onset of the study, the criteria included only two-parent nuclear families. During recruitment it became apparent that several families were one parent—families, and that their definition of the family extended outside the traditional nuclear family to include extended family and friends. Inclusion of these individuals highlighted the stressful situations the families experienced and their need to reach outside the nuclear family for the physical and emotional support to care for the child with autism. It seemed ironic that these individuals who provided

significant support to families were rarely included in the qualitative research studies that had been reviewed.

There was also an effort to include the voices of the families as a unit in family interviews. Family interviews have rarely been conducted by nurses due to the inherent challenges in coordinating and conducting family interviews ([Åstedt-Kurki & Hopia, 1996](#)). Individual interviews yield rich data and family interviews often yield information about family interactions ([Beitin, 2007; Donalek, 2009](#)). We found this to be the case and appreciated the opportunity to conduct seven family unit interviews with six families, though it was extremely difficult for families to find the time to meet together due to their extensive responsibilities caring for the child with autism.

In this study, the triangulation of the interviews with observations and the family lifelines provided a broad understanding of the family's lived experience. Observations of the home environment, family, and the child with autism (in the majority of cases) were all documented in field notes. Seeing home interiors devoid of decoration to thwart potential destruction by the child with autism; gaping holes in walls caused by toys thrown by the child with autism; and bars and locks on windows and doors, gave a clear snapshot of the severe conditions under which the families were living. Witnessing some of the children with autism not speaking at all or avoiding the touch of family members breathed life into the theme of isolation.

The family lifelines provided yet another piece of the puzzle which was a creative outlet for many families to portray in picture what they might not be able to express in words. Most included a chronologic representation of their family experiences and some included faces, words, and figures which virtually shouted “stress.”

In summary, there were six themes that emerged from the use of these research methods that summarized the family experience (see [Figure 5](#)). The families found autism mysterious and complex including the yet unknown etiology of autism, challenges in diagnosis and unpredictable nature of the condition. Unlike the study of [Hoogsteen and Woodgate \(2013\)](#), who found that the families of children with autism were surprised to find autism not as severe as they expected, these families found the condition more severe than they expected. One example of this is that the child's behaviors were often unpredictable, and changed often and dramatically throughout their life, such as the child speaking then losing the ability to speak. Similar to other studies ([Farrugia, 2009; Hoogsteen & Woodgate, 2013](#)), many families felt stigma or shame related to the invisible nature of autism and the public's misperception that the child's autism-related behavior was reflective of poor parenting versus a disability.

[Bultas and Pohlman \(2014\)](#) and [Larson \(2010\)](#) found fatigue among mothers was due to the erratic sleeping schedule of the child. A few studies mentioned specific stressful behaviors such as crying, sleep issues and general agitation ([Desai et al., 2012; Lendenmann, 2010; Lutz et al., 2012](#)). The severe behavioral issues discussed in this study,

Family Lifeline

Please draw a picture that describes your family life experiences from before the time your child with special needs was born to the present moment. You may draw high points and low points, use pictures or symbols, names and dates-anything that gives a picture of your family's experiences.

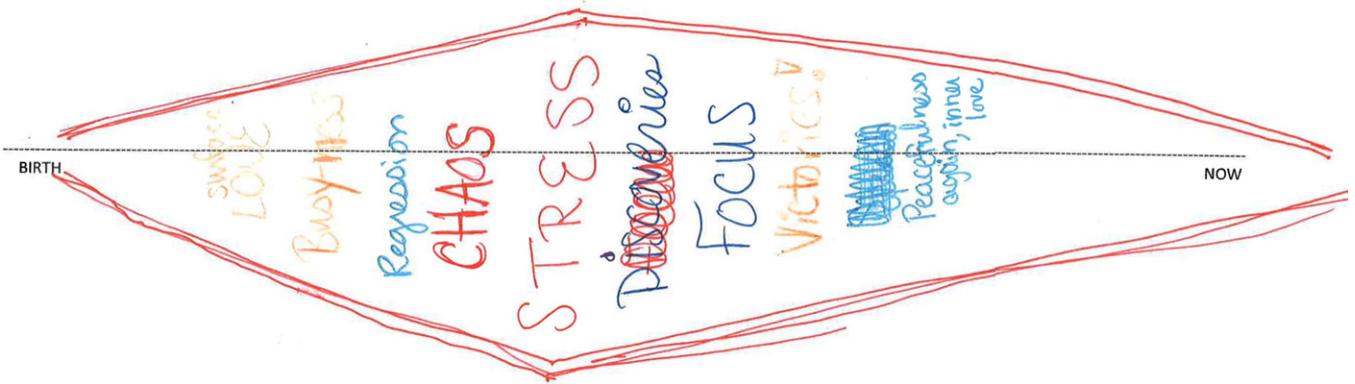


Figure 4 Box lifeline.

however, were numerous and quite severe. The behaviors became more challenging as the child grew in size and included: severe meltdowns or tantrums; severe lack of sleep, often lasting years; harming themselves and others; elopement; and significant destruction of the home.

The families faced profound communication challenges, as most of the children had few words in their vocabulary and most preferred to generally isolate themselves from others. In addition, the children often had delayed verbal and nonverbal connection to the family, such as not acknowledging family

members for years and not showing affection. This altered communication resulted in the family experiencing isolation from the child, something not particularly highlighted in previous qualitative research.

Although we framed the review of literature around family stress experienced by families with a child with autism, the synthesis of our data sources revealed more extreme situations than expected. Families described the child's chronic lack of sleep that resulted in severe, and often long-lasting sleep deprivation in family members. Family stress was also related

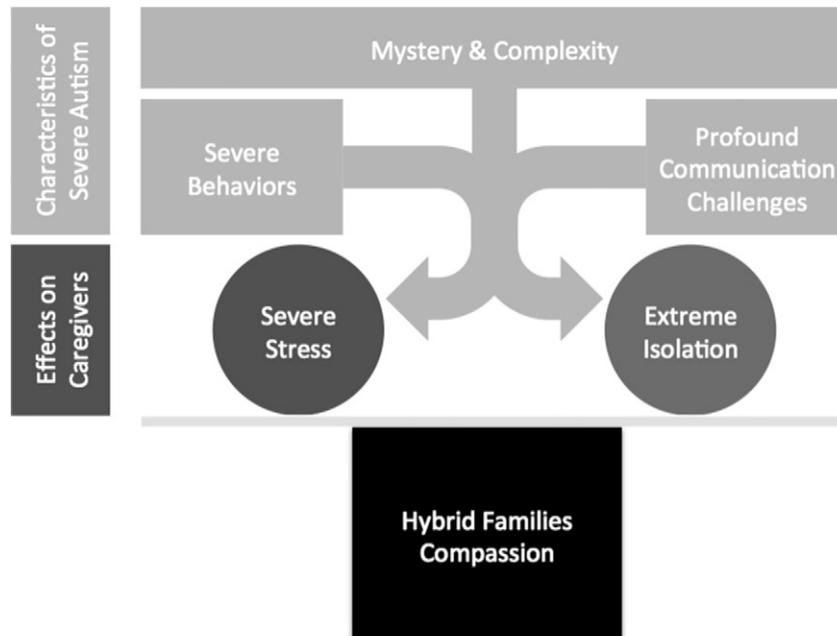


Figure 5 Theme schema.

to caring for a child who was developmentally delayed, and the inordinate amount of time coordinating health care services, educating the child daily, and out-of-pocket expenses.

Families additionally experienced extreme isolation from friends, schools, the public, and health care providers. The previous qualitative literature does support the finding that families of children with autism experienced isolation from friends and the public (Larson, 2010; Luong et al., 2009; Lutz et al., 2012; Phelps et al., 2009; Safe et al., 2012; Schaaf et al., 2011), but isolation from their child has generally not been a focus in the previous research.

The extended family was generally not included in previous study samples though a few studies found that the extended family were in fact unsupportive to the nuclear family who had a child with autism (Bilgin & Kucuk, 2010; Bultas & Pohlman, 2014; Safe et al., 2012). In this study there was evidence of a strong dependence on a network of extended family and friends, with families even forming hybrid families to care for the child with autism.

Lastly, in this research, families experienced a compassion for the child and for each other over time as they cared for their child. This was similar to the positive outcomes reported in other studies that describe empathy and compassion that the families learned from living with a child with autism (Bultas & Pohlman, 2014; Dupont, 2009; Mulligan et al., 2012).

Practice Implications

The findings from this research have implications for health care providers who provide direct care and psychological support to the family who have a child with severe autism. In addition, the findings may be instrumental in laying the groundwork for affecting health care policy change.

Practice implications can be based on the family health system construct discussed by Anderson and Tomlinson (1992). This construct highlights the need to consider the family as a distinct unit when understanding health and illness and when formulating research and healthcare interventions.

Practice implications may include, first, recognizing the unique needs of families of children with severe autism in the health care setting. Because of the behavioral and communication challenges of the child with severe autism, the family may require additional support when the child has a health care visit to a well-child clinic, dentist, or hospital. This should include more staff to support the family in assisting with procedures and healthcare providers who are sensitive to families experiencing significant stress.

Second, there is a need for improved psychological support by health care providers to mitigate family stress and isolation. Psychological support could include individual and family therapy, mentors for family members who have shared experiences, Web-based and in-person parent/family support groups, respite care for children to provide families much needed breaks, and home visits by health care providers. Other supports that may defray family stress could be coordinators or

advocates who could assist families in obtaining local health care services (e.g., behavior therapy, PT, etc.) to help navigate complex health care costs. Empathetic healthcare providers who recognize the unique situation of each family would also be beneficial.

The study findings underscore the need to increase the number and/or expand existing autism specialty clinics and services due to the long wait-times families experience to obtain autism testing and receive healthcare services. The development of a comprehensive autism treatment center model might be beneficial. These centers would provide centralized multi-disciplinary health care by autism specialists, e.g., psychologists, physical and occupational therapists, to provide multiple assessments and services at one location. This would improve coordination of care and alleviate the stress for the child and family traveling to various sites.

This research may also provide the catalyst for further research that explores the experiences of families of children with severe autism. Further understanding of family needs and resources may be used ultimately to affect the development of healthcare policy that is sensitive to the needs of the families of children with severe autism.

Study Limitations

The time since diagnosis of autism to the time of the interview varied within the study from 2 to 10 years with the mean of 5 years. This could be considered a limitation of the study because the varied times since diagnosis could result in very different family experiences.

A challenge of the study was that, although the sample was large, the types of family members who participated in the study were limited. For example, only one aunt, one sibling and one friend, and no grandfathers or uncles participated. Having participation from more of these individuals would have broadened the scope of the findings. Additionally, not all family members participated in the individual and family unit interviews and one family did not complete a family lifeline. Though this limited the information gathered, we felt fortunate to have the participation of those who did participate, despite their busy schedules.

Another limitation is that much of the family experience was observed over one day; approximately half of the families had one home visit (5 out of the 11 families) and the other six families had 2–3 home visits. One could argue that one visit gave a limited snapshot of family life, though one could also argue that we were fortunate to have as many contacts with the families as we did.

Conclusion

The aim or purpose of this research was to interpret the experience of families who live with a child with severe autism. The goal of the study was to include only children with severe autism while at the same time broadening the sampling parameters to incorporate all significant people who were considered family. Overall, the results were somewhat surprising. The study findings illuminated the

extensive hardships and challenges of families who have a child with severe autism; identified needed resources; and illuminated how families formed hybrid families for additional support. This new knowledge has implications for nursing and health care practitioners which encourages the development of strategies to provide quality care to children with severe autism and their families. This research also provides a foundation for future research that can influence the development of new healthcare policy. Further research is needed to extend our understanding of the unique issues that families of children with severe autism encounter so that overall care to these families can be improved in the future.

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