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utmb Health
Nursing PhD Program

REPORT OF FINAL EXAMINATION
NURSING PhD

Date: 02/29/2024

We, the undersigned, as the Supervisory Committee in charge of the work of

Michelle Nighswander , for the Doctor of Philosophy in Nursing Degree, report that we have examined this student on his/her dissertation, the general field of the dissertation, and the following other parts of his/her program.

The student named above has:

1. completed the work assigned by the Committee.
   [X] Yes [ ] No

2. passed all examinations required by the program, including the final oral defense of the dissertation.
   [X] Yes [ ] No

3. selected option 1: [X] a traditional dissertation
   OR

4. selected option 2: [ ] 3 manuscript(s) suitable for publication in peer-reviewed journals which meet the approval of the Committee.

5. completed either dissertation option 1 or 2 satisfactorily, which gives evidence of ability to do independent investigation in the major field, and itself constitutes a contribution to knowledge.
   [X] Yes [ ] No

6. The student's dissertation is accepted by the committee
   As Is [X]   With minor revisions [ ]   Not Accepted [ ]

We recommend that this student be granted the Doctor of Philosophy in Nursing Degree.

Chairperson: *Dr. Patricia Blair*
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Searching for their Path:

Understanding Parents of Children with Emotional Disturbance

by

Michelle Nighswander, MSN-Ed, BSN, RN,BC

Dissertation

Presented to the Faculty of the Graduate School of

The University of Texas Medical Branch

in Partial Fulfillment

of the Requirements

for the Degree of

Doctor of Philosophy

The University of Texas Medical Branch

February 2024

Dedication

To these brave mothers who told me their raw and heart wrenching stories, in hopes that it might help other parents.

To those special teachers who take on the challenge to connect with a child who is tougher to teach than others, who get to know their unique quirks and mannerisms, and teach that child (and their parents) that there is more than one way to complete a journey.

To those healthcare providers who look beyond the initial presentation of a problem, who keep searching for options D, E, F and beyond, when the most direct options fail.

To the children who teach parents about flexibility, creativity and tenacity to a depth parents never realized they needed to learn.

To the parents and families out there still searching for their path: hang on, there is light at the end of the tunnel, even if the tunnel is long and twisted.

Acknowledgements

A dissertation journey cannot be completed alone, and I have been blessed with the support and assistance of many special people as I completed this journey.

My family has been my rock. I want to thank my husband, Gabe, for always lovingly supporting my goals and dreams, no matter how many years of schooling they take. I thank my sons Reece and Brandon for their patience, love, smiles and hugs as I worked in my chair in the dining room, night after night.

Dr. Patricia Blair, my dissertation chairperson, has been a fierce and tireless advisor, mentor, advocate and counselor. She has always refused to accept limits and challenged me to constantly to see issues through a bigger and broader lens. Dr. Blair pushes me to see greater distances than I would ever see on my own. I am extremely grateful for the opportunity to learn and work with her, and so proud that my first publication was co-authored with Dr. Blair.

Dr. Bruce Leonard, who despite valiant attempts to retire and stay retired, has offered me unflagging encouragement every step of the way. From my first meeting with him as my academic advisor, to the last 15 minutes in his final day of his career, and throughout countless RV trips through the Rocky Mountains, Dr. Leonard has never failed to answer my calls for help and advice, even if he had to take the call from a state park out west.

I want to acknowledge the assistance and contributions of my committee members: Dr. Michael Leger for his wise and unvarnished advice, Dr. John Prochaska for the inspiration of viewing parent support through community hubs and connecting various communities together, and Dr. Rounds for her expert writing knowledge to ensure my research is presented in the best possible way.

Searching for their Path:

Understanding Parents of Children with Emotional Disturbance

Publication No._____

Michelle Nighswander

The University of Texas Medical Branch, 2024

Supervisor: Patricia Blair, PhD, LLM, JD, MSN, RN

Abstract

Background: Children with Emotional Disturbance (ED) have unpredictable reactions and behaviors, which cause significant problems for themselves, their families and society (Zionts et al., 2016). The child's reactions are highly disproportionate, chronic and frequent (Gage, 2013). These children have significant risks related to their ED, including school drop-out, incarceration, unemployment and substance abuse (Lipscomb et al., 2018).

Purpose: The purpose of this study was to explore participants' experiences related to raising a child with ED, participants' response to situations related to their child's ED, and how a child with ED impacted the family.

Method: This study explored the parenting experiences of mothers of children with ED, utilizing Naturalistic Inquiry as described by Lincoln and Guba (1985) and Erlandson et al. (1993). After IRB approval, eight mothers were recruited nationally through social media.

Results: Three overarching constructs emerged in the study. The first construct, "**concerns and suspicions,**" was the evolution of mothers' concerns, rationalizations, escalations, decision and eventual confirmation that their child was "different." **"Actions and adaptations"** depicted the actions used to manage their child with ED, along with actions for self-care and siblings' care. "**Altered families and advice for others**" described how every family member was impacted by

the child with ED and participants' advice on how to ease the difficulties for other families. Study findings suggested needed changes to nursing practice, education and policy.

Keywords: emotional disturbance, behavioral disorder, parents, perceptions, stigma

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List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
CBHSQ	Center for Behavioral Health Statistics and Quality
DoED	Department of Education
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Emotional Disturbance
ID	Identification (number)
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
IRB	Institutional Review Board
NI	Naturalistic Inquiry
OSEP	Office of Special Education Programs
NCSER	National Center for Special Education Research
SCDT	Self-Care Deficit Theory
SED	Serious Emotional Disturbance
SPED	Special Education
TEA	Texas Education Agency
UTMB	University of Texas Medical Branch
U.S.	United States

Abstract

Background: Children with Emotional Disturbance (ED) have unpredictable reactions and behaviors, which cause significant problems for themselves, their families and society (Zionts et al., 2016). The child's reactions are highly disproportionate, chronic and frequent (Gage, 2013). These children have significant risks related to their ED, including school drop-out, incarceration, unemployment and substance abuse (Lipscomb et al., 2018).

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CHAPTER 1: INTRODUCTION

This qualitative study focused on the phenomenon of emotional disturbance (ED) in children. Using Lincoln and Guba's (1985) Naturalistic Inquiry as the research framework, the investigation explored the phenomenon from the perspective of mothers raising children with ED. The exploratory study illuminated the participants' challenges related to their child's emotional disturbance, how they managed those challenges, and how the participant perceived their child with ED impacted the family.

Background of Problem

Children with emotional or behavioral issues cause problems in a variety of settings. These emotional and behavioral issues cause the child to react unpredictably. A child can be violent, aggressive, hyperactive, impulsive, or extremely anxious and withdrawn (Zionts et al., 2016). A child with ED exhibits extreme behaviors which occur frequently, over a long period of time, and are highly disproportionate to the circumstances (Bower, 1959; Zionts et al., 2016). Children with emotional disturbance explode without provocation and with little warning (Tahhan et al., 2010). In this study, "emotional disturbance" (ED) describes children with significant emotional or behavioral issues, as used in the Individuals with Disabilities Education Act of 2004 (U.S. Department of Education [DoED], 2020).

The results of unaddressed or unresolved emotional or behavioral issues in children is frightening (Harrison et al., 2013; Tahhan et al., 2010). These children have significant long-term risks to themselves, their families, and society at large. The children are more likely to be suspended, drop out of school, be arrested, go to prison, become unemployed, become addicted to drugs or alcohol or have relationship difficulties (Harrison et al., 2013; Lipscomb et al., 2018).

By the age of twenty-five, 60% of children with ED have been arrested *at least* once (Wagner & Newman, 2012).

Children with emotional or behavioral issues disrupt classes, social gatherings, professional offices and the home (Zionts et al., 2016). These behaviors can significantly impact the school environment. Schools are under pressure to increase academic rigor to achieve academic goals, but with larger classes and fewer staff (Flannery, 2023). Children with ED require teachers with expertise in adaptive instruction and increased resources, such as smaller classrooms (McKenna et al., 2019). Otherwise, the child's issues can create chaos in the classroom, negatively impacting other children's learning as well as their own (McKenna et al., 2019).

A child's emotional and behavioral problems do not suddenly appear when the child enters school (Simpson et al., 2005). Parents are generally aware when their child is developing differently than other children prior to formal schooling (Simpson et al., 2005). Many parents try seeking help from healthcare providers early but find interacting with healthcare professionals to be frustrating (Council for Exceptional Children, 2020; Kelson et al., 2005). The child's differences become more evident as the child grows older, engages with peers at school, and strives for "competence" (Orenstein & Lewis, 2022).

Unbeknownst to healthcare providers and educators, the ED issues are often significantly worse at home than observed in school or a healthcare setting (Tahhan et al., 2010). Hence, these professionals' efforts to assist these children are hindered without feedback from parents or direct observations of the child in a variety of settings. The child's parents have knowledge of the child's actions in multiple environments. Without information from the parents about the child's behaviors outside of the school or healthcare setting, experts' advice or interventions to assist

may be ineffective and frustrating for parents. Traditional child rearing advice is based on theories related to developmental norms (Orenstein & Lewis, 2022). A child with emotional disturbance does not react in society's interpretation of a "normal" way. Therefore, it is unlikely they will react "normally" to traditional teaching, discipline or parenting methods when stressed (National Center for Special Education Research [NCSER], 2017). Healthcare providers and educators need the context of a child's homelife to effectively advise and create appropriate management strategies.

Primary pediatric providers might recommend a psychiatric evaluation for a child with emotional or behavioral issues, but they may be unaware of challenges beyond a lack of available specialists or long wait times (Weitzman et al., 2015). One major challenge can be a lack of *pediatric* mental healthcare providers on the parents' insurance plan. Seeing an out of network specialist creates a financial barrier, because parents may have to pre-pay the specialists' fees. In the United States, it is the responsibility of a person with a disability (or the parent) to navigate the "quagmire" of their health insurance policy, benefits and documentation process to submit reimbursement claims for an out of network specialist, which can take significant time for the insurance company to process (Colorafi et al., 2023, p. 1593). Persons with disabilities reported the process was so stressful that the filing a claim was "navigating a dehumanizing system," (Saffer et al., 2018, p. 1562).

There is a dearth of literature focused on the experiences of parents raising children with ED. A few studies (Duppong Hurley et al., 2017; Green, 2016; Taylor Richardson et al., 2006) reported that parents of children with ED experience high levels of stress. One study (Tahhan et al., 2010) explored parents' experiences with their children with ED. However, this study was limited to children who required extended residential placements. However, none of these studies

explored the parents' actions at home, the management methods they tried, how they adjusted as the child grew older, as recommended by Taylor-Richardson et al. (2006). To date, there remains a lack of studies exploring how parents of children with ED manage their daily lives and care for their ED children at home.

Research Questions

The objective of this study was to gather narrative data from parents of children with ED about the participants' experiences and perceived family dynamics related to raising their child with ED. The study was guided by the following research questions:

1) What are the parenting experiences of parents of children with ED?

2) How do these parents respond to situations and challenges that arise due to their child's ED? Do these situations and parental responses change as the child matures?

3) How does raising a child(ren) with ED impact the family as a whole?

The guiding questions provided insight regarding parents' (1) experiences and needs, (2) management strategies and adjustments over time, and (3) perception of the impact on the family related to having a child with ED. The study also provided an opportunity for the voices of these parents to be heard and included in the broader body of research on this topic.

Conceptual Focus: Emotional Disturbance

Various terms are used to describe children with inappropriate emotional reactions or behaviors, including conduct disorder, behavioral disorder, serious emotional disturbance and explosive anger disorder (McLaughlin et al., 2012; Wery & Cullinan, 2011; Williams et al., 2018). However, "emotional disturbance" is used in educational research and in schools to identify children with reactions so intense that the child's learning or other students' learning is

impaired (Zionts et al., 2016). The intense reactions must last a "long" period of time (DoED, 2020). According to Zionts et al. (2016), this period of time is often at least three months.

A child with ED is identified by their observed functional learning impairment at school. Eli Bower (1959) first identified and published characteristics of ED. Characteristics of a possible emotional disturbance include: 1) an unexplained inability to learn, 2) inability to build or maintain peer or teacher relationships, 3) inappropriate behaviors or feelings under normal circumstances, 4) general unhappiness, or 5) development of physical symptoms or fears from school problems (DoED, 2020). Bower's findings were later incorporated into the Education for All Handicapped Children Act of 1975 (Hanchon & Allen, 2018). This law evolved over time and was later renamed the "Individuals with Disabilities Education Act" (IDEA) of 1990. The definition and characteristics of "emotional disturbance" have remained unchanged.

Terms for ED such as "serious emotional disturbance," "explosive anger disorder," and "conduct disorder" are more commonly used in healthcare literature (Ringeisen et al., 2017; Williams et al., 2018). However, the Diagnostic and Statistical Manual of Mental Disorders (DSM) has never clearly defined "serious emotional disturbance" (Center for Behavioral Health Statistics and Quality [CBHSQ], 2016). Rather, the DSM guidelines state patients must have a "DSM-based mental disorder," such as attention deficit disorder or disruptive mood dysregulation, in addition to significant functional impairment, for a concurrent diagnosis of "serious emotional disturbance" (CBHSQ, 2016). "Emotional disturbance" is a broad umbrella term used by educational professionals to identify children with impaired learning based on functional assessments. However, identifying ED in the school setting does not confer a diagnosis of a psychiatric condition from a healthcare provider (Hanchon & Allen, 2018).

This study focused on the term "emotional disturbance" as used in IDEA (2004). The IDEA (2004) mandates that teachers accommodate the learning needs of disabled children, including children with emotional disturbance. Emotional disturbance in IDEA (2004) is based on functional assessment. If a child is identified as having emotional or behavioral issues which are significant, persistent over a long period of time, and impact the child's learning or other children's learning, the child is eligible under IDEA (2004) to receive additional educational support through the special education department of a school.

Conceptual Focus: Mental Health Stigma

Societies define what are appropriate social behaviors, interactions and physical characteristics for its members (Hinshaw, 2005). Society stigmatizes individuals who do not conform to these rules by exclusion, isolation, discrimination or explicit punishment (Mak et al., 2007). Stigma is internalized when the stigmatized person agrees with the exclusion or isolation (Corrigan et al., 2012). Mental illnesses have been globally stigmatized, with societies being "repelled" by those with mental illness (Rabkin, 1974). Those with mental illness are viewed as "dirty, unintelligent, insincere and worthless" (Segal, 1978). Consequently, stigmatization is a "central issue" of mental illness, including ED, in erecting barriers for successful treatment (Hinshaw, 2005, p.714). Stigmatization of mental illness remains a significant barrier to timely diagnosis and professional treatment (Lavingia et al., 2020).

Mental health stigma impacts how society reacts to children who do not conform to implicit social rules (Hinshaw, 2005). Parents of children with emotional issues experience stigma and isolation due to their child's behaviors and internalize this stigma by doubting their own parenting abilities (Hinshaw, 2005). The researcher considered the prevalence and influence of mental health stigma during study design and during data collection interviews. There was a

high probability that participants had been stigmatized by others, either in public or when working with healthcare professionals. Therefore, words were chosen carefully to reduce the chance of unintentionally admitting a stigma bias into the study. To avoid inadvertently stigmatizing participants about their child with ED, the researcher used terms such as "outbursts," "emotional problems," or "reactions" during interviews.

Synopsis of Study Design

Approval for this study was obtained from the UTMB Institutional Review Board on March 2, 2023. The study used purposive and snowball recruiting of parents who are raising a child (or children) with ED. Using naturalistic inquiry methodology (Lincoln & Guba, 1985, Erlandson et al., 1993), data was collected via recorded semi-structured interviews that were conducted over Zoom or by telephone. Oral consent was obtained. Recordings were transcribed by Otter.ai, an artificial intelligence transcription service (https://otter.ai/). The researcher verified the accuracy of each transcription by listening to each recording and correcting any errors. Data analysis used the constant comparative method as described by Lincoln and Guba (1985). The data were further analyzed by bridging, extending and surfacing the data units into three overarching constructs, with supporting categories and themes.

Summary

This naturalistic inquiry study explored the experiences and perceptions of parents who are raising children with emotional disturbance (ED). A review of the existing literature revealed children with ED have significant risks related to their ED, including quitting school, incarceration, and substance abuse (Hanchon & Allen, 2018; Lipscomb et al., 2018). However, there is scant literature regarding the children's parents and families. Healthcare providers and educators do not have a clear picture of these parents' struggles, experiences, and parenting

techniques related to their child's ED, or how a child's ED impacts family dynamics (Green, 2016; Taylor-Richardson et al., 2006). With improved understanding of parents' needs and experiences, healthcare professionals, educators and parents can work together to improve the long-term outcomes of children with ED.

       The remaining chapters will include a review of the literature, discussion of the study methodology, study findings, and discussion on how the findings have implications for nursing practice and future research studies.

CHAPTER 2: REVIEW OF LITERATURE

This chapter reviews the pertinent literature regarding parents raising children with emotional disturbance. The review of literature orients the reader to multiple perspectives regarding the phenomenon of inquiry (Sandelowski et al., 1989). The literature review should also clearly identify what information is still lacking and why this information is significant (Mitchell, 2004; Randolph, 2009).

This chapter begins by explaining how emotional disturbance (ED) in children is recognized and defined within the literature. Variations in terminology, identification criteria and state policies create barriers to researching this phenomenon in the literature, which are outlined and explained. Next, the chapter presents the process used to review the body of literature focused on parents of children with ED. Evidence of stigma toward parents of children with ED and other disabilities as well as research demonstrating parents' strong potential influence to assist children with ED is explored. There was limited research regarding the experiences and perceptions of parents and families raising a child with ED. These studies are explored in depth. The chapter concludes with synthesis of the state of literature regarding the impact a child with ED has upon their parents and family and identifies the current gap in the published literature

Literature Regarding Children with Emotional Disturbance

Behaviors of Children with Emotional Disturbance

Children with emotional disturbance (ED) exhibit severely disruptive emotional responses and/or behaviors. Their emotional responses or behaviors are completely incongruent with the circumstances and persist far past typical childhood developmental stages (Zionts et al., 2016). These reactions manifest with such intensity that they negatively impact the child's education and functioning at school, at home, and in the community (Zionts et al., 2016).

A child's abnormal reactions do not necessarily mean the child is unaware or callous to social expectations of behavior (National Center for Special Education Research [NCSER], 2017). Children with ED often understand social expectations and will adhere to these expectations when they are calm, but they react in a highly emotionally disproportionate manner when triggered by certain stressors (NCSER, 2017). Although every child will exhibit challenging emotions and behaviors at times, the emotional and behavioral responses of children with ED are severely excessive, disturbing, and persistent over time (Bower, 1959; U.S. Department of Education [DoED], 2020).

The intensity and seriousness of the behaviors displayed by children with ED is difficult to convey. The behaviors are not the same as a child simply having a "bad day," or going through a difficult childhood phase. Children with ED demonstrate externalizing or internalizing behaviors (or both) in ways that are frequent, chronic and severe (Gage, 2013; Kavale et al., 2004). The problems caused by ED extend beyond the school environment. Externalizing behaviors include frequent fighting, an extremely volatile temper, promiscuity/ hypersexual behavior, attention spans as short as 20 seconds, extreme impulsivity, property destruction, and self-harm (Epstein et al., 1994; Zionts et al., 2016). Children with ED can become violent toward their parents, siblings, peers and staff at school, and may explode without provocation (Tahhan et al., 2010). Parents are frightened of being attacked verbally or physically without warning (Tahhan et al., 2010). The violence may require the child's removal from the home to protect the safety of the other family members (Epstein et al., 1994; Tahhan et al., 2010). Researchers and educators focus on children with externalizing behaviors because their behaviors can be dangerous to others and negatively impact other children's learning (Epstein et al., 1994; Gage, 2013.).

In comparison, children with internalizing ED behaviors may exhibit a persistent lack of interest in anything, pervasive sadness, developing physical symptoms or fears associated with school or personal problems, and avoiding other people (DoED, 2020; Kavale et al., 2004; Zionts et al., 2016). Research regarding recognition of ED in children with internalizing behavior was mixed. Some research has noted healthcare professionals and educators may have more difficulty identifying children with internalizing ED because internalizing behaviors do not negatively affect others and their emotions are not easily observed (Hanchon & Allen, 2018; Zionts et al., 2016). However, Gage (2013) reported encouraging results regarding teachers' ability to accurately identify children with internalizing ED and referring these children to the appropriate resources. Nonetheless, children with internalizing behaviors still have impaired learning, difficulty making social connections, and subsequent difficulties transitioning to adulthood as a result of their ED (Kavale et al. 2004; Zionts et al., 2016).

Children with ED remember and follow social rules when they are calm, but when they are emotionally triggered, they do not react normally compared to other children (NCSER, 2017). For example, a child with ED may violently strike a peer if they get the red ball instead of the desired blue ball at recess. The child's peers intuitively understand these reactions are outside of social expectations and may avoid or actively ostracize the child with ED. Educators or other adults may remove the child from a classroom or sports team to punish them for their behaviors (Lipscomb et al., 2018). Social exclusion may worsen the child's behaviors and negatively impact the child's self-esteem as they gain awareness of their behaviors compared with their peers. Children with internalizing ED behaviors may not be identified early because these children do not create chaotic scenes (Zionts et al., 2016). A child with internalizing ED may not speak with peers for months because of an embarrassment only the child perceived. However, a

child with internalized ED behaviors still has difficulty learning and interacting with others because their emotional reactions are outside of the norm (Gage, 2013).

Many children with ED are found to also have receptive language delays (NCSER, 2017). A receptive language processing problem exacerbates the child's inability to receive, follow or remember verbal directions, especially when they are in a stressful situation (National Academies of Sciences, Engineering and Medicine, 2016). A child's inappropriate reactions can be exacerbated due to difficulty processing incoming instructions, minor frustrations or peer messages (NCSER, 2017). The child's behaviors and receptive language issues negatively impact the child's relationships with peers, teachers, and family members.

Risks Related to Emotional Disturbance

Children with emotional disturbance (ED) have high risks of many short- and long-term problems (Gage, 2013; Lipscomb et al., 2018). Lipscomb et al. (2018) found children receiving special education services are suspended from school twice as often as the national average: 29% versus 14%. Removing these children from classrooms means they receive less education and less socialization, which exacerbates the child's impaired social skills even further. Up to 56% of children with ED drop out of school before graduating high school, which greatly impairs their ability to retain long-term gainful employment (Lee & Jonson-Reid, 2009; Reddy et al., 2009). Even in children with diagnosed mental health conditions, less than one out of eight receive treatment (Weitzman et al., 2015).

The consequences of poorly managed emotional disturbances can persist after school and throughout adulthood. Youths with ED comprise 15-20% of youths housed in juvenile detention facilities (Harrison et al., 2013, Wagner & Newman, 2012). Such children are also at risk for substance abuse, unemployment, and relationship difficulties (Harrison et al., 2013). Wagner and

Newman (2012) found that by age 25, 60% of youth with ED had been arrested at least once, and 44% had been either on probation or parole.

Definition of Emotional Disturbance

Defining "emotional disturbance" has been difficult, and there has been no true consensus around any published definition or set of criteria within the fields of education or psychology (Forness & Knitzer, 1992; Hanchon & Allen, 2018; Kavale et al., 2004; Wery & Cullinan, 2011). A clear and concise definition of ED is important because within the federal statutes, the definition of "emotional disturbance" determines who is legally entitled to extra assistance for education and to some extent, protection from legal consequences (Kavale et al., 2004; Hanchon & Allen, 2018). According to Kavale et al. (2004), part of the difficulty in defining emotional disturbance is because ED is viewed through cultural expectations and social contexts of what reactions are "appropriate" and "congruent" or "severe" and "incongruent." Kavale et al. state this places cultural subjectivity in the process of identifying ED. Despite repeated calls for the definition of ED to be revised within educational statutes, the defining criteria continue to be those that are nearly identical to those proposed by Eli Bower in 1959 (Hanchon & Allen, 2018).

History of ED and Educational Law. Emotional disturbance in children was originally conceptualized as a disability by Eli Bower, who termed the condition "emotionally handicapped" (Bower, 1959). Bower was a teacher, psychologist, and research coordinator for the California State Department of Education, specializing in the area of disabled children (Online Archive of California, 1992). Bower defined a child as being "emotionally handicapped" when the child exhibited "significant behavioral deviations to a marked extent over a period of time" (Bower, 1959, p. 8). According to Bower, behavior deviations involved one or more of the following five characteristics: 1) an inability to learn, 2) inability to build or maintain

relationships, 3) inappropriate behavior or feelings for the conditions, 4) a general pervasive unhappiness and 5) a tendency to develop unexplained illnesses or pains associated with school (Bower, 1959, pp. 8-9).

Bower's concept that children demonstrating these behavioral characteristics were "handicapped" was legally significant. Although the Supreme Court verdict of *Brown v. Board of Education of Topeka* (1954) determined children of different races were legally entitled to the same level of schooling, this decision did not specifically mention children with disabilities (Archer & Marisco, 2017). School districts used the Supreme Court's omission of disabled children to legally bar these children from attending school (Archer & Marisco, 2017). Court verdicts supported school districts' exclusionary practices, which included children who required assistance due to blindness, lack of mobility, or children who were deemed "unlikely to significantly benefit" from education (Archer & Marisco, 2017). In many states, parents of children with disabilities or any specialized needs were forced to relinquish custody of their child to the state in order for the child to receive state-funded care or education (Cohen et al., 1993). Without access to public education or state-funded health care, parents had few resources to raise their child into a functioning adult.

The class action suit of *Mills v. Board of Education of District of Columbia* (1972) became a turning point for children with ED (Archer & Marisco, 2017). Four children labeled as having "behavioral problems" were permanently excluded from school without parental notice, educational alternatives, or recourse for re-evaluation. The District Court ruled the students' exclusion from school was unlawful. In the course of the case, evidence was presented that the district's practice of excluding disabled children affected 18,000 additional disabled students within the Court's district (Archer & Marisco, 2017). This ruling, along with a similar ruling in

Pennsylvania Association for Retarded Citizens v Commonwealth of Pennsylvania (1972),

spurred congressional action to legislate educational rights for children with disabilities.

The United States Congress recognized the right of children with disabilities to receive

public education by enacting the "Education for All Handicapped Children Act" of 1975

(Hanchon & Allen, 2018). The Education for All Handicapped Children Act originally listed

"seriously emotionally disturbed" as a specific educational disability (Kavale et al., 2004). This

law was revised and renamed the "Individuals with Disabilities Education Act" (IDEA) in 1990.

The Individuals with Disabilities Education Act (IDEA) of 1990 mandated schools must 1)

identify children who may have a disability which impacts their ability to learn and 2) adjust the

child's educational program to meet the child's specific educational needs (DoED, 2020). The

revision of IDEA in 1997 changed the term "seriously emotionally disturbed" to "emotional

disturbance," which was continued in the 2004 revision.

The Individuals with Disabilities Education Act (1990) provided educators with a specific

list of criteria to evaluate children with ongoing emotional or behavioral problems which might

impair learning. The defining characteristics of "emotional disturbance" are written below from

the Individuals with Disabilities Education Act (1990), section 300.8.c4.

> Condition exhibiting one or more of the following characteristics over a
> long period of time and to a marked degree that adversely affects a child's
> educational performance, including (a) an inability to learn that cannot be
> explained by intellectual, sensory or health factors, (b) an inability to build
> or maintain satisfactory interpersonal relationships with peers and
> teachers, (c) inappropriate types of behavior or feelings under normal
> circumstances, (d) a general pervasive mood of unhappiness or depression
> and (e) a tendency to develop physical symptoms or fears associated with
> personal or school problems. Emotional disturbance includes
> schizophrenia. (DoED, 2020).

These criteria have been criticized for being vague and subjective (Kavale et al., 2004; Hanchon & Allen, 2018). For example, educators must decide how long is a "long period of time" and when a child's behavior is significant enough to be "a marked degree."   Kavale et al. (2004) point out "impaired learning" could be academic learning or social learning, and educators may struggle to judge when interpersonal relationships are "satisfactory."

Despite guidance from the IDEA (2004), state education departments may use different administrative terms to describe the condition of ED. Across the 50 states in the U.S., Wery and Cullinan (2011) discovered 17 different terms used to describe ED, including disorder of emotion/behavior, interpersonal problems, learning/achievement problem, and deviation from the norm. Wery and Cullinan also found the definition of ED in 43 states contained all five characteristics listed in IDEA (2004). Terminology does matter, though. Olympia et al. (2004) cautioned that states' differences in educational philosophies, terminology and assessment procedures could affect the number of children identified who need special education services.

From a practical standpoint, many educators and school psychologists use the criteria from IDEA (2004) to determine if a child has ED and is therefore eligible for special education services or accommodations (Wery & Cullinan, 2011). Eligibility is mainly based on impaired academic performance (Kavale et al., 2004). The specific cause of the condition is not as important as the impact of the behaviors on a child's learning (Zionts et al., 2016). The intensity, duration and level of learning impairment related to the behaviors are stressed in the school environment (Zionts et al., 2016, p. 5).

Emotional Disturbance in Healthcare Literature. Educators are provided a definition and list of observable characteristics in federal law, but healthcare providers do not have such clear guidelines. Medical and psychiatric literature tends to use the

term "serious emotional disturbance" (SED) more often than "emotional disturbance."

The definition of SED adopted by the Diagnostic and Statistical Manual of Mental

Disorders (DSM-5) was originally published in the Federal Register in 1992 (CBHSQ,

2016). The Federal Register defined "serious emotional disturbance" as:

> People from birth up to age 18 who currently or at any time during the past year have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet the diagnostic criteria specified within the *Diagnostic and Statistical Manual of Mental Disorders*, Third Edition, that resulted in functional impairment, which substantially interferes with or limits the child's role or functioning in family, school, or community activities. (CBHSQ, 2016, p. 1).

The DSM-5 has never defined SED as a specific, unique condition, but considers SED as

an extension of an accompanying psychiatric condition, such as Attention Deficit Disorder or

Oppositional Defiant Disorder (CBHSQ, 2016). The most recent DSM-5 TR does not list any

upcoming changes regarding the classification of SED or emotional disturbance.

An important distinction between the terms "emotional disturbance" and "serious

emotional disturbance" is the presence of a required psychiatric diagnosis. The DSM-5

guidelines indicate a "DSM-based mental disorder" such as those listed above *must be present* to

form the basis for a diagnosis of Serious Emotional Disorder (CBHSQ, 2016). On the other hand,

the IDEA (2004) classification for emotional disturbance does not include criteria for a

concurrent mental illness.

Research of issues related to ED hampered by the lack of a single, clear definition of

emotional disturbance. Definition differences exist between education and healthcare literature.

There have been no updates to the definition of "emotional disturbance" since the IDEA of 1997,

nor to the definition of "serious emotional disturbance" in the DSM-5 since the Federal Register

of 1992. Subjective verbiage within the definition "emotional disturbance" creates problems when identifying children with this condition, as well as for researchers, healthcare professionals and education professionals (Hanchon & Allen, 2018; Kavale et al., 2004). Kavale et al. (2004) point out the lack of a singular definition means "schools and mental health agencies…operate in a parallel rather than a cooperative…manner," (p. 49). This study utilized the term "emotional disturbance" for consistency and familiarity within the educational system.

Prevalence of Emotional Disturbance in Children

At least 8.3 million (16%) school-aged children have emotional or behavioral issues that are severe enough for parents to proactively seek assistance from a healthcare provider or educator (Council for Exceptional Children, 2020; Simpson et al., 2005). Determining how many of these children have emotional disturbance is more difficult. Inconsistent diagnostic criteria and variations of ED definitions create barriers to researching the true prevalence of childhood ED. Prevalence of childhood ED can be estimated by reviewing data from government reports regarding special education in public schools or by reviewing healthcare research. Each method has unique caveats which impacts the statistical accuracy and are presented here.

Prevalence per the U.S. Department of Education. The U.S. Department of Education (DoED) has agencies which track children identified as having ED. During the 2021-2022 school year, 7.3 million school aged children (9.8%) were identified as disabled and received special education services under IDEA (National Center for Education Statistics, 2023). Of these 7.3 million children, 4.6% were identified as having Emotional Disturbance (Office of Special Education Programs [OSEP], 2023). This equates to an estimated 0.7% - or 335,800 – of U.S. school children who have emotional disturbance.

There are several caveats which must be considered regarding the DoED statistics. The Office of Special Education Programs only monitor children who are 1) attending public schools, 2) enrolled in kindergarten through age 21, 3) receiving special education services and 4) are identified as having emotional disturbance (OSEP, 2023). In the U.S., administration of education is handled at the state level, and the definition and subsequent identification rates of ED vary widely between states. As discussed above, Wery and Cullinan (2011) found 17 different terms used at the state level to describe ED, including "disorder of emotion or behavior," "interpersonal problems," and "deviation from the norm." Across individual states, the percentage of children receiving special education services due to emotional disturbance ranged from 1.65% to 17.35% (DoED, 2020).

Political or policy factors can significantly impact the accuracy of statistics tracked by education agencies. In 2004, Texas' state legislature and the Texas Education Agency (TEA) imposed a cap on the number of students needing special education (SPED) services in schools (Mandel & Pendola, 2021). The TEA created a negative performance indicator for any school district with more than 8.5% of students receiving SPED services (Mandel & Pendola, 2021). The negative performance indicator triggered increased school audits, administrative monitoring and reduced the school districts' overall state funding. In 2004, 11.6% of Texas students qualified for SPED, but in 2016, only 8.6% of Texas students were SPED qualified (Mandel & Pendola, 2021). The practice triggered protests from parents whose children were denied SPED services by their school district, sparking an investigation by the U.S. Department of Education (DoED) (Swaby, 2018). In January 2018, the DoED found Texas violated federal law by failing to properly ensure students with disabilities were identified and failing to provide these students

with an appropriate public education (Swaby, 2018). In response to the investigation, Texas' state legislature passed a law which stopped the practice in May 2017.

There are ramifications from the years Texas' policy was enforced. Although Texas' most recent special education student statistics are closer to those of states with comparable-sized populations, there is still a gap. In the 2021-22 school year, 11.7% of Texas school children received special education services, compared with 13.1% in California, 14.8% in Florida, and 20.5% in New York (TEA, 2023). There is no way to go back for the children who did not receive needed SPED services between 2004 and 2017, and the ramifications of Texas' 2004 actions continue to impact both educators and children in Texas (Mandel & Pendola, 2018). Texas' example provides stark evidence that not all children with a disability will be identified as such or receive special education services. Therefore, the actual incidence of emotional disturbance in children may be higher than reported by the U.S. Department of Education.

Prevalence per Healthcare Research. Healthcare, psychiatric, and social science literature also demonstrate challenges when reporting the prevalence of children with ED. As discussed above, healthcare literature uses the term "serious emotional disturbance" more often than "emotional disturbance." Two recent meta-analyses attempted to measure the prevalence of "serious emotional disturbance" (SED) in children (Ringeisen et al., 2017; Williams et al., 2018). Ringeisen et al.'s meta-analysis of five large epidemiological studies concluded between 4% and 11% of U.S. children had serious emotional disturbance (2017). Williams et al.'s meta-analysis of 423 articles concluded approximately 10% of U.S. children younger than 19 have SED (2018).

Both Ringeisen et al. (2017) and Williams et al. (2018) noted the analyzed studies had significant variations in methodology. Although the individual study samples were large (n= 263

to N= 18,865), the age range of the children included in the studies was inconsistent. Williams et al. found studies with sample age ranges from 2-5 years old and as wide as 9-18 years old. Ringeisen et al. found studies with age ranges from 13-17 years old and as wide as 4-17 years old. Both groups of researchers noted studies did not consistently utilize diagnostic criteria of "serious emotional disturbance" from the DSM-5 or any consistent source (Ringeisen et al., 2017; Williams et al, 2018). These results were similar to those found in a secondary analysis of the National Comorbidity Survey-Adolescent Supplement by Merikangas et al. (2010). Merikangas et al.'s secondary analysis of more than 10,000 adolescents surveyed found that 19% of these adolescents met diagnostic criteria for behavioral disorders, and 14% met criteria for "mood disorders" (p. 980). The investigations of Merikangas et al., Ringeisen et al., and Williams et al. found much higher prevalence rates of childhood ED than government educational agencies have reported.

Due to the variation in epidemiological methods, Ringeisen et al. (2017) concluded no study could accurately estimate the prevalence of serious emotional disturbance in children on either a state or national level. The most recent SPED statistics estimate currently 335,800 (0.7%) school children have ED (OSEP, 2023). However, if 10% of U.S. children have ED as estimated by the findings of Ringeisen et al. (2017) and Williams et al. (2018), there would be *five million* school children with ED (National Center for Education Statistics, 2023; U.S. Census Bureau, 2021).

Literature regarding Parents of Children with Emotional Disturbance

Literature Review Process

This present study focused on exploring the phenomenon through the experiences of parents raising children with ED, rather than the children themselves. Multiple strategies were

employed to conduct a thorough review of the literature. In addition, the variety of terms used to

identify emotional disturbance created barriers to finding literature focused on emotional

disturbance rather than autism or other developmental conditions. The databases of PubMed,

CINAHL, ERIC, OVID and PyschINFO were searched using the terms "parents," "experiences,"

and children with "emotional disturbance," "emotional disorder," "behavioral disorder," and

"emotional/behavioral disorder,." This researcher also searched the body of literature using

"citation chasing," or reviewing the citations of relevant articles for additional information. More

than 900 abstracts were reviewed.

Initial search results listed a preponderance of articles focused on risk factors which

increased the risk of ED in children and were strongly focused on parents and the home

environment. Within this literature, there was extensive information indicating broad institutional

stigma against parents of children with ED or other disabilities. Additional literature was found

which provided evidence of the strong influence parents have upon a child's emotional state.

Although this research was conducted to benefit the children in the study, information regarding

the parents' experiences was discussed indirectly. However, literature which focused on the

parents' or the families' experiences, rather than the children's experiences, was difficult to find.

Using the process described above, a search of the literature identified 10 research

articles which focused on the experiences of parents or families of children with "emotional

disturbance" or "emotional disorder" which were published between 2003 – 2022. When the

terms "serious emotional disorder" and "explosive anger disorder" were included in the literature

search, four additional articles were identified published between 2003 - 2022. Due to the

sparsity of research focused on families' experiences when raising children with ED, the search

for literature was expanded. Additional literature was identified that examined the experiences of

families of children with disabilities. This literature included emotional disturbance amongst other disabilities, and either identified ED within the sample description or described behaviors and conditions similar to ED. Lastly, the search was expanded to include qualitative literature exploring the experiences of parents of children with any type of mental illness. These studies did not mention ED specifically, but revealed rich data of parents' challenges raising a child with unpredictable mental illnesses.

The relevant literature is summarized below. First, literature is presented which uncovers the institutionalized stigma toward parents of children with ED and how this stigma has impacted the working relationships between professionals and parents. Next, the review presents literature which demonstrates the powerful influence parents have over children with ED. Lastly, the review delves into the studies which explored the experiences of parents of children with ED and summarizes the knowledge gap that still remains in the body of literature.

Institutional Mental Health Stigma

There is evidence of institutional stigma from healthcare providers, educational experts, and policy makers toward parents of children with emotional or behavioral issues (Cohen et al., 1993; Jivanjee et al., 2007; Hinshaw, 2005; Resch et al., 2010; Leitch et al., 2019). Parents fear being blamed for their child's actions, which may cause parents to delay seeking professional assistance or evaluation for their child (Hinshaw, 2005). Evidence of this stigma was found in multiple realms of published research, including psychiatric research of risk factors for ED, state policies for obtaining supportive care, pediatric screening practices and educational research.

Stigma: Parents as Risk Factors. Throughout the 20th century, the predominant opinion in mental health research was childhood mental illness was directly caused by faulty parenting (Hinshaw, 2005). Researchers investigating risk factors for ED seem to reinforce the

predominant idea that parents are the cause of all childhood mental illness (Hinshaw, 2005). Emotional disturbance has been linked to a child's exposure to trauma such as war (Khamis, 2015), immigration/forced separation (Delgado et al., 2021), sexual abuse (Hebert et al., 2020), negative parenting styles or parental threats (Trent et al., 2019), lack of parental warmth/parental rejection (Okado & Bierman, 2015), or authoritarian parenting (Gulley et al., 2014). Even if a child has not been exposed to these conditions, researchers have linked parents' exposure during the parents' own childhood as possible risks to their child developing ED. These risks include a parent's personal mental illness (Melchior et al., 2012; Tabachnick et al., 2022) or parents' exposure to trauma, abuse, or violence (Powers et al., 2022; Schickedanz et al., 2018; Warmingham et al., 2020). Although a recent longitudinal study of more than 12,000 British mothers did not find a strong association between parenting styles and emotional problems in their children (Culpin et al., 2020), these potential risk factors identified in the literature may make parents of children with ED reluctant to seek help, fearing they will be accused of poor parenting.

Stigma from Policy. The stigma toward parents of children with ED or other disabilities extends into legal policies and procedures. A 1993 review of U.S. regulations found 28 states (out of 45 surveyed) had at least one state agency which required parents *to legally relinquish custody of their child* for their child to be eligible to receive state funded healthcare or educational services (Cohen et al., 1993). The state of Georgia required a child be a ward of the state to qualify for *any* type of state-funded care (Cohen et al., 1993). In the 28 states with these policies, parents' options to qualify for state funded supportive care were harsh. To receive state services, parents' options were: 1) voluntarily relinquish custody of their child, 2) be declared an unfit parent, or 3) bring criminal charges against their child (Cohen et al., 1993). The impacts of

parents and siblings losing a family member, feelings of parental failure, and child's fear of abandonment were viewed by some courts and policy makers as non-significant. In the New York class action case of *Joyner v Dumpson* (1983), the circuit court declared the transfer of custody of the child to the state had only an "incidental effect on the family life" and stressed the "voluntary" choice of parents to utilize state programs (Cohen et al., 1993, p. 126). Fear of losing one's child is a powerful incentive to delay seeking help.

      Stigma from Experts. Even interventions seeking to improve community collaboration uncovered judgement and stigma directed toward parents from mental health providers and educators. Potter (2010) conducted a qualitative study exploring mental health collaborative groups. The groups partnered community lay persons with healthcare, juvenile justice, and educational professionals to plan local children's mental health policy (Potter, 2010). Participants from each representative group revealed although professionals acknowledged community parents added a realistic perspective to the projects, professionals were also frustrated that the "wrong" type of parents were invited to participate (Potter, 2010, p. 1708). Examples of the "wrong type of parent" included parents "only out to help their own child," parents with "personal issues," and that the parent has the "same mental health issue as their child," (Potter, 2010, p. 1708). Potter concluded the professionals' view of the benefits of having community parents involved in the project was "more rhetoric than reality," (p. 1710). This negative perspective is highly detrimental. Children are not simply "little adults," and programs designed to support adults with mental health problems (and their families) are not appropriate for children with mental health problems (de Voursney & Huang, 2016; Pollio et al., 2006). When interacting with professionals for their child, parents consider honesty, a non-judgmental attitude, support,

and inclusion in decision-making as the professionals' most important qualities (Friesen et al., 1992).

Historical stigma is not the only barrier parents of children with emotional or behavioral issues face. Many parents of children with ED reach out to their child's pediatrician long before they start receiving school reports of behavioral problems (Council for Exceptional Children, 2020). Parents reported pediatricians do not listen to them and getting a diagnosis for their child's problem was very frustrating (Kelson et al., 2005). Weitzman et al. (2015) found only 13% of pediatricians felt confident in their own ability to screen and detect these types of emotional disorders. Eligibility policies for healthcare coverage, mental health programs and educational services are based on a child's specific diagnosis; with inconsistent definitions, eligibility and access to programs are also inconsistent (de Voursney & Huang, 2016; Olympia et al., 2004). When a child does not have a diagnosis, the child cannot qualify for help (Kelson et al., 2005). Most parents of children with emotional or behavioral problems found interacting with the healthcare system frustrating and unhelpful (Kelson et al., 2005; Resch et al., 2010).

In schools, parents of children with ED reported their input was not valued in the educational planning process (Jivanjee et al., 2007). Jivanjee et al. (2007) found the parents who were successful in influencing their child's special education services each had personal or unusual expertise, such as being a disability attorney or special education expert working in the same school district. Other parents discovered their child's educational rights and options by "luck" or by "fighting" (Kelson et al., 2005, p. 6). Although 70% - 80% of parents with kindergarten-aged children with ED are involved with their child's school, this number falls to 40% of parents of these children once the child reaches secondary school (NCSER, 2017). Unfortunately, the NCSER study did not investigate why so many parents withdrew from school

involvement. Given that family functioning impacts a child's classroom behavior (Stoutjesdijk et al., 2016), it is important that educators understand parents' needs and perspectives to have a strong, effective working relationship with parents.

Parents' difficulty collaborating with educators or healthcare professionals directly conflicts with the goals of the 2003 New Freedom Commission on Mental Health, which advocated for greater focus on family involvement in children's mental health (Potter, 2010). Several studies discuss parents' desire for the ability to make shared decisions about their children (Friesen et al., 1992; Lipstein et al., 2016; Potter, 2010). Furthermore, several studies have demonstrated the strong influence parents have over their child's emotional regulation, even with children who have emotional disturbance. These studies are presented below.

Parental Influence over Children with Emotional Disturbance

The influence of parents and parental bond upon a child's emotional self-regulation are well documented (Barbot et al., 2016; Johnson et al., 2022; Lee et al., 2013; Manczak et al., 2019; Paley & Hajal, 2022; Welch et al., 2006). Parental stress, negative parental emotions and day-to-day interactions greatly affect a child's emotional self-regulation (Berenguer et al., 2021; Li et al., 2016; Stoutjesdijk et al., 2016; van Eldik et al., 2017). When observing the behaviors of a child with ED, it might be assumed the child is insensitive to other peoples' reactions or influence (O'Conner et al, 2016). However, observational research demonstrated the presence of callous or ego-centric behaviors in children did not correlate to decreased sensitivity to parental influence (O'Connor et al., 2016). Parental influence can leverage powerful positive outcomes. Even prolonged parental embraces have been shown to impact stress adaptation and improved behaviors in children with behavioral disorders (Welch et al., 2006). In addition, DeVet et. al

(2003) found children with close maternal relationships had improved results from mental health treatment.

The inter-connectedness of the parent-child bond, childhood emotional regulation and effectiveness of mental health care demonstrates the importance of a family-centric approach to caring for children with emotional disturbance or serious behavioral problems. Higher levels of collaboration between schools and community support systems yielded positive effects on functioning and lower severity of behavioral problems in children with ED (Lee et al., 2013). Community-based treatment for children with ED indicates family members' knowledge and collaboration are required to ensure a systemic assessment of the child (Barbot et al., 2016). Many states in the U.S. utilize a framework of "wraparound care" to coordinate and deliver services to children with ED (Bruns et al., 2015; Chitiyo, 2014; Olson et al., 2021; Sather & Bruns, 2016). "Wraparound care" is an intensive team-based process to plan, implement and monitor the individual child's care plan (Olson et al., 2021). Although true fidelity to the multi-discipline and family integrative team concept to varies widely (Bruns et al., 2015; Olson et al., 2021; Sather & Bruns, 2016), a meta-analysis of 17 wraparound research studies suggested the care concept did positively correlate with improved outcomes, increased maintenance of the child within their homes, and lower service costs (Olson et al., 2021).

Various parenting techniques have been studied to improve the behavior of children with ED (Johns & Levy, 2013; Helander et al., 2018; Mayoral et al., 2020; Sourander et al., 2016; Williamson & Ennals, 2020; Wynne et al., 2016). The primary purpose of these studies was to improve the child's behavior, rather than assisting the child's family, but details regarding the parents' experiences were indirectly discussed. All of these studies determined that it was more effective to utilize parent-child interventions and education plus training compared with child

only interventions or education alone. Along with improved behaviors, some researchers incidentally found improved parental mental health (Wynne et al., 2016) or increased parent-child bond (Johns & Levy, 2013).

The evidence regarding parental influence on children's emotional regulation, as well as within interventional research, provides additional rationale to understand what parents of children with ED perceive as their greatest needs. Research which focused on the experiences and perceptions of parents raising children was very limited. This research is explored in depth below.

Experiences of Parents of Children with Emotional Disturbance

Using the literature search process described above, the researcher identified 14 studies published between 2003 and 2022 that focused on the experiences of parents or families living with a child who has ED. Nine of the 14 articles used quantitative methods to examine parents' stress levels (Duppong Hurley et al., 2017; Green, 2016; Green et al., 2019; Herbell et al., 2020; Kutash et al., 2011; Taylor-Richardson et al., 2006; Wynne et al., 2016) or perceived barriers to parental participation at school (Jivanjee et al., 2007; Kruzich et al., 2003). Four of these publications were from a single randomized clinical trial (Duppong Hurley et al., 2017; Green, 2016; Green et al., 2019; Kutash et al., 2011). The remaining five studies included two qualitative dissertations exploring special education (Gonzales, 2014; Snyder, 2012) and a qualitative dissertation which explored families and children with ED housed within the juvenile justice system (Kerbs, 2008). One researcher introduced pilot parental support program (Pollio et al., 2005). Finally, Tahhan et al. (2010) used Classic Grounded Theory to explore parents' experiences when their child with ED required residential care.

Barriers to Parents' School Participation. Parents of children with ED perceived significant barriers which impact parents' participation at their child's school and in their outpatient mental health care (Jivanjee et al., 2007; Kruzich et al., 2003). Parents perceived receiving a "teacher knows best" message coupled with a lack of understanding of certain legal or education terms used during special education meetings (Jivanjee et al., 2007). Parents were frustrated when they observed teachers' lack of mental health knowledge and inconsistent implementation of their child's educational accommodations (Jivanjee et al., 2007). Although parents noted tangible barriers to mental health care such as cost or lack of transportation, parents also experienced negative attitudes and a lack of communication from mental health care staff (Kruzich et al., 2003). Barriers such as those found by Jivanjee et al. (2007) and Kruzich et al. (2003) can lead to parents' disengagement with school and healthcare professionals.

Factors which Impact Parents' Stress and Strain. Several researchers examined the "strain" experienced by parents of children with ED and explored potential interventions to help caregivers (Duppong Hurley et al., 2017; Green et al. 2019; Green, 2016; Herbell et al., 2020; Kutash et al., 2011; Taylor-Richardson et al., 2006; Wynne et al., 2016). Kutash et al. (2011) conducted a proof-of-concept study to determine if peer support would increase parent engagement in school and perhaps lead to improved academic performance in children with ED. "Veteran parents" received training and offered weekly calls to other parents of children with ED attending middle school. Duppong Hurley et al. (2017) continued research of the program in a randomized controlled trial. Duppong Hurley et al. noted increased parental involvement improves children's educational outcomes, but families of children with ED are less likely to be involved in school than children with other types of disabilities. Duppong Hurley et al. investigated if parents of children with ED with higher levels of strain are more likely to utilize

the peer-to-peer support program than parents with lower levels of strain. A questionnaire measured baseline levels of strain and data was gathered regarding the frequency and length of telephone support calls in the peer support program. Parents with higher levels of strain utilized the program more often than parents with lower levels of strain (p = 0.003). However, the actual difference in calls per month was 2.3 versus 1.52, or four to seven additional calls over the academic year (Duppong Hurley et al, 2017). The sample distribution (n= 52) was atypical: 58% were Black, 64% were below the poverty line, and 87% of the children received free school lunches (Duppong Hurley et al., 2017). The study was not designed to examine participants' rationale for using or not using the program.

Two studies investigated potential factors that may have affected the level of self-reported caregiver strain (Green, 2016; Taylor-Richardson et al., 2006). "Caregiver strain" was defined as "the demands, responsibilities, difficulties, and negative psychic consequences of caring for a relative with special needs," (Taylor-Richardson, et al., 2006, p. 157). Green (2016) conducted her dissertation research as part of the above Duppong Hurley et al. (2017) study, searching for factors that correlated with utilization of school-based mental health services or increased strain in parents of children with ED. Taylor-Richardson et al. (2006) conducted a secondary analysis of two previously published studies of military families and Medicaid families with children who have ED. Both investigations found higher levels of caregiver strain in parent caregivers and those caring for male children with ED when compared with non-parental caregivers or those caring for female children with ED (Green, 2016; Taylor-Richardson et al., 2006). Furthermore, Green found non-Hispanic Black parents reported lower levels of caregiver strain when compared with non-Hispanic White parents or Hispanic parents. Green did not find a correlation between increased caregiver strain and utilization of school-based mental

health services. Taylor-Richardson et al. (2006) did not report on any differences due to racial factors, but investigated different types of strain, including financial, subjective/emotional, and isolation strain. Non-parental caregivers of ED children reported lower levels of guilt, anger and sadness compared to the parents of ED children (Taylor-Richardson et al., 2006). Medicaid caregivers reported higher financial strain and social isolation than military caregivers reported, but military caregivers reported higher levels of unhappiness, embarrassment, and overall family toll (Taylor-Richardson et al., 2006).

In another subset of the peer-to-peer support trial, Green et al. (2019) examined the ability to measure a new concept, "parent activation." Parent activation was based on "patient activation," defined as a patient's "willingness to manage their health…and having the knowledge, skills and confidence to do so," (Green et al., 2019, p. 306). With 156 parents, Green et al. initially validated a new empowerment scale to measure parents' confidence and willingness to manage their child's ED. Although the scale generated positive results, Green et al. noted the new scale needs further validation with a larger sample.

Reducing Strain with Resilience. While the above studies examined the toll of parental stress, three other studies measured the protective concepts of family resilience and parental bonds in families raising children with ED. Herbell et al. (2020) examined family "resilience" and child "flourishment" through a secondary analysis of the 2016-2017 National Survey of Children's Health. The study sought to identify factors which promoted resilience in families raising children with emotional or behavioral disorders. According to Herbell et al., family resilience promotes child flourishment, and parental coping is positively associated with child flourishment. However, despite 66.5% of families reporting resilience, only 6.3% of children with ED were rated as flourishing. An Irish study by Wynne et al. (2016) found parent stress,

child goal attainment and general family function improved after a parent training course.

Another study showed how the quality of the maternal – child bond positively correlated with the

efficacy of mental health treatment in children with ED (DeVet et al., 2003). In addition, the

strength of the maternal-child bond did not decrease based on the child's behaviors or the

mothers' personal distress (DeVet et al., 2003). All three studies demonstrated that parents and

families must function well for the child with ED to have the best opportunity to improve.

The above quantitative studies all reported increased strain in parents of children with ED

(Duppong Hurley et al., 2017; Jivanjee et al., 2007; Kutash et al., 2011), or discovered factors

which affect stress levels experienced by parents and caregivers of children with ED (DeVet et

al., 2003; Green, 2016; Green et al., 2019; Herbell et al., 2020; Taylor-Richardson et al., 2006).

Due to the quantitative research design, participants are inherently limited to a range of pre-set

responses. The questionnaire used by Herbell et al. (2020) contained single items to assess

participants' perceptions of "coping" and "support," which may not fully demonstrate the range

of participants' perceptions. Research on caregiver strain indicated the high stress levels of

caregivers of children with ED, but additional research is needed to understand the nuances of

parents' needs and challenges.

Qualitative Research Regarding Parents of Children with ED. Qualitative research

can provide rich details regarding the nuances of person's experiences and contextual

background (Erlandson et al., 1993). There was extremely limited qualitative literature regarding

the parents of children with ED. Five qualitative publications were discovered published between

2003 and 2022, but none of the studies focused on the home environment. Two dissertation

studies examined the perceptions of parents as experienced during the special education

proceedings for their child with ED (Gonzales, 2014; Snyder, 2012). Both Gonzales (2014) and

Snyder (2012) found parents desired to be active partners in their child's special education planning, but both studies were strictly limited to the parents' experiences as they related to special education planning. Kerbs (2008) conducted a dissertation research study which examined family participation in the treatment of children with serious emotional disorder who are in the juvenile justice system. Kerbs found that families did not always connect their own participation to the child's progress or lack of progress, but families did note participation helped improve their personal functioning. Kerbs also found that families with higher income correlated with increased participation and an overall decrease in the child's criminal activity.

Two qualitative studies were identified which had indirect connections to life experiences of families raising a child with ED (Pollio et al., 2005; Tahhan et al., 2010). Pollio et al. (2005) conducted a pilot school-based education and support program for parents of children with ED. The program consisted of eight to twelve group sessions, consisting of presentations of relevant educational topics, coping methods, and group support time. Despite high approval ratings by participants, there was no indication that the program was continued (Pollio et al., 2005).

The final qualitative study provided evidence of the seriousness of parents' struggles at home from their child's emotional disturbance. Tahhan et al. (2010) used Grounded Theory to explore the experiences of Canadian mothers with a child who required residential placement due to their ED. Although the study focused solely on children who required residential care, participants described some of the child's problems at home and in school (Tahhan et al., 2010). Mothers reported being isolated physically, emotionally, and socially, because friends and family were uncomfortable being around the child (Tahhan et al., 2010). The severity of the child's explosions caused mothers to fear for their child's safety and that their child might harm their siblings or the mother herself (Tahhan et al., 2010). Even when the child's treatment was

considered "less successful" by the mental healthcare team, mothers viewed the placement positively (Tahhan et al., 2010). Regardless of treatment outcome, mothers reported the child's time in residential care allowed mothers to spend quality time with siblings and relieve their own isolation (Tahhan et al., 2010).

The majority of prior research focused specifically on parents of children with ED has been quantitative measurements of stress and strain (Herbell et al., 2020; Taylor-Richardson et al., 2006) or interventional research to increase parental engagement at school (Jivanjee et al., 2007). Only one qualitative study focused on parents of children with ED (Tahhan et al., 2010), but this study focused on children with ED in residential care. Tahhan et al.'s (2010) findings did demonstrate that parents face serious problems at home which affect the entire family.

Experiences of Parents of Children with Disabilities Including ED

As stated earlier, the literature search was expanded to include studies which focused on families of children with disabilities and either listed or described "emotional disturbance" within the sample characteristics. Literature was excluded if 1) the sample characteristics only listed physical or developmental disabilities or 2) was published prior to 2000. Six articles were identified which investigated the experiences of parents of children with disabilities, including ED and behavioral disorders.

Parents' Experience with Stress. Mothers and fathers reported considerably higher parenting stress raising a child with Attention Deficit Hyperactivity Disorder (ADHD) compared with other parents, but mothers' stress was higher than fathers (Li et al., 2016; Wiener et al., 2016). A Chinese study (Li et al., 2016) and a Canadian study (Wiener et al., 2016) compared stress and quality of life factors of parents raising children with ADHD with a control group of parents. Li et al. (2016) reported between 40 and 60% of the children with ADHD also had

Oppositional Defiant Disorder, which meant these children "violated social rules" often (p. 128).

Mothers "committed their entire lives" to caring for their child, leading to sleep problems,

isolation, and health issues (Wiener et al, 2016, p. 562). Parents felt unfulfilled, were socially

alienated, and suffered more marital difficulties compared with parents raising children without

ADHD (Li et al., 2016; Wiener et al., 2016). Both studies found mothers reported higher levels

of stress and in more domains of life (social isolation, feeling incompetent) than fathers did, but

neither study explained this finding. Wiener et al. (2016) hypothesized mothers may conflict with

their child more often due to more responsibility for the child's activities, but stated the

differences between parents should be researched further.

     Other researchers found parents want to participate in shared decision making with their

child's teachers and healthcare professionals, but face barriers from these professionals when

trying to participate (Lipstein et al., 2016; Malsch et al., 2011). Parents of children "at risk for

serious emotional/behavioral disorders" were interviewed as their child entered kindergarten

(Malsch et al., 2011). Parents desired increased communication, emotional support, and

education so they may be their child's advocate at school (Malsch et al., 2011). Lipstein et al.

(2016) examined shared decision making between healthcare providers and parents of children

with ADHD, children with autism, or children with asthma. Parents of children with ADHD or

children with autism were significantly less likely to report shared decision making compared

with parents of children with asthma, indicating a potential stigma from healthcare providers

(Lipstein et al., 2016).

     Exploring Challenges through Focus Groups. Two researchers conducted focus groups

to explore parents' challenges regarding their child's ADHD (Leitch et al., 2019) or disabilities

including "mental" disabilities (Resch et al. (2010). Challenges stemmed from their child's

behavior, unmet needs for support, and social stigma (Leitch et al., 2019; Resch et al., 2010).

Parents described their child having an "ADHD rampage," and their child's meltdowns were

"like a volcano going off" (Leitch et al., 2019, p. 4). Parents and children experienced stigma

from the school and the community (Leitch et al., 2019; Resch et al., 2010). Parents reported

getting a reputation as being "trouble parents," (Resch et al., 2010, p. 144) or suffered "political

backlash" (Leitch et al., 2019, p.6) when they advocated for their child at school. Parents were

also judged by society: "I've been told I'm a lazy parent because my kids are highly medicated.

If I learned to control my kids there wouldn't be a problem," (Leitch et al., 2019, p. 6). Parents

were even told to "belt it [ADHD] out of them" (Leitch et al., 2019, p. 6). The children

themselves faced rejection by the school or community when trying to get on a sports team or

included in an event. "There's a lot of fear…The other people are afraid of our kids," (Resch et

al., 2010, p. 144).

Parents in both studies identified that the unpredictability of raising a child with a

disability negatively affected the entire family. This impact included on feelings of guilt because

the sibling "gets forgotten," and increased tension on the parents' relationship at home (Leitch et

al., 2019, p. 6). Parents need support services "apart from coffee and Valium" (Leitch et al.,

2019, p. 6). The findings pointed to problems due to the unpredictability of the child's issues and

community stigma directed toward their child and the parents (Leitch et al., 2019; Resch et al.,

2010).

Interventions to Aid Parents. Two studies investigated methods to aid parents and

families of children with ED or similar disabilities, rather than directly aiding the child (Chua &

Shorey, 2022; Kim-Godwin et al., 2020). Chua and Shorey (2022) conducted a systematic review

of mindfulness-based therapy and acceptance commitment-based therapy demonstrated that both

therapies successfully decreased parental stress, anxiety, and depression in parents of children with disabilities including ED. In Kim-Godwin et al.'s (2020) study, gratitude journaling was taught to parents of children with parents of children with "emotional or behavioral issues," which included several mental health conditions as well as substance abuse. Kim-Godwin et al. reported journaling improved parents' emotional well-being as well as forced parents to engage in self-care by the detaching from stressors to complete the journaling itself.

Experiences of Parents of Children with Any Mental Illness

Lastly, additional qualitative research explored the impact on parents caring for their child (or their adult-child) with a mental illness such as anxiety, mood disorders and schizophrenia (Johannson et al., 2010; Kelson et al., 2005; Klages et al., 2020). These studies did not specifically mention emotional disturbance (ED). However, the studies provided a vivid description of the parents' emotional responses, including constant worry, isolation, living in uncertainty, and living in fear (Johannson et al., 2010; Kelson et al., 2005; Klages et al., 2020).

Worry and fear were common themes among these studies. Mothers had to permanently alter their lives to care for their adult child, therefore their adult child was "always on my mind" and mothers were "living with an emotional burden" (Johannson et al., 2010, p. 694). In Klages et al.'s (2020) study, all the mothers concurred that having an adult child with mental illness meant "living with fear and distress" (p. 1809). Parents' fears included fears of the future, fear of community stigma, fear their child will never manage without the parents' care, and fear for their child's safety (Johannson et al., 2010; Kelson et al., 2005; Klages et al., 2020). In addition of fearing for their child, mothers expressed fear *of* their child and potentially being assaulted by them (Klages et al., 2020).

Participants reported how the child's behavior impacts the rest of the family, including things siblings receiving less personal attention from parents and an inability to enjoy spontaneous family activities (Johannson et al., 2010; Kelson et al., 2005). Community stigma was also common. Parents noted when children without a visible physical disability misbehaved, the parent would be blamed for not "controlling him properly" (Kelson et al., 2005, p. 6).

Unlike the much of the literature, these studies also explored how caregivers attempted to resolve the emotional toll of caring for a child with a mental illness. Mothers of adult children with schizophrenia coped by "rebalancing" their fears and uncertainty with advocacy and resolution (Klages et al., 2020, p. 1811). Mothers found "light in the darkness" by taking great pleasure in small moments and living "in the present," (Johansson et al., 2010, p. 697). Although "feeling better" took "several years," most parents noted their circumstances and coping skills improved as the child grew older (Kelson et al., 2005, p. 7). Out of 26 participants, two caregivers never experienced any improvement. The participants recently experienced marital and death, and the subsequent isolation and poor health were likely factors (Kelson et al., 2005).

Summary of Current State of Literature

Parents of children with ED face immense challenges raising their child due to their child's reactivity and high risk of legal problems, school dropout and employment problems (Harrison et al., 2013). Parents are generally aware when their child is not meeting developmental expectations (Simpson et al., 2005). Parents often seek advice for their child's emotional or behavioral issues (Council for Exceptional Children, 2020), but parents encounter barriers and stigma from healthcare and educational professionals instead (Kelson et al., 2005; Leitch et al., 2019; Resch et al., 2010). There is considerable evidence of stigma toward parents of children with ED or other disabilities from healthcare providers (Potter, 2010), policy makers

(Cohen et al., 1993), educators (Jivanjee et al., 2007; Kelson et al., 2005) as well as society itself (Hinshaw, 2005). Stigma emanating from an institutional level is especially detrimental given the evidence of parents' strong influence to a child's development of self-regulation (Barbot et al., 2016; Johnson et al., 2022; Lee et al., 2013; Manczak et al., 2019).

There were very few studies that focused on the experiences and perceptions of the parents and families raising children with ED. Research examined the stress and factors which may impact stress levels as experienced by parents of children with ED (Duppong Hurley et al., 2017; Green, 2016; Herbell et al., 2020; Taylor-Richardson et al., 2006). Interventional or qualitative research has been conducted to increase parental engagement in schools (Gonzales, 2014; Jivanjee et al., 2007; Kutash et al., 2011; Pollio et al., 2005), but did not explore the home life of these parents. Studies which combined families of children with ED with families of children with other disabilities reported parents' struggles with stress, isolation, marital problems, and community stigma (Leitch et al., 2019; Li et al., 2016; Resch et al., 2010; Wiener et al., 2016). Parents of children with a mental illness report feeling stressed, worried, sad, frightened frustrated and socially stigmatized (Johannson et al., 2010; Klages et al., 2020.) Children with ED may require residential care for the safety of their siblings or parents (Tahhan et al., 2010). In Tahhan et al.'s (2010) study, mothers reported physical and social isolation because their friends and family were uncomfortable in their home, and the mothers could not leave their child alone, even to get groceries. Although Tahhan et al. explored parents' experiences with children who required residential placement, no additional qualitative information was found which explored the day-to-day parenting challenges which arise at home.

Current Gap in the Literature

The dearth of ED - specific research examining parents and families is unsurprising, given the lack of a singular definition for emotional disturbance and the lack of standardized criteria for identification. By using different terms such as "emotional disturbance," "serious emotional disturbance," or "behavioral disorder," with individually inconsistent definitions, healthcare research and educational research is created in tandem rather than in collaboration (Kavale et al., 2004). The above literature demonstrates parents of children with ED face very challenging situations. Presently no studies have been identified which provide an in-depth, narrative account of the experiences of parents of children with ED, their coping methods or how the parents manage the daily challenges which arise due to a child's ED.

Healthcare and educational professionals must understand parents' experiences at home, what parents perceive as their greatest needs and the strategies parents have already tried in order for professionals to effectively collaborate for the child's betterment (Lipkin et al., 2015). This present study seeks to provide data to reduce the current gap in the literature. This information can assist healthcare providers and educators who interact with children with ED so they may collaborate more effectively with the child's parents to help the child with ED.

Chapter Summary

This chapter provided the reader with an orientation of the phenomenon, emotional disturbance in children, as well as the current state of literature regarding parents raising children with ED. Currently, there is a lack of narrative data which explores parents' experiences while raising a child with ED at home. To address this lack of data, this study used naturalistic inquiry (Erlandson et al., 1993; Lincoln & Guba, 1985) explore the research question: "What are the parenting experiences of parents of children with emotional disturbance?" The study's findings should enhance understanding and provide insights into the lives of parents of children with ED

and their families, including how parents manage challenges related to raising a child with ED on a day-to-day basis. The study will also give a voice to the parents of these children, whose stories are often hidden due to isolation or social stigma. Potentially, the study findings could lead to more effective healthcare and educational support interventions for these parents, their families, and their children with ED.

The next chapter will include a discussion of the methodology and data analysis process used in the study. Chapter Four will present the demographic and qualitative data findings generated by the study. The study will conclude by presenting a discussion of the findings, including how the findings relate to the review of literature presented here, and implications for nursing practice.

CHAPTER 3: RESEARCH METHODOLGY

Chapter 3 describes the research design and methods which were used to conduct this research study. The chapter begins by describing the study's qualitative research framework, naturalistic inquiry. The techniques used for participant sampling, recruitment, data collection, data management and analysis will be described. Finally, the chapter will outline the methods used to demonstrate scientific rigor of the results.

Research Design

This study was conducted using Lincoln and Guba's naturalistic inquiry investigative framework as presented in *Naturalistic Inquiry,* (Lincoln & Guba, 1985) and described by Erlandson et al. (1993). The dearth of qualitative literature addressing the experiences of parents of children with emotional disturbance (ED) indicates this phenomenon is poorly understood, and an exploratory qualitative design is recommended (Morse & Field, 1995). Erlandson et al. (1993) describe naturalistic inquiry (NI) as a constructivist qualitative research methodology that strives to "see what is happening" (p.9) within a phenomenon that "begs for additional understanding" (p. 43).

The naturalistic inquiry research methodology was developed through sociology researchers such as Willems and Rausch (1969), Denzin (1971), and Guba (1978) (Schwandt, 2011). The theoretical basis for NI research was expanded upon in the text, *Naturalistic Inquiry*, by Lincoln and Guba (1985). In contrast to positivist research with hypotheses and predicted relationships between variables, an NI study begins with a phenomenon of interest, but the research design is quite fluid (Lincoln & Guba, 1985, p. 221-2). Lincoln and Guba rejected the idea of one discoverable "truth" in favor for multiple constructed truthful realities. Because no two persons have the exact same experience, no single reality can fully explain the phenomenon

(Erlandson et al., 1993). Naturalistic research emphasizes that context is key for understanding behavior (Carl & Ravitch, 2018).

An NI study can uncover important information about "special populations," such as people who are underrepresented, marginalized or stigmatized (Curry et al., 2009). Parents of children with mental disabilities face both marginalization and stigma due to pervasive societal stigmatization of mental illness (Bhurgra, 1989; Hernandez et al., 2016; Rabkin, 1974). In addition, previously published literature indicated parents of children with ED face significant challenges, including high levels of stress and strain (Duppong-Hurley et al., 2017; Taylor-Richardson et al., 2006). However, the literature did not provide the context of these parents' experiences. Interviewing marginalized persons empowers the participants to convey those things most important to them, versus assigning a scale rating of agreeance or dis-agreeance to a statement of the researcher's choosing. Given the uniqueness of the parenting journey for parents raising children with ED, utilizing a naturalistic design framework can aid to accurately portray the context of the participants' individual parenting realities.

The theoretical view of Lincoln and Guba's Naturalistic Inquiry (1985) guided each step of the research study process, including recruitment sampling, data collection, data analysis and provisions for scientific rigor. Although no study can describe the entirety of a phenomenon (Erlandson et al., 1993), a naturalistic study can expand the body of knowledge by describing a portion of what the participants experienced. By having the participants raising children with ED describe their own lives and perceptions of the parenting challenges related to ED, the data regarding the context surrounding parents' needs, problems, and management techniques will be enhanced.

Recruitment

Naturalistic inquiry research utilizes purposive recruitment and sampling by directly seeking participants with first-hand experience with the phenomenon. This purposive sampling strategy enhances recruitment of participants with "rich detail" about a phenomenon (Erlandson et al., 1993, p. 33). Prior to any recruitment procedures, the study and its procedures were reviewed and approved by the University of Texas Medical Branch Institutional Review Board (IRB) on March 2, 2023 (IRB # 23-0049; Appendix A). After IRB approval was obtained, recruitment was initiated by sharing the recruitment business card (Appendix B) and recruitment flyer (Appendix C) with the researcher's personal and professional network. This network included pediatricians, school nurses, special education advocates and individuals who encounter parents of children with ED. The recruitment flyer was posted on the researcher's personal Facebook and LinkedIn pages. The flyer was made "shareable," enabling the researcher's contacts to re-share the flyer on their own personal pages and beyond. In addition, an IRB-approved recruitment letter (Appendix D) was posted with a recruitment program, ResearchMatch.org, which is funded by the National Institutes of Health.

In addition to purposive recruitment, snowball sampling technique was used. Snowball sampling publicizes the study directly to others who may meet inclusion criteria and have rich experiences to share. Early participants are asked to share study details and the recruitment materials with other parents within their social network who might be eligible and interested in participating.

Sample and Inclusion Criteria

Participants were parents raising children with ED. People who experienced the phenomenon first-hand can provide the most "faithful" and "authentic" data (Schwandt, 2011). In naturalistic research, recruitment sampling is not designed to ensure generalization but rather

to "maximize the scope and range of information" (Lincoln & Guba, 1985, p. 224). Study

inclusion criteria were chosen to ensure participants were parents with direct, recent experience

living with and raising a child with ED. Although other adults, such as grandparents or foster

parents, may be the primary caregiver, research demonstrated different types of caregivers

experience a distinctly different set of challenges and responses when compared with parents

(Labella et al., 2020; Taylor-Richardson et al., 2006).

Participants were eligible to be included in the study if:

- they were parents, adoptive parents, or stepparents of a child who had been diagnosed with ED by a healthcare provider or education specialist, or who self-identified that their child has "emotional or behavioral problems."

- the affected child had emotional or behavioral problems for at least six months

- the affected child was less than 24 years old at the time of data collection

- parents had lived with the affected child for most of the child's pre-adult years and when the child was exhibiting the emotional/behavioral problems

- parents had access to a computer, the internet, or a telephone

- parents were able to read, write, and converse in English

Potential participants were excluded from the study if:

- they were foster parents, custodial caregivers, temporary caregivers, or grandparents of the affected children

- the child had not exhibited/did not exhibit emotional or behavioral problems for at least six months

- the child with ED was more than 24 years old

- the parent did not live with the affected child for most of the child's pre-adult years or when the child was exhibiting the emotional/behavioral problems

- they did not have access to a computer, the internet, or a telephone

- they were unable to read, write or converse in English

No potential participant was excluded from the study based on age, gender, race, ethnicity, marital status, or sexual orientation.

Thirteen potential participants initially responded to the recruitment efforts. One potential participant did not meet eligibility criteria. Four participants initially contacted the researcher but did not respond to any follow up calls or emails. The final sample was eight participants, who were all mothers. Two of these participants were well-known to the researcher. Five participants responded to the recruitment flyer via Facebook, and one participant was recruited via snowball recruitment. The exact sample size for a naturalistic study is unknown in advance. Naturalistic researchers should stop sampling when data has reached "informational redundancy," which is the point of data analysis when subsequent interviews reveal scant or insignificant new information (Lincoln & Guba, 1985, p. 234). Informational redundancy was achieved after analyzing eight participant interviews. Informational redundancy will be discussed further in data analysis.

Setting

The data collection sessions were conducted according to the participant's preference, either using Zoom (an online video-audio conferencing platform) or by telephone. This setting allowed participants to choose a comfortable location, such as their own home, for the interview. The researcher conducted all interviews in her private home office. The Zoom platform contains secure recording capability. All meetings were conducted on the researcher's password protected

computer with end-to-end meeting encryption. This encryption ensured the recording was only saved to the researcher's personal computer and not on any cloud platform. The researcher used a handheld digital recorder as a back-up audio recording of the interview.

Seven of the eight data collection interviews were conducted via Zoom. For increased security of the Zoom sessions, unique meeting ID numbers and passwords were created for each interview session. Zoom's waiting room feature was utilized to ensure only the participant was admitted to the meeting. The researcher used the same office setting for one participant who preferred to be interviewed by telephone. This interview was recorded using the handheld digital recorder.

Data Collection

Data generated during the study consisted of demographic data of the participants and their family members, interview data, field notes, memos, and the researcher's reflexive journal. The participant interviews were the primary source of data. Participation was voluntary and oral informed consent was given prior to any data collection.

Prior to the data collection interview, the researcher spoke with potential participants by phone to explain the purpose of the study, describe study participation processes, and answer any potential participant's questions. This initial conversation took place before oral consent was given; therefore, potential participants were not asked any data or personal questions. Study inclusion criteria were read to the potential participant, who affirmed if they believed they met the inclusion criteria. If the potential participant agreed to continue with the study, a date was set for the interview and a copy of the Study Fast Facts Sheet (Appendix E) was sent via email or text for review. All potential participants who affirmed they met the study inclusion criteria did agree to participate in the study.

Informed Consent

At the data collection session, the researcher greeted the participant, engaged in small talk and answered any questions about the study or the Study Fast Facts Sheet. Once all questions were answered, the researcher read the IRB- approved oral consent narrative to the participant (Appendix F). The consent narrative explained the potential risks of the study, which included a breach of confidentiality, fatigue, and emotional distress. The consent narrative informed participants that the researcher is required by law to report any concerns for possible child abuse or neglect, and that the participant may decline to answer any question or choose to end the interview at any time. After the oral consent narrative was read, the researcher answered any additional questions from the participant. All participants agreed to continue with the study. At this point, the recording device was started, and the participant was asked to restate that she did consent to participate in the study on the recording.

Demographic Data

Participant demographic data was gathered using the demographic data form (Appendix G) and is reported in Chapter 4. The demographic form was read by the researcher during the interview so participant responses were captured on the transcript. The demographic data included the age, gender, working status and ethnicity of the participant and their family, as well as any other people (related or otherwise) living in the home. Lastly, the demographic data was gathered about the child with ED, including any co-morbidities, current school status, and if the child with ED received special education services in school. The demographic questions gave the researcher a basic understanding of the family composition, which the researcher could reference to prompt interview dialogue.

Semi-structured Interview

A semi-structured interview guide was created for the study (Appendix H). A "semi-structured interview" is guided by basic topical questions but is not a structured list of pre-determined questions to be posed in an exact order (Erlandson et al., 1993, p. 86). The interview questions were broadly designed to prompt participant responses about their daily lives and the types of challenges they encountered due to their child's ED. This interview structure encourages dialogue between the researcher and the participant to reconstruct the participant's experiences and surrounding context (Erlandson et al., 1993). Follow up questions prompted participants to discuss how they managed the challenges as well as any impact on other family members due to the ED child's emotional or behavioral problems.

The opening grand tour question was: "As you know, I am interested in learning about the lives of parents of children with emotional or behavioral difficulties. I would like to hear your story." If participants hesitated with this question, as if they did not know how to begin, the researcher posed a secondary question: "When did you start noticing things about your child that caused you to think your child might have an emotional or behavioral problem?" This concrete example within the broader question elicited rich details and stories about the participants' experiences. Additional questions included: "What were some of the common, 'everyday life' problems that occurred due to your child's ED?" "How have your child's issues impacted you? How have they impacted your spouse?" Conversational probes were used when needed, such as "how did you deal with that problem?" or "how did that affect your other children?" These probes encouraged participants to share additional context regarding their experiences. Naturalistic inquiry research emphasizes the exploration of a participant's personal contextual story to gain a better understanding of the phenomenon (Carl & Ravitch, 2018). Therefore, the

interview questions were adapted to the participant's responses. This allowed the interview to delve deeply into the areas that were personally meaningful within that participant's life.

None of the interviews raised any ethical concerns for child abuse or neglect as discussed in the verbal consent process. The average interview was 76 minutes long (range of 53 - 95 minutes). The researcher initially stopped all participant discussion after 90 minutes in an effort to prevent participant fatigue. During subsequent interviews, if the interview was approaching 90 minutes in length, the researcher offered the participant the choice to end the interview, continue the discussion, or reschedule for a future time. No participant chose to end the interview, and the longest interview lasted 95 minutes. For the final interview question, participants were asked if there was a message the participant felt the "world should know" or if there were other topical questions the researcher should have asked. Subsequent interview questions were added based on participant suggestions, such as asking if there was financial hardship as a result of the child's ED.

Lincoln and Guba (1985) describe the interview process itself as interpretive, because the researcher compares and contrasts subsequent participant responses with earlier participant responses. As an example in this study, early participants reported that "old school" or consequence based- discipline styles were ineffective for their child with ED, even if they were effective for the participant's other children. During subsequent interviews, the researcher might reference this data to determine if the current participant also had this experience. By employing this technique, the researcher performs aspects of member checking and data triangulation with participants directly during the data collection sessions. At the end of the interview, member checking was conducted restating salient details of the participant's story and asking the participant to confirm or clarify the researcher's understanding of the participant's experience.

Field Notes, Memos and Reflexive Journaling

Field notes are a written account of the researcher's observations and thoughts which occurred during data collection (Morse & Field, 1995). During the interviews, the participant's body language, reactions, emotions, and demeanor were observed closely. Minimal notes were written during the interview to ensure the participant felt the researcher was completely focused on their dialogue. Immediately after the interview, the researcher generated an electronic field note of her observations of the participant interaction, non-verbal body language and her ideas. The field notes were dated, timed, and labeled with the participant's identification number. After the transcription was completed, the field notes were reviewed so non-verbal cues could be added to provide richness to the participant's story. Field notes were re-reviewed while conducting data analysis.

The researcher also used memos and a reflexive journal to document her personal ideas and insights about the study. The memo log documents the "logistics, insights, and reasons for methodological decisions" within the memo log as recommended by Erlandson et al. (1993, p. 143). Methodological memos included ideas about potential interview topics to compare participant experiences or logistical management of the interview process. For instance, the researcher noted she became tired after interviewing for 60 minutes, which resulted in more conversation than probing techniques. The researcher placed hard candies out of sight from the participant with a reminder for her to use them after 60 minutes, which assisted to keep the dialogue more focused.

Lastly, the researcher kept a personal, reflexive journal to track her reactions, ideas, feelings and preliminary themes throughout the study. In a naturalistic inquiry, the researcher is the primary instrument (Lincoln & Guba, 1985). Lincoln and Guba stated the researcher will

already have a constructed reality based on the researcher's tacit knowledge and personal

experience. These qualities will influence how a research study develops (Lincoln & Guba,

1985). The reflections within the journal assisted the researcher to recognize her own position

within the data, acknowledge personal assumptions, and aided to prevent bias in data analysis.

Data Management

Measures were taken to reduce the risk of a breach in participant confidentiality. Data

was secured during the online interviews by enabling end-to-end encryption of the Zoom

meeting on the researcher's password protected personal laptop. Each interview was recorded

using Zoom's recording feature and a digital audio recorder as a back-up in case of a technical

problem. Meeting encryption ensured the Zoom recording was only saved on the researcher's

laptop, and not saved on any cloud storage. For the interview conducted by phone, the digital

audio recorder was used for recording. The recordings were uploaded to Otter.ai's secure portal

for transcription using artificial intelligence technology. The confidentiality agreement from

Otter.ai may be reviewed here: https://otter.ai/privacy-policy. After transcription, the researcher

reviewed the transcript for accuracy. Any errors were manually corrected. Non-verbal cues such

as voice inflections or pauses were added in brackets to the transcript. The original recording and

transcript were stored on a password protected, encrypted external hard drive. The recording and

transcription were deleted from Otter.ai's transcription portal. Recordings were deleted from the

digital recorder as well.

Unique identification numbers were created for each participant. All data containing

participants' names, including the master list of identification (ID) numbers, original transcripts,

and audio recordings, were stored on a dedicated hard drive, and locked in a secure location

separately from all other study data. A second copy of the original transcript was created and

labeled with the participant's ID number. The researcher masked the second transcript by

removing any data that could identify the participant or their family, including names, names of

schools, or cities. This second version of the transcript was used for data analysis. A second

dedicated, password-encrypted hard drive stored the masked transcripts, memo log, reflexive

journal, audit trail log and electronic field notes. All data within this second hard drive was

labeled with participant ID numbers only. This second hard drive was stored in a different locked

security box and in a separate location from the box with the master list of participants. An

additional copy of the masked transcripts was stored by the dissertation supervisor on her

personal, secured laptop. This safeguarded the masked data at a second location away from the

researcher's home.

Data Analysis

Data analysis in an NI study is conducted in two phases: during the data collection

session itself and again away from the research site (Erlandson et al., 1993). Data analysis begins

on the first day of data collection so the data collection process may be "fine-tuned" and revised

based on emerging information (Erlandson et al., 1993, p. 114). Initial data analysis began by

recording observations into field notes directly after the data collection interview. The researcher

reviewed the field notes for indications that revisions of the interview questions or new questions

were needed regarding an emerging element of the phenomenon. Review and interpretation of

early data allows adjustment of subsequent data collection, so that the collective participants'

reality is reflected in the overall findings.

The second phase of data analysis consists of descriptive statistical analysis of the

demographic data and analysis of the interview data after transcription was completed. In a

naturalistic inquiry investigation, the second phase of data analysis consists of several steps: 1)

identifying significant units of data, 2) designating categories, 3) searching for negative cases

and 4) bridging, extending and surfacing the data (Erlandson et al., 1993; Lincoln & Guba,

1985). Patton et al. (2017) point out that naturalistic research requires an openness to emerging

themes, rather than seeking to create broad generalizations. This openness to emerging themes

demonstrates how data analysis is intricately tied to data collection, with early analysis

influencing subsequent data collection sessions. This approach allows the research focus to shift

to reflect what is meaningful to the participants themselves (Lincoln & Guba, 1985).

Step one of analysis is identifying significant units of data (Erlandson et al., 1993). The

initial analysis process uses the constant comparative method as described by Lincoln and Guba

(1985). The masked transcript was read several times to identify and highlight data units. Data

units could be individual words or sentences that convey a single idea (Erlandson et al., 1993).

Examples of data units included the phrase: "that's when I knew it was like, me and "R" against

the world," or words such as "frustrating" or "hard." Data units were sorted into groupings of

related ideas. This process was repeated until all data units from a transcript were placed in

groups of ideas. These were tentative groups only that could be challenged by negative case

information gathered later.

Step two of data analysis is designating categories (Erlandson et al., 1993). The

researcher used Microsoft Excel to store, organize and sort the data. Highlighted data units from

the transcript were copied into a Microsoft Excel spreadsheet. Initially, each participant's data

units were stored on individual pages within Excel. Descriptive labels were added to the data

unit, such as "**related to early infant care:** 'I don't know if she was remembering what it was

like, living with her [biological mom], and being dumped off while she went to party.' " With

one participant's data units stored on a single page, the researcher sorted the units into columns

of tentative idea groupings. This allowed the group of ideas to be compared and contrasted as a whole, and specific data units which did not fit within the grouping were easily moved to another column.

As data collection progressed, grouped ideas became potential categories. Initially, the researcher actively refrained from combining categories. After four participants, there were 34 smaller categories identified under 14 broader categories. The columns could be easily moved as categories were bridged together, or divided as new data was gathered. New Microsoft Excel workbooks were created and organized by tentative category, rather than by participant. This allowed the researcher to view multiple participants' data in a column to analyze if the units "fit" together. As subsequent transcriptions were analyzed, the pages were labeled by the emerging categories.

Step three of data analysis is searching for negative cases, which can represent minority opinions or balance implicit biases (Erlandson et al. 1993). As data units were sorted and categorized, the researcher sought negative cases which contradicted early hypotheses. Negative case data was labeled "negative case" and highlighted in red text in the column. For example, two early participants had significant financial problems due to their child's ED. Questions about potential financial hardships were added in subsequent interviews to explore this issue. However, later participants denied significant financial problems. New versions of category groupings were dated and saved as unique Excel workbooks. The process to review emerging categories and re-sort the data was easy to repeat because older versions could be retrieved if needed.

Critical incidents are different from negative cases and warrant special consideration when doing data analysis and reporting study findings. Erlandson et al. (1993) define "critical incidents" as events which either embody the norms of a phenomenon or sharply contrast with

these norms (p.103). This study uncovered deeply troubling incidents which were only experienced by one or two participants, including abuse of children by professionals and suicidal thoughts. Two participants' children experienced blatant physical abuse from their teachers or were treated with overt racial discrimination. Even though this treatment was far from common, the injustice of the event means this data must not be set aside just because "only two" participants reported them. The researcher is ethically obligated to bring these critical incidents to light through the study findings, even if the event was only experienced by a single participant.

Step four of analysis is bridging, extending, and surfacing the data (Erlandson et al., 1993). By re-sorting the columns of categories, the researcher identified possible links which "bridged" two categories. For example, participants had widely divergent experiences with their child's school. Half of the participants received wonderful support from their child's schools, while for others, school was the worst battleground they had. Originally these experienced were categorized as "supportive measures" and "barriers." However, all the participants were *seeking expert assistance* through the schools, even if some participants did not actually receive assistance. Therefore, these data units were bridged under the category of "seeking expert assistance," rather than a separate category of "problems with schools."

Data was extended when early interviews indicated an important but incomplete category and guided future interviews to specifically probe the topic. Participants with multiple children discussed the emotional impact of their child with ED on their brothers and sisters. Some participants had to take additional action for these siblings, such as ensuring their physical safety. Actions taken for the siblings' specific benefit was extended from the emotional impact on the sibling into the construct **actions and adaptations**.

Data were surfaced when analysis revealed a potential category within a previously defined category. Participants described their child's early concerning behaviors, and then immediately rationalize the child's behavior in the same sentence. The rationalization process became increasingly significant and surfaced as a unique sub-category within the first category, **realizing my child is different**. Data from field notes were reviewed for additional descriptive details regarding participant behaviors or reactions during the data collection session. Field note data were added as memos to the Excel spreadsheets.

As discussed above in the sampling process, Lincoln and Guba (1985) advise naturalistic investigators to stop participant recruitment when data reaches informational redundancy. Detailed description of the analytic process is vital to demonstrate how the researcher concluded that informational redundancy has occurred and justified ending participant recruitment (Bowen, 2008). After six participants, no new categories emerged, and informational redundancy was suspected. A complete redundancy analysis was conducted after seven participants. The codebook (Appendix I) was used to analyze the data for redundancy and saturation. All categories and subcategories were listed, with all the participants represented within that category/ subcategory. The respective transcription line numbers were listed with the participant number. All major categories had representation from all seven participants. Subcategories were represented with at least six participants each. Critical events were listed but not subjected to broad participant representation.

When the transcript from the eighth participant was analyzed, no new categories were revealed. This participant's experiences mirrored many of the previously identified categories. At that point, the researcher considered the eighth transcript informationally redundant and stopped recruiting participants.

Maintaining Trustworthiness

Trustworthiness in qualitative research is comparable to validity and reliability in quantitative research. Lincoln and Guba (1985) cautioned that the fluidity of naturalistic inquiry research does not mean there is less rigor in the scientific process. Trustworthiness determines if "the results are worth paying attention to," (Lincoln & Guba, 1985, p. 290). Trustworthiness is a critical evaluation of the accuracy and truthfulness of the findings from a qualitative research study (Creswell & Poth, 2018). Lincoln and Guba proposed four criteria to demonstrate trustworthiness in naturalistic research: credibility, transferability, dependability, and confirmability.

Credibility

Credibility is the "degree of confidence in the 'truth' of the findings" (Erlandson et al., 1993, p. 29). Processes used to establish credibility included peer debriefing, data triangulation and member checking. Peer debriefing assists to guard against bias by having an outside, uninvolved researcher review the study as it unfolds (Lincoln & Guba, 1985). Two of the researcher's dissertation committee members reviewed the data, data analysis, and findings with the researcher. Data triangulation verifies that key findings originate from multiple data sources rather than a single source of information (Lincoln & Guba, 1985). Data triangulation was established during data analysis and by the redundancy analysis. The code book (Appendix I) is a log of data triangulation. Member checking allows participants to verify their responses were correctly understood by the researcher (Erlandson et al., 1993). The researcher performed member checking during the interviews by repeating participant's statements and asking the participant to confirm the researcher's understanding of the experience. Member checking was specifically conducted at the end of each interview. As on the interview guide (Appendix H), the

researcher recapped two or three of the participant's salient ideas and asked the participant to confirm or clarify the researcher's understanding directly.

Transferability

Transferability indicates the extent to which the study's findings could be applied to other people or situations (Erlandson et al., 1993). Demographic data of the participants, their children and their family composition are contained within Table 1 and Table 2. Study results included illustrative participant quotes and rich detail to describe participants' stories and experiences. This descriptive data assists to build a database that allows a reader to evaluate the transferability of the study findings to the reader's own setting (Lincoln & Guba, 1985, p. 316).

Dependability

Dependability is comparable to the quantitative research criterion of reliability. Dependability is supported by providing evidence tracing the findings to the data source (Erlandson et al., 1993). The researcher maintained an audit log with all the generated data, including transcripts, field notes, memos, reflexive journal entries, and notes from supervisory and peer debriefing meetings. The codebook (Appendix I) also supports dependability by listing the participants with common experiences. With these documents, an independent auditor could trace this study's data sources and findings through to the study's conclusions.

Confirmability

Confirmability correlates to objectivity from the paradigm of quantitative research (Lincoln & Guba, 1985, p. 290). Similar to dependability, confirmability demonstrates the degree to which the findings are derived directly from the data, and can be "tracked to their sources" (Guba & Lincoln, 1989, as quoted in Erlandson et al., 1993, p. 34). The findings were supported by quotations identified with the participant ID and transcription line number. Confirmability

was also supported by data triangulation in the code book (Appendix I) as well as the

researcher's audit trail log. The informational redundancy analysis demonstrated strong data

triangulation of key findings with multiple participants supporting each category, subcategory,

and theme.

Ethical Considerations

Prior to participant recruitment, all study procedures, including the Study Fast Facts

Sheet (Appendix E) and narrative for oral consent (Appendix F), were submitted to the

University of Texas Medical Branch Institutional Review Board for approval. The study was

approved on March 2, 2023 (IRB # 23-0049). Each study participant was provided the Study

Fast Facts Sheet (Appendix E) by email or by text prior to the interview session. The researcher

reviewed the potential risks of the study, answered all questions, and obtained verbal consent

from the participant before posing any interview or demographic questions.

The study posed a very low risk to participants. The primary risks included a breach of

confidentiality, emotional distress, interview fatigue, and potential revelation of abuse or neglect

of a vulnerable adult or child. Several processes used to reduce these risks.

To reduce the risk of a confidentiality breach, the researcher assigned each participant a

unique identification number (ID). All transcripts, recordings, quotations, and demographic

information were labeled with the participant's ID only. The master list of participants and their

assigned ID number was securely locked as described in the data management section. Any

potentially identifying data from the transcripts were removed or masked by the researcher. Only

the researcher had access to the original, unredacted data.

Potential risks included emotional distress or fatigue during the interview. The researcher

is an experienced triage nurse with a strong awareness of signals and non-verbal cues which

indicate a person may be distressed or fatigued. The data collection interviews were limited to 90

minutes. One interview lasted 95 minutes because the participant preferred to continue when the

researcher offered to end the session. No participant indicated any fatigue during the interview.

Occasionally, a participant was tearful when they recalled a particularly painful episode. When

this occurred, the researcher offered empathetic listening and encouraged the participant take as

much time as they wished to answer. No participant became extremely upset or wanted a break

from the session. Although the researcher was prepared to offer counseling resources and stress

relieving techniques for any participant in distress, no participant needed these resources.

All children are legally vulnerable, especially children with disabilities, and as such, are

at risk for abuse or neglect by their caregivers. Prior to starting the interview, the researcher read

the oral consent narrative to participants aloud (Appendix F). The oral consent narrative

reminded participants that study participation was voluntary, listed the potential risks of

participation, and that participants can end the interview at any point. At the end of the interview,

the researcher re-reminded participants that study participation was voluntary, and they may still

withdraw their consent even though the interview was finished.

Both the oral consent and Study Fast Facts sheet explained the researcher's status as a

mandatory reporter of abuse or neglect of children or vulnerable adults. The following paragraph

was read to all participants verbatim prior to starting the data collection interview:

> The following information is very important. As a nurse, I am required by law to report any suspected child abuse or neglect (or abuse/neglect of an adult who is disabled). In Texas, these reports must be made to the Texas Department of Family and Protective Services. I will not be asking you any questions about abuse, but if any information is revealed during the interview that creates a concern for potential or ongoing abuse or neglect of a child or disabled adult, I am required by law to notify the authorities. At that point, your confidentiality will need to be broken so that I can report the issue to the proper authorities. If that were to happen, I would let you know immediately.

Although the researcher did not pose any questions regarding abuse or neglect, the researcher was alert for the possibility a participant might reveal concerning information for possible abuse or neglect of a child or vulnerable adult. No collected data suggested any potential abuse or neglect of a child or vulnerable adult from any of the participants in this study.

Summary

The study design framework for this research was naturalistic inquiry as conceptualized by Lincoln and Guba (1985) and described by Erlandson et al. (1993). Naturalistic inquiry emphasizes the context of the participants' behaviors and experiences (Carl & Ravitch, 2018). Curry et al. (2009) stated naturalistic research is well-suited to explore the perspectives of people who are underrepresented, marginalized, or stigmatized. Naturalistic inquiry methods guided the study processes including purposive sampling, semi-structured interviews for data collection, and data analysis (Erlandson et al., 1993). Lincoln and Guba's (1985) criteria for establishing scientific rigor were followed.

Chapter 4 will present the data generated by the study. The chapter will present the constructs, categories and themes which emerged from the data. Chapter 5 will begin with a synopsis of the findings and then orient the findings within the concept of stigma and the published literature. Chapter 5 will conclude with a discussion of implications based on the findings, study limitations, and potential future research trajectories to extend the study's findings.

CHAPTER 4: FINDINGS

This study explored the experiences of parents who are raising children with emotional disturbance (ED). The findings describe how parents responded to the challenges created by their child's ED, and how raising a child with ED impacted the family as a whole.

As discussed in Chapter 2, children with "emotional disturbances" have been described using various terms in different realms of literature. The researcher used "emotional disturbance" because this term was used in the most recent version of special education law. An older term was "emotional and behavioral disorder," to specify the observable, unexpected and/or disruptive behaviors which impact the child's learning or functioning in society. This term was later changed to "emotional disturbance," as the inappropriate behaviors are external signs of an internal emotional issue.

The results suggest parents realize their child is "different" and may have a problem outside of normal variations of childhood development patterns after a series of stages of concern and suspicion. The parents' concerns stimulated them to search for possible explanations for their child's unusual behavior patterns. When the parents received confirmation of their child's emotional problem from an expert in education or healthcare, parents utilized a significant number of actions and adaptations to manage the challenges due to their child's ED. Lastly, the entire family is altered from the experience of raising a child with ED. Participants were eager to advise other families, as well as the community at large, of the lessons they learned from their unique parenting journey. Commonalities among the participants' experiences were identified and then organized to provide a conceptual basis for the reader to envision the unique challenges faced by parents raising a child with ED.

Demographic Profile of Sample

The study sample consisted of eight participants, who were all female/mothers. The mean age of the participants was 48, ranging between 29 to 62 years old. Six participants were married, one was divorced, and one participant was single/never married. Seven participants were White/Caucasian, and one participant was Hispanic. Five participants worked outside the home, while three participants did not. Five participants had biological children, one participant had adopted children, and two participants had both biological and adopted children. Of the eight participants, six participants had more than one child, and two participants had two children who both had an emotional disturbance. The mean number of children was 2.6, and families ranged between one and four children.

Table 1

Sociodemographic Data: Parent Participants (n = 8)

Gender	Female = 8		
Age	Mean = 48 years	Range = 29 - 62	
Marital status	Married = 6	Divorced =1	Single = 1
Ethnicity	White = 7	Hispanic = 1	
Work outside the home?	Yes = 5	No = 3	
Adopted or biologic children?	Adopted = 1	Biologic = 5	Both adopted & biologic children = 2
Total number of children in family	Mean = 2.6	Range = 1 – 4 children	

The eight participants had 10 children identified as having an emotional disturbance. Two mothers (one adoptive mother, one biological mother) each had two children with ED. All 10

children received a diagnosis of ED from a healthcare professional. Seven children with ED were female, and three were male. Four of the children were adopted by the participants, and six of the children were biologic children of the participants. The children's ages ranged from 5 to 23 years old. However, the age distribution of the sample was uneven. There were three children aged 5 to 9 years old, zero children aged 10 to 14 years old, and seven children aged 15 to 23 years old. The children's mean age was 15, and the median age was 16 years old. Four children were living at home at the time of the interview. Nine of the children had entered school (one was in kindergarten), and all nine children attended public school for at least a portion of their education. Of the nine children who had entered school, eight children received official special education services. Only two children had any type of chronic illness or physical health problem in addition to their ED. One child had recurring ear and tonsil infections as well as Ehlers Danlos syndrome. The other child was born 10 days after his due date and had a serious infection at birth. In addition, this child had tongue, tonsillar and adenoid problems requiring surgeries to correct. The remaining eight children did not have any physical health problems throughout their childhood.

Table 2

Sociodemographic Data: Children with ED (n = 10)

Gender	Female = 7	Male = 3
Age	Mean = 15, Median = 16	Range = 5 - 23
Ethnicity	White = 7, Black = 1, Black/White = 1, Hispanic = 1	
Adopted or biological child?	Adopted = 4	Biologic = 6
Currently living at home?	Yes = 4	No = 6

Received special education services at school?	Yes = 8	No = 2 (one child not enrolled in school yet)

Summary of Constructs and Categories

The data gathered from the participants was extensive and detailed. Along with the researcher's field notes, reflexive journal and memos, the study data was analyzed using the constant comparative method of naturalistic inquiry. Naturalistic inquiry focuses on developing an understanding of events experienced by the participants directly, in order to develop a greater comprehension of the phenomenon of interest (Erlandson et al., 1993). Data generated during the study were analyzed to answer the study's three research questions:

1) What are the parenting experiences of parents of children with emotional disturbance?

2) How do these parents respond to the situations and challenges that arise due to their child's ED? Do these situations and responses change as the child ages?

3) How does raising a child with ED impact the family as a whole?

When using naturalistic inquiry methodology, data analysis includes reviewing the transcripts, field notes, the reflexive journal and memos to discern units of data, sorting the data units into categories of ideas, analyzing negative cases, and constantly comparing the data units and categories to each other. Five conceptual categories emerged and are reported here under three constructs. The constructs and categories provide answers to the study's research questions from the participants' perspectives. The three constructs are labeled as: 1) **Concerns and Suspicions**, 2) **Actions and Adaptations** and 3) **Altered Families and Advice for Others**. These constructs were further delineated into five data categories: 1) **Realizing my Child is**

Different, 2) **Responding to the Challenges**, 3) **Changing over Time**, 4) **Altered Families**, and

5) **Advice for other Families**.

The table below summarizes the constructs, categories, subcategories, and themes which

emerged from the data. The **<u>constructs</u>** are underlined and in bold print, the **categories** are in

bold print, the *subcategories* are italicized, and <u>themes</u> within the subcategories are underlined.

The corresponding research question is listed above each set of constructs and data.

Table 3

Summary of the Findings' Constructs and Categories

#1: What are the experiences?	# 2 a. How do parents respond to challenges arising from the child's ED? b. Do responses change over time?		#3: How does child impact the family?	
<u>Construct 1</u>	**<u>Construct 2</u>**		**<u>Construct 3</u>**	
<u>Concerns & Suspicions</u>	**<u>Actions & Adaptations</u>**		**<u>Altered Families & Advice for Others</u>**	
Category I	Category II	Category III	Category IV	Category V
Realizing my Child is Different	**Responding to the Challenges**	**Changing over Time**	**Altered Families**	**Advice for Other Families**

Concerning behaviors:
 	
<u> My child does this, but others don't</u>
	For the Child w/ ED:
	
	<u>Parenting using past experiences</u>
	
	<u>Using outside expert assistance</u>
	  a. Healthcare
	  b. Government
	  c. School
	
	<u>Switching to intentional responses</u>
	  a. Parent adapts self
	  b. Adapts environment
	  c. Teaching child about the world
		Seeing through Child's Eyes
		
		<u>How child sees the world</u>
		
		<u>Unable to stop behaviors</u>
		
		<u>Suffers in silence</u>
		
		<u>Unaware of social rules</u>
			Impact on the Parent
			
			<u>Always on alert</u>
			
			<u>Stress</u>
			
			<u>Frustration</u>
			
			<u>Employment problems</u>
			
			<u>Social isolation</u>
			
			<u>Guilt</u>
			
			<u>Fear</u>
			
			<u>Loss of dreams</u>
				Kids Really are All Different!
				
				<u>Typical parenting fails</u>
				
				<u>School focused on speed, not success</u>
				
				<u>Ignore differences, address the disruptions</u>

Rationalizing Concerns Child's early experiences Just circumstances Just their personality In my own head	*For the Parent: Self-care* Connecting with others Time away Consciously changing reactions Therapy/ Beliefs Researching Personal Safety Unhealthy coping	*Perspective Changes* Understanding allows for compassion Find right the environment Not lack of willpower Struggle with nuance	*Impact on the Spouse* Doesn't see the problem Rejection Tension Unbalanced load Best friend	*We Need help, not Blame* Not our fault We need tools Healthcare needs wider view
Escalating Suspicion: Continued problems Nothing's working	*For the Siblings* Protection/ Safety Individual attention	*Child's Positives with the Problems* Who my child is My child's strengths My child for a reason	*Impact on the Siblings* Stress Harmed siblings' bond Overprotective	*Survival Tips for Families* Be open to learning Connect with others Child may be suffering Ride the wave
Deciding: Something is Wrong Catalyst Deciding there's a problem		*Past reflections: I did my Best* Regrets I did everything I could I did the best I could		
Confirming: Consulting Experts		*Future: No longer a child, not yet an Adult*		

Acknowledgement Barriers: Delay, divergent opinions		Game changes Not yet an adult Desire for balanced mature connection Broken relationships		

The first construct, **<u>Concerns and Suspicions</u>**, describes the journey from participants' initial concerns over their child's behaviors to eventually deciding something is definitely wrong with their child. **Category 1**:**Realizing my child is different** describes the stages of increasing concern and suspicion as participants encountered difficulty with their child. This category concluded when the participants consulted with experts for confirmation. The second construct is **<u>Actions and Adaptations</u>** with two data categories. **Category 2: Responding to the challenges** describes the specific actions the participants used to manage the issues they encountered related to their child's ED. The scope of these responses for the child with ED meant additional actions were now necessary for the participant as well as for other siblings living in the household. Participants discussed how their responses to the challenges **changed over time**, which became Category 3. These ongoing adaptations demonstrated the participant's personal change in perspective as their child grew older. Finally, the third construct, **<u>Altered Families and Advice for Others</u>**, describes how living with a child with ED impacted the family as a whole. The challenges created by the child's ED, and the participants' responses to those challenges **altered the family** (Category 4). Participants were given an opportunity to share a personal message, which participants used as an opportunity to help other families like their own. **Category 5: Advice to other families,** presents participants' advice to others about the lessons they learned through this experience.

In the sections below, "participants" or "mothers" will be used interchangeably, because all of the participants were mothers. "Parents" will be used to indicate both the mother and the father. Quotations will be identified by participant number and line number within the transcript (i.e.: P2 L 152).

Research Question 1: What are the parenting experiences of parents with emotional disturbance?

Concerns and Suspicions: Realizing My Child is Different

The first research question sought to explore the experiences of parents who are raising children with emotional disturbance. Although individual experiences will be described throughout this chapter, participants experienced many similarities during the initial, "realization of a problem" process. Erlandson et al. (1993) state a naturalistic researcher uses data collected during early interviews to generate emergent "working hypotheses," which are then tested during subsequent interviews. Early participant interviews indicated they did not immediately think their child had a "problem" per se but had concerns which evolved into deep suspicions. Subsequent interviews revealed participants' thinking process might linger in this "suspicious" state based on impacting factors, such as other children with more obvious problems or if their spouse thinking the ED child's behaviors were not "all that bad." Construct 1 encompasses the participants' **Concerns and Suspicions**.

For Category 1, **realizing my child is different,** there are five subcategories in Table 3 which will be discussed. Category 1 describes the process from the participant's initial thoughts about their child's behaviors to the participants' conclusion that their child was different. *Concerning behaviors* is the first subcategory, with the theme <u>my child does this, but others</u>

don't. The second subcategory emerged from the participants' *rationalizing their concerns*. As the child's problems continued, the third subcategory described participants' *escalating suspicion* about their child's behaviors. Participants eventually concluded their suspicions were valid, and *decided that something was wrong*, the fourth subcategory. Lastly, participants sought a professional evaluation from either an expert in mental health or childhood development, *confirming: consulting experts*. Themes included barriers participants encountered as well as the acknowledgement that their child did have a problem which was inhibiting the child's expected behavioral growth trajectory.

Concerning Behaviors

Each participant was asked what behaviors initially raised the participant's concerns. The first subcategory, *concerning behaviors*, had a theme of participants noticing that my child does this, but others don't. Participants described seeing their child move, react, and interact in ways that other children simply didn't. They saw how their child could not get along with peers, regardless of the activity, or how their child might fly off the handle at the slightest provocation. One nine-year-old child violently attacked a friend at recess when he would not follow the rules of the make-believe game. Her mother said "you can almost see the wires crossing" on her child's face when someone was doing something she didn't want them to do. The child would not hit the peer just once out of frustration, but would flat-out attack the peer, requiring the teachers to intervene for the peer's safety.

> Her anger is… just hitting someone once isn't enough...It's almost like
> she hasn't gotten her anger all the way out. And so, she has to keep
> going (P4 L 392, 396)

Table 4 lists each participant's child with the child's behaviors and reactions. The behaviors often began when the child was very young but escalated in severity as the child entered elementary school.

Table 4

Behavioral Problems of Participants' Children with ED

Age	Gender	Behaviors
23	F	Extremely active, hit/fought others frequently, very strong willed, defiant, refused to do schoolwork
5	F	Extremely active, barks like dog at strangers, screams at teachers in class, hyper-regimented rules regarding food or getting dressed
19	F	Extreme anxiety to be "best," intolerant of others not conforming to rules, emotionally volatile, screaming outbursts at family and friends, suicidal thoughts
21	F	Self-harms, panic attacks, hide in closet, screaming attacks at school, extreme social anxiety
15	M	Violent outbursts at school, aggression to staff/ peers, violent to biological sibling, adoptive parents, theft, armed robbery
15	F	Extreme need for control, extreme anxiety response to any outside situation, emotionally volatile, unaware of social rules with peers
5	M	Requires "deep touch" for soothing, such as banging head on concrete, constant spinning, highly reactive to changes in environment, inconsolable crying spells
22	M	Screams at any transition, extremely active, emotionally volatile, sobbing for extended period in public (at age 17), unable to read social cues
9	F	Reactions highly disproportionate to situation, will fly into rage at peers, attack adults, run away from school/ in stores, extremely inflexible
17	F	Hypersexual (age 3), cursing/violent in preschool, violent to teachers/ peers requiring police at school, rage, steal, runaway, threatened sibling with knife, promiscuity/ seeking sexual encounters on internet at age 12

The children were highly volatile and disconnected from seeing anyone else's perspective. The children were unable empathize with others at all or even consider if another person's needs conflicted with the child's own wishes. The emotional volatility combined with a lack of perspective meant anyone could be blasted with an emotional or physical reaction without warning. One mother said, "She almost…sometimes controlled our house with her emotional outbursts" (P5, L 285). Another mother said her child had no "concept of time, or other people's time, or that anybody else was kind of, around," (P3 L 225).

Other children acted bizarrely or were extremely active. One child would randomly start barking like a dog at other people while at the grocery store, and another child would uncontrollably sob at the movies, even at age 17. At the pediatrician's office, one child would act as though the office was a jungle gym.

> In the exam room. Or climbing up on the table, jumping off, climbing
> up on the table, jumping, climbing up on the table, jumping off… she
> did not hold still the whole time. (P2 L 479, 488)

Mothers had concerns about their child's behaviors at a young age, usually before their child entered school. Some mothers became concerned when their child was still an infant or even in utero.

> Crazy thing was, when I was pregnant with her, I could feel her moving
> super early. And I know this is bizarre. And I kept telling my OB-GYN
> and he's like, no, no, no, it's not time. It's not time. And, and when it was
> the right time, he's like, so, are you feeling the baby move? Like, yes.
> Like, I've been telling you...(P1 L 176)

> She was always like extremely willful…even before she had hair, I knew
> she was gonna be a redhead, because she had a redheaded personality
> (chuckles). She was just like, extra fiery (P7 L 159).

Only one mother sought assistance immediately at the first sign of problematic behavior. This child was placed with her as a temporary foster child, although the parents

did adopt the child a few years later. The child made blatantly overt sexual statements

toward her foster father at only three years old, and the mother notified the social worker

right away.

> We had some red flags go up right away with placement. She literally
> would say to my husband, "Do you think I'm hot? Do you think I'm
> sexy?" And it was like, whoa! (P6 L 402).

Rationalizing Concerns

The participants did not seek assistance immediately but instead, they tried *rationalizing*

their concerns about their child's behaviors by blaming an outside factor as the cause of the

problem, the second subcategory. Mothers thought the behaviors were related to medical issues

during infancy, an adopted child's neglect or poor care by their biological parents, or just a

challenging personality. Other mothers thought these behaviors were just temporary, and related

to current circumstances, or possibly just in the mother's own head.

Two biologic mothers thought their child's early medical issues were to blame. One child

was born with a serious infection and had to stay in the hospital for several days after birth. The

other child had numerous infections and was having hearing problems.

> She had a double ear infection that perforated both of her eardrums...
> we took her to the ENT, and they did a hearing test. She passed her
> newborn screening and failed the hearing tests at 10 months. They
> automatically did, adenoids, tonsils, ear tubes, the whole gamut. She is
> the one in 200,000 children whose tonsils grow back!...L 197: she has
> had five sets of ear tubes. She has had her tonsils out twice. (P7 L 187)

Adopted children may not have ideal infant or pre-natal care, and adoptive

parents may not always know all of the details of their child's early experiences. One

adoptive mother described her daughter's neglectful and inconsistent care as an infant,

and thought her bizarre behaviors were related to her feelings of abandonment. Another

adoptive mother wondered if her daughter was confused and insecure due to the

shifting circumstances around her.

> Or I don't know if she was, you know, remembering what it was like
> living with her [biological mother] and she has some built up
> resentment about you know, being kind of dumped off all the time
> while mom went out and partied for ...because that's what she [child's
> mom] would do. She dumped her off with whoever would watch her
> and then, you know, take off for three days at a time. (P2 L 716)

> I think there was... a lot of confusion for her during that period before
> we were able to adopt her because she was like, "Where do I belong?
> Who do I belong to?" (P6 L 478)

Three mothers thought their child's reactions could just be a characteristic

of their personality. They rationalized that maybe this child's personality was

simply more challenging to live with.

> We thought she was just dramatic. And like any little thing was just
> such a big deal to her were like, just chill out, stop being so dramatic.
> (P5 L 247)

Three mothers initially blamed temporary circumstances, including COVID and the

resulting school changes due to COVID, or changes in routine. They thought these difficult times

were creating anxiety and stress, causing the child's outbursts at school. Since the stress was

caused by the situations, the mothers rationalized these behaviors would be not permanent.

> But when I talked to the school about it, you know, during COVID,
> everyone was kind of like, it's not ideal. (P4 L 166)

Finally, one mother started thinking "it was all in my head for a while" (P4 L 729). She

stated, "I felt like I started noticing things, but I was the only one noticing things," (P4 L 1206).

As time passed and the child's behaviors continued or worsened, the participants started

questioning their own rationalizations.

Escalating Suspicions

Participants discarded their initial rationalizations of the child's behavior as the outbursts and over-reactions continued. Participants described *escalating suspicions*, the third subcategory. All of the participants expressed frustration that "<u>nothing was working</u>" as participants had <u>continued problems</u> trying to stop the outbursts. Children who weren't violent were still frustrating parents with their unusual or bizarre reactions to mundane situations. For children who entered school, behaviors were now occurring in school. Participants got calls from teachers and told by others in the community about the problems occurring with their child. Participants' suspicions were escalating, and one participant said, "I started talking with other parents. My 'mom gut' was telling me something's wrong," (P8 L 219).

All of the mothers said their child simply did not respond to typical parenting techniques, either in terms of discipline or in terms of comforting. Mothers said their child seemed oblivious to grounding, yelling, or consequences of any type. One mother stated that spanking or yelling at her child never had the desired response, and only kept her daughter "heightened" (P4 L 551). Other mothers described how typical parenting just "wasn't working."

> Just anything that, like, we grew up being parented as, you know
> what our parents did, none… none of that worked. [nervous
> chuckle] So you tried to use the things that you grew up with those
> just.. in that quickly was like, Okay, this isn't working. (P1 L 152)

> I would yell at her to stop. N, just stop doing it! And then you realize
> she can't stop. So how do we make her stop? (P2 L 518)

Participants struggled to comfort their child when they were upset. A mother said nothing would comfort her child when he was upset. He would "scream, cry, scratch, hit, just completely out of control," (P4 L 220). One child, age eight, seemed genuinely confused why his mother was

hugging him, and would try to side hug, standing far apart, with only fingertips touching her

shoulders.

> There was a disconnect for him about…what are we doing? Why
> are we…why are we touching one another again? (P3 L 249). And
> then someone who doesn't like hugging, and so how do you comfort
> …someone who doesn't want to be touched necessarily? (P3 L 314)

Throughout the study, participants explained that typical parenting techniques, as they had been

taught or experienced themselves as children, were completely ineffective when used with their

child.

For children who had entered school, the behaviors were occurring in school as well as in

the home. Participants got calls from teachers and told by others in the community about the

problems occurring with their child. Their child was having serious problems in school,

including temper tantrums, inflexibility, inattention, or an extreme need to be in control. Mothers

were trying to help the school staff but were unable to affect the behaviors. One mother stated

her child would fly into a rage at school, "like zero to 60," (P4 L 412).

> Then in her second-grade year... we started to notice that there was some
> emotional issues, she was having trouble... with her peers, she had a
> couple problematic relationships with her peers, very, like kind of love-
> hate relationship, or most where she couldn't stay away from these
> children.... having arguments with them. And when she got upset,...she
> would have physically, like hit them or pull her hair or something like
> that. (P4 L 170)

Another child's outbursts were so out of control the police needed to "lock down" and clear the

classroom for the other children's safety. One child's need for control was so strong that she

complained that her first day of school was the worst day of her life, because "the teacher was so

in charge!" (P7 L 228).

However, various situations made it harder for the participant to know if their child had a

problem or not. Children often "suffered in silence," and did not always tell their parents of the

problems they were facing in school or within themselves. One mother had two children with

emotional disturbance, and both experienced abuse from different teachers at different schools.

One child was being pulled from the classroom and berated by her teacher for her dyslexia,

telling the child the dyslexia was not real. Her other child was being physically hit, kicked, had

her chair removed and was seated in the corner by her teacher. Neither child informed their

mother of the problems they experienced at school, and the mother found out from other parents

or teachers, not from her children.

> I would have never known. Because "D," "D" felt that, you know, she was
> doing wrong (because the teacher was punishing her) (P1 L 482).

Another mother was unaware her teenage daughter was only getting two hours of sleep

per night due to the child's extreme anxiety and drive to be "perfect." The mother trying to give

her teenage daughter space and privacy but had no idea her daughter was subjecting herself to

these lengths.

> Because she's so overachieving. I mean, she was in every AP class you
> could think of... she was not sleeping, because apparently she was up to
> four o'clock- and we found this out later- she was up till 4am every
> morning studying, and just getting a couple of hours sleep. And then
> going to band practice in the morning at 6am. (P5 L 591)

Her daughter was getting good grades and appeared successful, so it was more difficult for the

mother to know the true extent of the child's problems.

Sometimes a participant's spouse did not notice the problems or thought the child's

behavior was not that concerning. One participant's spouse felt their daughter's behavior was "an

excuse for her to be on medication," (P5 L 374). Outside family members directly blamed the

participant for the problems, indicating they just needed to apply typical parenting methods more

stringently.

Some of the other family wasn't so supportive because they thought, maybe
that I was the problem. (P6, L 1372).

Eventually, the participant's suspicions escalated to the point that each mother decided that

"something" was definitely wrong.

Deciding: Something is Wrong

"Deciding something is wrong" was gradual process for some participants, while other

participants had a specific catalyst which prompted this decision. Some mothers described a

specific event that convinced her that something was truly wrong with her child, and this

problem required a professional evaluation One mother immediately knew her adopted child had

an emotional problem when her three-year-old child made overt sexual comments immediately

upon moving into her home. Another family had a close friend commit suicide. This friend's

death prompted the mother to approach her teenage daughter with the mother's concerns and

have a discussion about mental health. During this conversation, the daughter agreed she was

having problems and requested a formal mental health evaluation.

I think she just knew that, that she didn't want to get to the point of our
neighbor who'd never got help, never got on any type of medication. (P5 L
234)

But for other participants, coming to this decision took longer. Other life situations

diverted attention away from the child's behavioral problems. These situations included health

crises in other family members, siblings with more obvious issues requiring attention, the child's

own physical problems, or discovering a teacher abusing the child at school. Eventually, each

participant came to the conclusion that despite any circumstances, their own initial

rationalizations, school problems and problems at home, their child did indeed have "something"

wrong, even if the participant was not certain what the "something" was.

> Like I said, started to get more like this...something's not right here. Like something's, you know, her responses aren't normal. Well, I hate to use that word. But her responses are not the normal responses (P4 L 734).

> Then I was like, well, I don't think this is just a phase anymore. (P8 L193)

This decision led all of the participants to seek a professional evaluation of their child and their child's behaviors.

Confirming: Consulting Experts

All eight participants *confirmed* their suspicion by *consulting a mental health or childhood development expert* to evaluate their child. Each participant's child also received an acknowledgement, agreement or a specific diagnosis confirming there was indeed something causing their child to have emotional or behavioral outbursts which are outside the range of "normal" for other similarly aged children. The participants tapped into different realms of expertise, including counseling therapy, psychiatry, pediatricians, occupational therapy, and early childhood education experts. For many participants, this was consultation also became the initial treatment employed to address the emotional disturbance.

Even though all participants found experts to evaluate and diagnose their child's emotional disturbance, most participants encountered significant barriers to receiving this assistance. Only one mother, whose adopted child verbalized sexual comments at age thee, received an immediate expert evaluation and support. The remaining participants all experienced either a delay or other barriers to accessing expert care. Participants learned these types of experts had long wait lists and could be expensive. The consultations required time away from the participant's job to attend. Lastly, experts did not always agree with each other, leading to multiple consultations. Some experts still told participants their child was just "slower" than

others but did not think the child had an emotional disturbance. Participants had to sift through divergent opinions to decide the best route for their child.

> (The first child development department) had told me, "It's okay, he's just a boy, boys are delayed, it's fine. You don't have to worry about it." (P8 L 175)

> In the testing with the university, he wouldn't read, or couldn't read, what was put in front of him. But he would do... nonsense sounds, and that he would parse out for them read perfectly...there was a lot of kind of, Is he? Isn't he? Is it....what's really happening? (P3 L 455)

> I really pushed for, you know, a Q EEG, and a psych eval and all the things, I fought with them tooth and nail to get all these things in place for her. (P7 L 511)

By receiving the diagnosis, or at least an acknowledgement, that there was indeed an emotional problem from an expert outside the family, the mothers were galvanized into action.

Research Question 2a: How do these parents respond to the situations and challenges that arise due to their child's ED?

Actions and Adaptations

Now that the participants' suspicions were confirmed, participants had to figure out how to manage the situations that were happening due to their child's emotional disturbance. The second construct, **Actions and Adaptations**, emerged as participants seemed to leap into action. **Category 2: Responding to the Challenges** emerged from the vast range of attempted parenting strategies and adaptations that the participants used to respond to their child's problematic behaviors. Although some of the strategies were specific acts the participants tried, many of the actions were adaptations. Participants adapted themselves and the environment to better suit their child with ED, rather than focusing on changing the child's behavior to fit better with others.

Participants used a massive number of actions and adaptations to respond to their ED child's emotional and behavioral challenges and spent an enormous amount of energy and time engaging in these acts. The actions, adaptations and energy required by ED child's specific needs created new problems for other family members as well as the participant. Data was sorted into three main subcategories: *for the child with ED, for the parent: self-care*, and *for the siblings* in the home. Themes emerged from each subcategory. When discussing their child with ED, participants described <u>parenting using their past experiences</u>, <u>seeking expert assistance</u> (which included healthcare, government and schools), and <u>switching to intentional, planned reactions</u>. Within *for the parent: self-care,* participants talked about <u>connecting with others, getting time away,</u> and c<u>onsciously changing their internal thinking</u>. *For the siblings*, participants had to provide <u>protection</u> for other children in the home, as well as find new ways to provide these other children with <u>individual attention</u>.

Responding to the Challenges for the Child with ED

Participants initially tried <u>strategies based on their past experience</u>, which were often reactionary, authoritarian, and used punishments to control their child's outburst. Participants sought <u>expert assistance</u> from healthcare professionals and state agencies, as well as schools and education professionals. Perceptions about educational assistance was evenly divided, as four participants (with five children) experienced positive support from schools, while the remaining four participants (also with five children) found schools were one of the biggest and most challenging barriers they faced. As time moved on, participants switched gears from these methods and started <u>utilizing more intentional, planned strategies</u> rather than reacting to their child's behaviors.

Parenting using past experiences. As discussed in above, most participants found typical parenting techniques did not work with their child, which was one of the concerns that led them to suspect their child was "different." Even after learning of their child's diagnosis, some mothers continued to try typical parenting methods, which were based on their own childhood experience and referred to as "the old school way." This method used an authoritarian approach, and included yelling or anger, each "transgression has a punishment" response, or trying to convince the child to change.

> Very much what I would say the old school way, like, this is the rule.
> You follow the rule. Don't follow the rule, this is your consequence.
> (P4 L 1235)

> If your kid's a jerk, you just punish them. (P4 L 1299)

> I guess I was tough on them to just try to get them to stop being so out
> of control when we were at family functions and stuff. Because they
> would just be over the top! And it's like, Stop! (P6, 1375)

When mothers tried to convince their child with logic or persuasion, the conversations backfired and only made the child angrier. One mother said when her child wanted to quit activities, she "used to try to talk her out of it, or point out the good things," (P4 L 637). One mother tried to convince her child to watch a live-streamed graduation ceremony during Covid-19, and the blessing of having a way to experience the celebration, with the seriousness of high Covid-19 death rates. Her daughter was not convinced.

> And she didn't want to have anything to do with it. [daughter said] "I
> don't care about people that are dying!" (dramatically). It's what's in
> her world. (P5 L 443-445)

This parenting approach never worked for any of the participants. One mother said it very succinctly:

> I can tell you that yelling at her or if I was to hit, like…she **does
> not**…**It does not** produce the same response it produced in me as a
> child. She is…defiant. And it just keeps her…heightened. (P4 L 551)

Using outside expert assistance. All of the participants engaged a mental health or

educational professional to initially evaluate their child. Most mothers continued to use

healthcare professionals for help managing their child, which included therapy, medications, or

residential placements. One mother obtained support through her state health department for both

mental healthcare and legal support. All participants sought assistance through their child's

school. The participants' interactions with school experts were very divided. Half of the

participants (with half of the children) had extremely positive school interactions and support,

while the remaining half of participants had extremely troubling and frustrating interactions with

schools.

Assistance from Healthcare or Government Professionals. Seven participants consulted

healthcare professionals to help manage their child's behaviors. Participants tried psychiatry,

individual, group or family therapy, occupational therapy, and play therapy.

> We did play therapy was because she was having so many behavioral
> issues. (P2, L 218)

> Because we'd go to therapy, we'd go to family therapy. They would
> teach her how to manage her emotions and how to manage her...
> everything. (P6 L 693)

Therapy was very helpful for some participants. One child was much more relaxed with

occupational therapy, with the bright colors, gym, and toys to interact with: "she's like, this is

more my speed than sitting on a couch!" (P4 L 321). One counselor remained involved with the

participant's family for several years.

> [The counselor] actually stayed with [my daughters] from elementary
> through high school and we still talk to her...once she got to know us,
> she would try and help with, to just asking, how are things at home,
> what are you feeling at home? (P1 L 1098)

Some children had physical issues, blending the line between mental health and physical health problems. The problems included numerous ear infections, tonsil problems, tongue ties, vocal cord nodules, and delayed walking. Sorting through the various issues took time, delaying interventions.

> They found that she had lots of frontal lobe slowing, and we finally
> got, sort of like a good psych eval and some, like, solid, concrete
> data. (P7 L 513)

If therapy wasn't working, participants had a hard time knowing if the therapy needed more time or if the therapist wasn't a good fit for their specific child. Participants struggled to decide how long to stick with a specific therapist versus changing directions.

> How many sessions do we try with this person? How much time do
> we give them? (P1 L 161)

> She was seeing a counselor since September, so several months
> every other week, but there wasn't a great connection there. (P4 L
> 228)

Participants also dealt with long wait times or disagreements between professionals. One child had to obtain therapy via telehealth out of state, because there weren't any available professionals at her university. Disagreements between different types of professionals caused confusion and frustration. A child with both physical and emotional problems was repeatedly bounced between the pediatrician, the Ear, Nose and Throat specialist and the speech therapist. Each professional said they couldn't start treatment until another professional approved it, creating a round-robin situation the mother never resolved. She ended up teaching herself speech therapy from the internet, just to give her child some assistance, as the ongoing delays lasted

over a year. Due to these challenges, participants had to be extremely vigilant with experts and their advice.

> You're surrounded by these professionals, and so you can't get lulled
> into, "Oh well, it's all good with the doctor"…you have to be on it. (P1
> L 1414)

Medications were tried to reduce the severity of a child's behavior and were helpful for some children. One child was started on medication in kindergarten due to uncontrollable behavior. One mother found anti-inflammatory medications could mitigate some of her child's behaviors, if taken early in the behavioral episode. However, some participants were hesitant to try medications, while some spouses thought using medication was "too easy" or only used as a last resort. One teenage child asked to start medications to control her anxiety and depression, but both parents were reluctant to allow it.

> I wanted her to try other things...but she just wanted a quick fix. And
> my husband was like, well, don't let her [get on medication]! (P5 L
> 1240)

Medications did not always help. Sometimes, children refused to take the medications, or the medications were simply ineffective. In one case, the child developed an allergy to a very effective medication, amantadine, but the allergy meant the child had to switch to a less effective drug.

Five children had such severe outbursts that a temporary residential placement was necessary. Residential facilities were supposed to provide intensive therapy for the child over a period of several weeks. Two of the children had several residential placements at different facilities. Unfortunately, the placements were rarely helpful in terms of reducing the outbursts and two participants' children were worse off after going. One child was in a facility for 63 days, but her psychiatric condition actually worsened.

> It was a terrible experience…I wouldn't put my dog there…she was
> super aggressive in a way she had never been before…she was
> actually growling at us like an animal. (P7 L 476; L 487)

Another child was sexually assaulted by his roommate. His mother was furious when she learned

about the assault. She was even more angry when she learned the facility had not moved the

roommate from her child's room but expected her son to simply stay in the same room or be

discharged to home instead. The mother insisted the facility move her son to a private room that

day and continue his care. One child ran away from the placements repeatedly. For this child,

any behavioral changes after placement were temporary.

> She would go and we thought thing were going better. And she would
> come home and go right back, within months, back to the same
> behaviors. (P6 L 795)

Participants did feel residential stays helped by giving them a break from the turmoil and

chaos. Residential placements provided respite for the family members at home and gave the

participant and the rest of the family "an opportunity to breathe a little bit," (P7 L 541).

One mother was able to gain support and resources through her state's Department of

Human Services. She identified her child as a "child in need of assistance," which gained initial

access to state supported family therapy. She adopted her children, who both had ED, through the

foster to adopt system. As foster children, the state government would help find daycare options

for her. This was very helpful, because several daycares refused to care for her children after

repeated outbursts. The police came to her home after violent fight between the two children.

Seeing the chaos and obvious need for help, the officers themselves contacted the Department of

Human Services, which helped the mother find residential placements and respite care for the

family. She was the only participant who received this type of government support, but this

support significantly reduced the financial burden and delays that other participants experienced.

Two mothers had significant financial burdens related to their child's care, but surprisingly, finances were not a factor for other participants. One child's residential facility required a $35,000 payment upon admission, which the mother learned the day before admission. She switched to outpatient therapy but said the months of outpatient treatments, paid by credit cards, probably cost the same amount in the end. In a NI study, data analysis is conducted throughout data collection, and researchers should seek out negative cases which may refute the researchers "early reconstructions of reality," (Erlandson et al., 1993, p. 121). The researcher hypothesized finances could be a significant barrier and searched for negative cases by directly asking about financial impact in subsequent interviews. The researcher was surprised to find the initial financial concerns from two participants were not significant for subsequent participants. One participant's child received mental healthcare through services expanded due to Covid-19 and a strong employer insurance plan. She denied experiencing any financial hardship from her child's ED at all. Another participant obtained assistance and healthcare through her state's adoption agencies and state health department. Despite having two children with ED, who required multiple residential placements, therapists, and medications, she did not experience financial hardship due to the state support. The remaining participants did not have any significant financial impact related to their child's ED.

Seeking Assistance from Schools. All participants sought teachers' or educational professionals' advice and assistance. One child had not yet entered formal schooling, but all of the other children had some level of formal school identification and legal accommodation due to their emotional disturbance. Participants were evenly divided regarding their experiences with schools. Half of the participants, with five children, reported only positive relationships with their child's school, while the remaining participants (also with five children) said despite the

positive aspects of school and teachers, overall, schools were their worst battleground. The participants whose children were in formal school were all aware of the options and pathways to obtain special education support through the school systems. However, the school experience was "amazing" for some participants, and "horrific" for others.

Most participants described specific supportive school benefits, especially finding supportive and engaged teachers. Even when the school's interventions failed her children, mothers felt the school staff honestly tried their best. Participants said certain teachers were extra calm, extremely patient, and seemed unflappable during outbursts.

> That first year, Mrs. G, she was a saint. She loved "D." She loved the
> challenge [of trying to help her]. (P1, L 604)

This same teacher remained in touch with this mother as her children grew older. Years later, she informed the mother of serious problems her younger daughter was having at school. One teacher proactively contacted a different participant, in a curious, non-judgmental manner, to "get a better understanding" of her child after she had a ranting outburst during a student council meeting. Her child's teachers created pseudo-accommodations which helped relieve the child's anxiety even before the child was officially diagnosed or given "official" accommodations. These teachers saw her daughter's anxiety when other students finished tests before she did and allowed her to test in private rooms.

School accommodations, such as Independent Educational Plans (IEP) and 504c disability identification, were obtained by all children who had attended formal school at the time of data collection.

> In (public school), she got a lot more services. She got a lot more help.
> A lot more accommodations, you know, she got accommodations.
> Yeah, and when things were bad, you know, that's what helped the
> most. (P1 L 626)

These accommodations, which allowed for alternative assignments or extra time for homework, could reduce the child's stress and anxiety, but still provide education the child needs at a pace the child could accomplish.

> The IEP is very descriptive. I was very specific about what the IEP said, and I knew the power of the IEP to, you know, give a word bank to my child. (P3 L 423)

When participants understood the potential power of the IEP, they would leverage that power to turn down the tension in their home.

> That's when the accommodations would get really good. The math teacher gives "D" 50 problems to do. I'm like, does she really have to do ***50 problems***? [emphasized 50] What if we get 10?...Her counselor in particular would be like, Okay, well, what do you think you can get done? Or what can you try? Or what can you do? And then they (the school) would change, you know, her lesson plans, which was a great relief to me. (P1 L 1103; L 1125)

Two participants enrolled their children in alternative schools. For one participant, the alternative school had more safety equipment and staff trained to handle her child's aggressive behaviors.

> They had smaller class sizes, they actually had, the blue pads that you can hold up, when they (children) come to attack you?...And then they had counselors on site and tailored to kind of get him if they see him getting aggressive. They had a room that they would have him go and just sit and chill, to just try to chill out. (P6, L 948)

Unfortunately, this child did not improve in the new school. However, another participant saw great improvement when she enrolled her child in a public online school. Although she was initially disappointed that her child was not attending traditional school, she eventually found online schooling's inherent flexibility to be hugely helpful.

> My whole thinking changed with "C." Because, you know, I thought well, brick and mortar school and (local high school), there's other ways

> to do school. And so that's when my mind opened up with that, with online school. (P1, L 1139)

> When we decided, okay, we're going to do online schooling, I thought, Okay, this is the end of the world, but now it's better. You know, she could do her appointments. And it was okay, if she had a bad day. I was like, yeah, we can do the school on the weekend and watch all the lessons. And so, it was it was good fit for her...(P1, L 1470)

Unfortunately for half the participants, school interactions were negative, ranging from disappointing to frankly abusive. Problems stemmed from both individual teachers and from administration/ school system decisions. Even participants who spoke highly of teachers suffered as frequent teacher turnover wreaked havoc on carefully laid educational plans.

> Consistently, our team would fall apart every six, seven months or so. Someone would quit. Someone would move on. Someone would decide they didn't want to attend. (P3 L 1282)

Participants struggled to communicate with schools, receiving scant or no responses despite participants' active requests for progress information.

> I have sent probably countless emails saying, hey, do we need [School District child development program] involved or do I need to check out any other therapies on my own time, because I will gladly take him. Because I don't want him to be struggling when I can fix this, and I never got a straight answer. (P8 L 974)

Other participants tried to "teach the teacher" about interacting and instructing their child, or about how gluten affects her child's inflammatory response. Schools which were extremely responsive to peanut allergies barely shrugged at her child's gluten intolerance. A mother offered to buy her child's pizza or provide gluten-free snacks, but schools would not communicate when the special days were occurring.

> She was being willful. Well, yeah, but the problem is, when her brains inflamed, she can't write... Because that's like a hand-eye-brain coordination thing that sometimes she has a hard time doing. Researcher: "but she can do it when she's not in an inflamed state?" P7: Right. (P7 L 1167)

Participants shared their child's background and pleaded with teachers to consider their child's

emotional state to reduce inflexibility.

> But a lot of people, you know, they didn't know. And I gave them a bit of
> her background. And this is typical with children who had, you know,
> meth in their system, and have, you know, bad, very unstable
> backgrounds before they can get into foster care. (P2 L 1132)
>
> I was like, "You can give him his paci [pacifier]. If that means that he
> can participate, then you can give him the paci. I'd rather have him
> happy and participating then secluded and screaming." (P8 L 792)

Despite having legal accommodations, school systems could be staunchly inflexible, and

refused to alter assignments, class schedules, or grading, which harmed the children. Mothers

could not always force the schools to follow the IEP accommodations. One participant, whose

child was attending her own childhood school, was directly refused IEP support.

> The principal and the counselor at H Elementary school, where my mom
> had worked, (voice catching),..a "school of standard," told me "no, they
> would not." [follow the IEP] And they wouldn't help me with the IEP.
> (P3 L 687)

This mother sold their home, moving not only her child with ED but also his two siblings, to

another school across town, to ensure her child would receive his IEP accommodations.

However, problems continued, when teachers refused to grade her child based on his IEP

accommodated work, but instead based it on the grade level standard.

> I was told so many times that that the IEP didn't matter. That IEP didn't
> mean that they.... They couldn't give him an A in the class, even though he
> completed all the work that they had given him (emphasis "him"), but it
> wasn't fair to the other kids if he got an A, and the other ones didn't. (P3, L
> 1355)

Some school systems or teachers required strict adherence to the curriculum despite the

child's documented inability to meet the curriculum's pace and standards. These schools required

the child to give up all lunch time, recess, curriculars and still have several hours of homework

every evening, creating a ripple effect of stress from the child to the participant, and eventually

to everyone in the family.

> Could you give him less questions? Could you make sure he gets the crux
> of what the item is, you know? Can we can we not, you know, have him
> have to write it all out, because it's never going to come out correctly....
> Can he, can you use some of the assistance (assistive devices) things? And
> it would just be, "He's fine. It's fine. He can just come on after
> school."…He spent most of his time coming in after school to ... make up
> for whatever it was. It was, "This is the curriculum, there's nothing we can
> really do."   (P3 L 427; 433)

> Trying to get her to read and it was like, you know, cuz you'd have those
> reading logs. And I'm like, Yeah, you're killing me. I mean, she won't read.
> (P1 L 1123)

Some schools managed a child's by physically isolating them, causing additional

frustration for their mothers. School education is not just about test scores and curriculum, but

also about learning how to learn and social connections. Removing the children as a permanent

solution harms the child's ability to absorb both curriculum and social interactions.

> Because they go, well, we're gonna try this and see if we can do that.
> And like now, he has like his own little desk outside, with Legos that he
> gets to go to. Like he doesn't...he doesn't even walk with the class back
> to the classroom, from like, stuff… we can't make exceptions for his
> behavior like this. This is rewarding him. [with toys] (P8 L 977, 981)

> And I was looking at the desk structure. And the kids looked at me, and
> they're like, "Oh, your daughter sits over there... in the corner. " And she
> was totally, in the far end of the room with a desk up against the wall.
> And that's when I was like, they can't handle her here. (P1 L 562)

One school system scheduled a required math course, with six special education children, at the

same time as marching band, despite the mother's vigorous protests. Her child spent years in

private lessons to learn an instrument, waiting for the time they could perform in front of a

cheering crowd, but was never able to play in the band again.

And you have decided through your school, that the special ed kids that
are coming in, can't participate in band...you've decided that those kids
aren't worth.... because they can't do it...you've just other'ed them into a
place where no special ed kid at "K" High School can be in band…his
math class was always during band for the next years. That was that the
decision was made at a higher level, that those kids didn't deserve to be in
band (L 477; 517) I would love him to have the support of that
community. What a fantastic way for him to be able to function through
this. And it was taken (from him by the school).
Researcher: He never got to play in band again?
P3: No. (quiet, sad) (P3 L 494)

Mothers desperately wanted their children to receive their education and succeed, but

when the pace of school was beyond the child's ability, difficult choices had to be made.

Everything gets a little smaller, right? So, there aren't the big family
trips, you're not doing extra things because it's very home oriented,
there's just no time, whatever the... whatever the kids need to do takes a
lot longer for each and every one of them. (emphasized "each & every
one of them") So we probably conflated when "T" in school, we
probably conflated his schoolwork with "L"'s, but having them sit
together, there wasn't a lot of time to not like, you're both doing math
right now (P3 L 743).

In addition to schoolwork, one mother had to attend every school function as a chaperone

for her child, or her child would not be allowed to go. Essentially, "You go, or she doesn't."

There was one school year where I was just flat out told, "if you want
your kid to go on any kind of school trips, you will always be there with
her. And by the way, we're also going to give you two or three others,
you know, pretty much just like her and you're responsible for them."
(P1 L 391)

Worst of all were the children who suffered abuse from their teachers, apparently from

the teachers' frustration over the child's behaviors. One child was kicked by her teacher in class,

while another was berated that her dyslexia was "just in her head."

I found out that she was mentally abusing "C." L 1220: like for her
accommodations for dyslexia. You know…she's like, "that's just in your
head. That's stupid." You know, she wouldn't let her go to the

> bathroom, wouldn't I mean, would pull her out on the deck, of the
> portable (classroom) and yell at her and her other friend. (P1 L 1214)

> The teacher was hitting her, [researcher gasped] kicking her, taken
> away her chair, making her kneel on the floor at her desk. (P1 L 458)

Another teacher forced a child to run for an hour after school while other students watched him

and was called racial slurs by a different teacher. One preschool teacher refused to change the

child's diaper because he cried too much, resulting in bleeding diaper rash.

Children kept silent about the abuses they endured, and mothers discovered the abuse

from other teachers or parents.

> I would have never known. Because "D," "D" felt that, you know, she
> was doing wrong. (P1 L 482)

> Researcher: [clarifying] They may not tell you when an adult is
> doing something badly?
> P 1 : What's going on…yeah. Because they feel like they're, they're
> going to get in trouble, then it's their fault, yeah. And sometimes it is.
> Sometimes it's not. (p1 L 1438)

In all of the cases, the participants immediately intervened to protect their child. One mother

filed an ESC complaint, and another mother required their child never be alone again with their

abusive teacher. But protecting their children still came with a cost to these participants. The

abusive teacher was "beloved" by other parents, even though it was discovered this teacher

abused several other children, too. By exposing the abuse, the mother and her child were isolated

within the school by others who adored this long-term teacher. A mother offered to change her

own child's diaper every time if the teacher would notify her, since she worked at the same pre-

school. However, she was reprimanded by her boss for making such a request, even though the

lack of care was physically evident.

For the participants in this study, schools were either their child's greatest ally or their worst battleground. For the participants who found allies within school, school was full of opportunities for support and knowledge.

> When I meet parents, like, if they have a three- or four-year-old, and they don't have them and PPCD, and I'm like, why aren't you utilizing these professionals there? (other parents) "Well, I just don't think that it's the right place for him or her." And I'm just like, you have free help! use it! (emphatically) (P5 L 1428)

Participants recognize teachers have a difficult job and that teachers must balance needs of the overall class with the resources the teachers are given.

> Some school years were better than others, depending on the teacher. Some teachers are very equipped to handle kiddos who think differently, need different things and other ones are not. And some of it is, you know, how many kids do they have in the classroom? …It's hard for them, they've got to deal with a whole classroom. (P1 L 373; 383)

For the participants who struggled with their child's schools, school extracted a heavy toll. These mothers had to fight for their children, understanding that their child is not like the other children, but frustrated at the powerlessness to change the school environment.

> After a long day, when they're barely functioning at level anyway, to ask them to come back after class or over the lunch hour or whatever. And then he would come home, after being after school, and still not be done with his homework. And so, it was probably eight o'clock at night before we would be done with both of my boys doing "homework." (air quotes) (P3 L 534)

> But sometimes I feel like people don't think of the sensory aspect of things. They think it's just a naughty boy, who's acting out in class and can't sit still. [mocking voice at "naughty boy"] (P8 L 1011)

These extra battles lead a couple mothers to reflect on problems within society that are reflected within the schools' philosophies.

> Unfortunately, in the school system now, like the only way to get the services you need, is to be a thorn in their side. (P7 L 1231)

> What we're (schools) looking for now is not necessarily (educational) success, but expediency. They just want to get the child through.... this thing. (P3 L 1548)

Even as participants tapped into healthcare experts and schools for assistance, participants started changing their parenting approach. Mothers consciously shifted away from reacting to behaviors to intentional, planned responses.

Switching to intentional, planned actions and adaptations. All of the participants spoke of specific actions they used which were pre-planned and intentionally thought out. Major themes of intentional actions were 1) parent adapts self, 2) adapts the environment, and 3) teaching the child about the world. Most of these actions revolved around deliberately adapting the participants' own reactions and decisions or adapting the child's environment. Although many of the adaptations could benefit any child, these adaptations were required for the participants' children due to the severity of the child's outbursts. Actions which are *nice* for other children are *necessary* for children with ED.

Parent adapts self. All of the participants gave examples of how they intentionally changed their own responses toward their child. One mother described this as realizing she had a "special needs kid that needs a lot more and a lot different parenting than my other kids," (P7, L 566). When participants deliberately changed their own reactions, they were more successful both interacting and communicating with their child. Participants started planning with more realistic expectations of how their child with ED would likely react considering the environment, time of day, or overall requirements of the event. Adaptations included changing communication styles, praising small but good decisions within an overall outburst, defusing emotions,

emphasizing natural consequences, and deliberately avoiding battles. One mother called it

"responding with intentionality."

> We don't respond to the outburst. We respond with intentionality to make
> sure that he understands that there's safety and that there's a schedule or
> that there's boundaries. (P3 L 364)

Many participants changed their communication styles. One mother found sympathizing,

rather than conversing, worked better when her child was upset. She said, "I'm her sounding

board," and she stopped trying to share her own perspective when her child was upset.

> I know you feel that way, "O," but I promise you it's not. I know, it's okay
> to feel and it's okay to feel that way. But everybody has their struggles.
> Just remember that we're all struggling with something. So, I'm not
> saying things like "get over it," you know, "at least you're still on the
> team." You know, I didn't say I'm not saying things like that. Like I
> probably would have said when I was when she was a little bit younger.
> (P5 L 472)

When the mother changed to this communication style, her daughter was able to communicate

better with her. Then her spouse saw when the participant deliberately acted as only a sounding

board, rather than advising, the communications improved.

> I think he's starting to realize…He won't just demand things from her,
> he'll just give ideas. He's like, "I think she needs to come up with it on
> her own." (P5 L 959)

Another participant found she could negotiate with her son by changing her communication. She

is an introverted person who prefers extra personal space, but her son wants to touch her

constantly.

> And I'll always tell him like, Okay, Mommy doesn't want to be
> touched like that right now. I'll give you a big hug. And but, you have
> to give me some space. Not all the time, obviously, does he listen
> because he's still a kid. But he is like, "okay!" and kind of goes off.
> And then he'll come back for another one. (P8 L 593)

Participants adapted themselves in ways that seemed awkward but pressed on to help their children. One young child seemed confused why family members hugged each other. When he hugged his mother, he would lightly touch her shoulders with only his fingertips. The participant started intentionally asking him if it was ok for her to hug him.

> I intentionally ask him consent to, "is it okay if I hug you?" and then offer it every time he leaves to go on the bus… "Okay, we're gonna hug now, if it's okay with you." (slowly asking, then fast "if its ok")... You're asking consent of an eight-year-old (P3 L 241- 248).

Another mother altered her role to join whatever group, club, or hobby their child was interested, knowing her child's participation in the group may not last long.

> I swallowed my pride and go in every year and Okay, well I'm gonna be your best friend. I'll be your best horse friend, you know, as a parent. Here's what we're gonna face. Let's see how it goes. You know, help me help you. (P1 L 999).

Both participants felt awkward doing these actions, but as one mother stated, "It's really not about you, it's for the child." (P1 L 165).

Mothers deliberately avoided battles. One mother frequently chose to simply walk away or ignore behaviors that did not harm or disrupt others, even when her child's behaviors were against convention.

> She'll bark like a dog [at the store) and you know, I'm going, "N," just stop barking at people today. And of course, they think it's funny. Some people give me weird looks but... Your kid's barking? Yeah, she is...[but] it's not really hurting anybody if she walks by and goes, "ruff!" (P2 L 815)

Another mother also said avoiding arguments was more effective for her.

> Because she just wants to argue. So, if I stop arguing, usually I have better results. (P4 L 648).

The researcher and the participant compared avoiding arguments without emotion as similar to playing tug of war, but then dropping the rope. Without holding the other end of the rope, the

child has nothing to tug against. This mother also handed over control to her daughter, allowing

her daughter to decide when and how her mother could comfort her.

> I'll be like, "Can I come and sit with you?" And I get like, (from child,
> angry voice) "No, go away!" or I try to hug her, and I get "Don't touch
> me!" And then when I back off, or I do try to go away, (then) she
> goes, "Oh, Mommy." (sad, whiny, and reaches for a hug). And then
> that can help calm her down. (P4 L 589)

Along with avoiding battles, mothers prioritized defusing the emotional turmoil over

responding to the emotional outburst or bad behaviors. One mother learned "she's incapable. You

cannot reason with her until she's finally calm," (P4 L 561). Therefore, she was trying to change

into "calmer parent" to "defuse the situation," (P4, L 480, L 550). Sometimes, the defusing stage

was difficult, and this meant asking the other parent to take over in the middle of the storm.

> My husband and I both definitely, like have to walk away sometimes
> because they're just pushing and pushing and pushing. And we know we
> can't fly off the handle. So sometimes we'll walk away and be like, "I
> gotta walk away for a minute!" (whispered urgently) (P4 L 574)

The participants found that defusing the situation first, and dealing with the outburst later, was a

more effective approach than reacting to the outburst immediately.

No individual technique worked every time or for all participants, and this was the case

with defusing, walking away or taking time outs. Mothers would take their child home if they

were acting out too much in public, telling their child to "just be kind in respectful, and we

won't have to leave," (P8 L 649). Another mother with two children with ED frequently had to

leave restaurants due to the children's outbursts.

> I was tough. You don't get away with these behaviors, like if they were
> misbehaving. And when we were out at a restaurant, I would leave, I
> would be like, "Okay, let's go, I'm not going to do this at the restaurant."
> I used to do this in public. And I guess I was tough on them to just try to
> get them to stop being so out of control when we were at family
> functions and stuff. Because they would just be over the top. (P6 L 1373)

However, sometimes children would defy a time out or continue with defiant behaviors despite

the participant's actions. The participant may stay outwardly calm and resolute, but the child may

continue to rage.

> And he pretty much said to me, "F-U, you F-ing 'you know what," I'm
> not gonna stay here. I'm not gonna do any of those things." And I was
> like, "Well, I'm sorry. But that's gonna be the rules here now." (P6 L
> 1505)

Seven mothers altered their personal expectations to be more realistic for this specific

child. One mother knew any call from her daughter was only going to be about her daughter,

with no questions about other family members, so she changed her expectation to be a "sounding

board only" during these calls. Mothers planned extra time for a child's resistance to the time

schedule or placed themselves in areas to minimize disruptions to others.

> I know that when I take her to church, we're going to be up and down
> and up and down and go to the bathroom, and coming back in and go the
> baby room and get up and coming back in… So, we try to take a seat
> that's towards the back and away from other kids. (P2 L 1062, L 1074).

Mothers considered if the environment would affect their child. One mother said her child

"doesn't do well in hot and cold, big temperature changes," and these temperature changes

would spark an inflammatory behavioral reaction (P7 L 358). Sometimes mothers adjusted a

location for gatherings with friends to be outdoors instead of an inside location.

> There's certain settings that we know that we can take him and if we're
> gonna go out to the apple orchard where he can just run free. That's a
> better experience for him than going out to dinner with everyone. (P8 L
> 573)

Lastly, six mothers intentionally switched to a "natural consequences" viewpoint, while

simultaneously looking for small, but smart decisions their child made even in a storm of bad

behavior. Participants explained this did not mean no consequences or that they would argue

against a school punishment, but they decided not to "concoct a punishment for later," (P4 L 677).

Natural consequences ranged from mild to serious. When a child threatened to throw away her art project, her mother responded, "If you throw it away, there's food in the trash can, it's gonna get gross," (P4 L 616). Another mother explained, "there's no punishment for a bad grade, [because] the punishment exists already," - the grade itself (P3 L 793). Serious natural consequences included school suspensions and police arrest. After her daughter was suspended for fighting in school, the principal was surprised when the mother did not argue about the punishment.

> I'm not gonna fight her going to [in school suspension]. It's not appropriate. And I looked at her, I said, "it's not appropriate, you can't do that, you should have gone and talked to the teacher." I said, "but you did it yourself." And I said, quite honestly, "she's not going to be in trouble at home, because she stood up for herself" [against a bully] (P1 L 948)

One mother notified the police herself when she learned her child had robbed a store, "because I'm not that mom," (P6 L 1460). However, she continued supporting her child and allowed him to keep coming back home even after repeated arrests.

By removing themselves from administering additional punishments, participants saw and praised the good decisions buried within the problem. Another child who frequently lashed out from anxiety told her mother she only felt bad for 30 minutes and used her emergency medication. Her mother recognized the progress, saying "I'm proud of you! That's good!" (P5 L 504). When a child struck a peer at school and started to run away, the principal advised her to make a "better choice" (than running away). The child stopped, and her mother praised her for this good decision within the overall conflict (P4 L 399). For a child who really struggled in school, his mother supported his efforts, without focusing on the outcome.

> You're at school, you're doing the best that you can do. Here's the deal.
> I'm not going to argue with you about a good decision that you make.
> You've done the best that you can in the situation and it's okay with me.
> (P3 L 790)

Other participants used praise and rewards in a more traditional manner. A mother would recognize stressful situations, and say, ""Guess what? You're not losing it! And I'm proud of you!" (P5 L 492). One child was always moving during church, and didn't appear to be paying attention, but she knew all the answers to the pastor's questions. She would glow with the positive feedback:

> You knew all the answers to those questions, you did a really good job,
> and she'll be proud of herself. (P2 L 1101)

Another participant combined her child's love of loud, crazy energy with schoolwork.

> "L" liked being able to choose a song to play really loud. So, if he
> finished his worksheet, it was called Dragon Dance. When homework's
> done, you get to pull your name out and get to choose any song you want,
> and you get to dance as fast as you can, as big as you can. (P3 L 1639)

All of the participants adapted themselves to their child, so they could interact with their ED child more effectively. Participants "reacted with intentionality" and decided in advance how they were going respond to the ongoing challenges from their child's ED.

Adapts the environment. Just as all of the mothers adapted themselves to their child, they all made significant changes to their child's environment. Rather than changing their child to fit into the world, mothers tried to find the right setting for their child, to give their child the best chance of success. Two mothers adjusted their child's diet or clothing to decrease their child's reactivity, while several mothers focused heavily on safety measures. Six mothers changed or adapted the actual setting for their child, by changing schools, peer groups, outside support, or things within their home.

Two mothers found changes in the home, such as using timers, an uncluttered house, or avoiding certain foods decreased their child's reactivity.

> Timers are a huge thing in our lives. We live by them. So, if we are leaving the house and I accidentally don't set a timer, it's a very hard situation to leave the door. He has to hear it. He has to be prepared. (P8 L 460)

Both mothers adjusted the foods or substances in their child's diet or clothing to mitigate reactions.

> I didn't care how badly I struggled, I wanted him to have the best diet he could have, because I knew that was gonna affect behaviors. So, we were on the Paleo diet. (P8 L 704)

This mother also tried using organic diapers and diaper paste to decrease any reactions within her child's system. She also found that certain foods would soothe him, such as spicy gum. The spice sensation in his mouth seemed to soothe him and refocus his attention. Another mother found her child had inflammatory reactions to gluten, and was extremely sensitive to fluctuations in blood sugar, hydration, and electrolyte changes. She would encourage her child to eat protein and take electrolyte packets with her to school, as well as give her homeopathic supplements to decrease inflammation.

> Lemon balm for calming, magnesium, potassium, and valerian root for sleep, and then all the big-time probiotics (P7 L 1048).

This mother also found ibuprofen helpful to decrease inflammation, which could decrease behaviors if taken before the child got too out of control.

Mothers focused on creating a safe environment for their child, especially during an outburst. Safety measurements included monitoring the child during medication adjustments, ensuring they aren't exposed to dietary triggers at away from home, moving away from threatening family members, or physically restraining their child if the child was out of control.

> When she gets upset, she wants to run. She wants to leave the house. We
> have to kind of physically stop her, as in standing in front of the door,
> closing the door. (P4 L 218)

One mother's child would self-harm when she was upset, and this mother said safety was always

the top priority: "just to make sure I keep her safe," (P1 L 344).

Most participants adjusted the physical environment for the child. Seven participants

found doing physical activity together with their child was helpful. Often, the child controlled led

most of these activities.

> Let's go for a walk. And once we get out, we start going for a walk, then
> she calms down, we can just kind of start talking and, and, you know, I'll
> say, you pick the direction, and I'll just go where you want to go. And
> that, that seems to help calms both of us down and, and we're doing
> something together. And, you know, I'm not yelling at her and, and, you
> know, she's feeling relaxed and, and everything. (P2 L 1013)

Another mother with two children with ED became highly involved in physical clubs and groups

her daughters were interested in, and used these activities to demonstrate her commitment to her

girls:

> I was able to be involved in activities…If it's important to you, it's
> important to me…girl scouts, band, swimming. (P1 L 1005)

One participant's spouse took the lead on physical activities with their ED child.

> And then he's also the one to intentionally say, okay, twice a year,
> whatever, you guys are going out in the woods, and you're going camping
> for a few days, because around a fire, shoulder to shoulder, men going
> hiking in the woods. (P3 L 944)

Participants found the togetherness of the activity reduced their children's behaviors as well as

increased their own bond with their children.

Participants continually committed to new peer groups or activities to enhance their

children's opportunities. One child had repeatedly run away from placements over the years.

However, she wanted to re-start by taking new job but needed transportation. Both parents would

re-engage to support her.

> [she would say] "I'm gonna do that job. I want to go to college." And he's
> like, "hey, you know, if you're willing to do it, I will support you again."
> (P6 L 864)

Other participants would try groups such as scouts, martial arts, or band.

> We thought we had found something with band...And he was ready to
> start band, he'd gone to band camp, he had done it all through junior
> high…This could help him really want to go [to school], he loves
> performing. He loves that noise. And that sound is just fantastic for
> him…We have spent years on private lessons. (P3 L 462; 473)

This approach was not always successful. One mother thought starting an in-home

daycare might provide her son with instant peers. Unfortunately, her son did not adjust to having

other children in the home, despite playing together well during visits (P8, L 888). Ultimately,

she decided to disband the daycare because of the problems it caused for her son.

Mothers made big environmental adjustments by changing their jobs, changing schools,

changing living arrangements, and even selling their home and moving. Three mothers changed

jobs or left their jobs so they could provide more direct care for their children. One participant's

partner moved into her home to provide childcare at night, while another participant had to move

out of their home because their partner refused to care for her child when she wasn't there. Five

participants, one with two children with ED, had to change their child's school. This included

changing from private schools to public schools, public schools to online schools, moving to a

smaller town with smaller schools, or because a school bluntly refused to follow their child's

IEP.

> We did have to switch schools because one of the schools refuse to.... to
> enforce their IEPs. They told us that they didn't have enough money to
> go ahead and do IEPs at "H" elementary school… we moved across

>town to the east side of town, to a different school where my mom knew
>the principal. (P3 L 677, 691)

Participants had to make these life-altering changes to get what their child needed. One mother was asked why she chose to live in a small town without a lot of heath care options and farther away from her own parents.

>I've made the choice to live further away from home, just because … I
>feel like for "C," it's easier for me to make things happen for him. (P8 L
>421)

Some adaptations left lasting frustration or were impossible to make. A mother was told by her son's school principal the school was not going to follow the IEP at all, and her only option was to sell their house and move to another school.

>So, we moved across town to the east side of town, to a different school
>where my mom knew the principal…I picked a house that was in the
>district that I did not love. So how did we manage home life? It was
>everything! (P3, L 691).

She and her spouse lost their dreams to raise their children in their childhood neighborhood and attend their childhood schools. Her son, as well as his siblings, lost their classmates and home. Her entire family lost things in the effort to get the school support her ED son needed and was legally entitled to. One adoptive mother who had two children with ED had tremendous violence erupt between the two children. The children would fight to the point of drawing knives and police were called to stop the fighting. A therapist told this mother she may have to pick the one child to live with and send the other child to foster care: "you can't live with both of them [because] they can't live with each other" (P6 L 975). This was an impossible choice for this mother. She never considered going through with this option, despite the ongoing sibling violence.

Teaching the child about the world. Lastly, seven mothers tried to expressly teach their

child implicit social rules of interacting with others, since the child with ED wasn't absorbing

these life lessons independently. This included directly explaining about other's feelings and

appropriate behavior for school versus professionals' behavior seen on TV. For example, one

child loved watching professional soccer and played on his school soccer team (P3 L 1124). He

would mimic a superstar's celebration moves on his school field. His parents tried to teach him

that these behaviors are not acceptable in high school level play. He struggled to understand why

he couldn't act just like the superstar player, despite being given penalties for his

unsportsmanlike celebrations. Another child would aggressively run up to other children or even

strangers to hug them. Her mother tried to teach her child about others' feelings by explaining

how a person looks when the person doesn't want to be hugged.

> I'll say, "N," I don't think she wants a hug right now…they look angry
> and trying to push her away. And we're trying to teach her you can't
> really just walk up and hug people! (P2 L 792)

Children with ED don't innately perceive or register these implicit social rules within their own

mind. The participants' children would not understand they were breaking social rules, but only

feel rejected.

> She'll say, kids don't like me, and I say, well, maybe they're just...
> because she can be so overbearing. I said, well, maybe, you know, they
> just weren't in the mood to play what you wanted to play. And you
> know, I, I don't want to come out and tell her well, that's because... you
> scare them. (P2 L 774)
>
> There's is always just an innate [pauses for thought] deficit when it
> comes to making and maintaining friendships, you know? She just
> perceives a lot of slights (P4 L 905)

Teaching the child about the world was very difficult when the world was treating the child badly, but the child couldn't see it as wrong. When a mother learned her child was being isolated from the class by an abusive teacher, she took measures to stop the isolation. This upset her child, because the child didn't perceive any problems in school, even if her desk was in a corner far away and the teacher was kicking her as punishment.

> It's not okay for you to be punished. It's not okay for you to always sit in a corner away from the class. Like. so far away from the class, [emphasized with her hands as far away] and I'm like no, it's that's not how it's supposed to be. (P1 L 607)

Despite the difficulties for the child to perceive acceptable social interactions, all of the participants had stories of when they tried to actively teach their child the unspoken rules of society.

When participants switched to intentional, planned reactions, their reactions were based on three major areas: adapting themselves, adapting their child's environment, and directly teaching their child about implicit social rules. All of these actions and adaptations could be considered "just good parenting" and may benefit all children. However, children without an emotional disturbance possess an inherent adaptability than a child with ED does not possess. For parents raising a child with emotional disturbance, the actions and adaptations they utilized were not simply ***helpful***, but ***essential*** to giving their child the best chance to become a functional adult in society. The prior literature regarding children with ED showed that these children face significant problems when transitioning from childhood to a functional adult member of society. The consequences of ineffective parenting are very high for children with an emotional disturbance.

As expected, no single strategy worked all the time for any participant. Participants had individual challenges of having two sets of rules due to a divorced household, or children who

repeatedly ran away or engaged in criminal behavior. Furthermore, children were sometimes just overloaded, and didn't respond positively to the most intentional of actions. One mother told her son, "I'm going to walk away, you're safe in your spot," (P8 L 225) and would "let him just lay there" until the outburst was over (P8 L 223).

For the parent: self-care

Even with a well-constructed plan in place, executing the plan required significant energy and self-control by the participants. The wide expanse of actions and adaptations the participants used, as well as the ongoing challenges the child's ED created, sprouted a chain reaction of additional needs and problems for the participant as well as other family members. Participants were asked what actions they did to help themselves during these times. Major self-care themes across multiple participants included <u>connecting with others</u>, <u>time away</u>, <u>consciously changing their internal reactions</u>, and <u>therapy/ belief systems</u>. In addition, some participants found independent <u>researching</u> helped their emotional state, while individual participants focused on <u>personal safety</u> or <u>unhealthy choices</u> such as alcohol use or obsessive cleaning.

All participants stressed the benefit of connecting with others, especially their spouse if they were married. Married participants spoke highly of their spouses, and two mothers had been married for more than 30 years. One participant became tearful, thinking of her spouse: "he's my best friend. So, we always work our way back," (P1 L 816). Another participant made a pact with her spouse to always support decisions made in the absence of each other.

> We made agreements. Basic agreement is whatever decision you make,
> you've made the best decision you can make, we will never argue about
> a decision somebody else makes. And that conversation happened with
> my spouse. (P3 L 784)

Participants <u>connected</u> with other family members, friends, and coworkers, which let participants

to vent, do activities and relieved isolation. One mother said the therapists in her office were

"amazing" and "a great supportive network," (P7 L 977), while another mother's friends would

check in on her personally, "Hey, how are you today? Like how are *you*? Not, just, how are

things." (P8 L 636). Participants found friends and allies who were understanding, sometimes

from places they worried would be unwelcoming.

> Some of the ladies said, Yeah, we noticed that she's pretty active in
> church, but it doesn't bother us. We want children in church, that's our
> future. And so sometimes I think some of the stigma is more my
> perception and my expectations than, you know, other people's.
> They're not as bothered as I think they should be. (P2 L 1139).

Participants, especially adoptive mothers, found other parents dealing with similar problems.

> Over the years you find those other parents that are having those same
> struggles. So, you make your own little group of friends. (P1 L 238)

> The teacher adopted two kids who are drug babies…And that she has
> two adopted kids that were in the same position as "N." And she's
> very, she's a very patient and understanding with "N." (P2 L 884)

Participants said their friends, family members, allies and spouses sustained them through tough

times.

Unfortunately, sometimes participants were disappointed and hurt by their friends or

spouses. Two participants sadly walked away from some friends because the friends couldn't

handle the participant's situation.

> I thought the lady was my friend. [paused at 'thought'}And she's like,
> well, what's going on [with your daughter]? I would tell her, and
> because, you know, she was acting out. And she's kind of looked at
> me, and she's like, "wow, well, she looks really normal." [P paused,
> looked away, eyes tearing up] (P1, L 207)

> Some people just don't have the patience. And I don't get mad at it
> anymore. I used to take big offense to it. But then I'm just kind of
> like, okay, if we're all stressed, he feeds off of that stress. It's
> probably best for all of us. (P8 L 570)

Their child might have a crisis which interrupted plans with friends, who may not understand

why the participant had to leave immediately.

> You go out to dinner with your girlfriend. Oh, sorry, I gotta cancel, or
> oh, I know we haven't eaten but I need to leave. Or, you know, there's
> not...there's not a lot of people that can handle that and not take it
> personally. (P1 L 1358)

Participants tried to take <u>time away</u> from their heavy responsibilities by going to work,

playing piano at church, personal passions or just taking a drive. Participants volunteered for

their local special needs community, exercised, or did little creative projects to get mental down

time.

> I'm glad to get [my job] done and go home, but it gets me away
> from…from that [chaos] and from her, which sounds terrible (P2 L 999).

> I know when I do play (piano for my church), I just I leave her at home,
> and I just go play and that's relaxing. And it's just, it's nice to sit in
> church without her, you know, her antics and things, I can just sit and
> just play. (P2 L 1082)

> I'd literally just go for a drive, just go find somewhere quiet and sit in
> my car, away from chaos, because I just I couldn't deal with chaos at
> that point. (P6 L 1352)

Some participants' family members would provide childcare to give the mothers some respite

time and another divorced participant got respite time when Dad's weekend for her child to visit

(P7 L 769).

Getting time away was always reliant on having people who could physically take care of their child with ED. Finding people who could provide care was a frequent problem, increasing the stress and workload on the mothers.

> So, he [spouse] tries. And sometimes it's great, and it works. And other times, I get the call, "okay, you've got to come home," or "this is what's going on, I don't know what to do. How do I make it better?" (P1 L 698)

> [My in-laws] could never take both of the two together, the adopted ones, because they were too much. They would physically harm each other all the time. And so, one could go, the other can go but not both together. (P6 L 749)

Another mother was fearful her child would lash out and run away. She constantly worried that her child might harm someone else if she was not there to watch her. After her child got upset and ran away from her grandmother in the mall, her mother was hesitant to even try to get respite.

> I almost need it but don't want to do it because I'm just too worried.
> (P4 L 817)

Even if the child wasn't violent or in danger, the child's actions would overwhelm and wear others out. Participants had to be careful to not ask any one person for assistance too often.

> My adult sons watch her, and I know sometimes they've had to get after her... my one son, I was over there picking her up He kept saying, "N," you know, get away from there. "N," don't do that with the dogs. And she wears people out... I go to get her, and I [would ask] "how'd she do?" "Oh, she was... she was okay" [downward inflection] (P2 L 902)

In addition to external sources of support, six participants consciously changed their mental reactions to relieve their own pressure and stress. Mothers considered where their own emotional reactions originated from.

Now, I try to not take it personal. (P5 L 1054).

My mom, who I love, crossed some lines physically with us and wasn't the greatest disciplinarian, in that she was a little bit too excessive. And I don't want that…I don't want to say trauma, like I don't feel traumatized, necessarily, but it may be a little? And I just don't want that negativity there. I don't want that trauma there. (P4 L 493).

Mothers started prioritizing the "here and now" issues while letting go of "normal" expectations. One mother described it as using a series of baskets, while another mother strategically divided up the responsibility with her spouse.

"A" is safety, always. Move items from "C" up to "B" as you can…And still to this day, that's pretty much how I think, you know, when things come up, but I go, What's in my "A" basket? What's in the B's? I don't even know that I care about "Cs" anymore. (P1, L 1039, 1065)

Being really, really careful about boundaries. selection of between me and my husband of who's responsible for what meeting. Who's doing.... The breakdown of what's happening..(P3 L 728)

Once this mother and her spouse divided the spheres of responsibility, she said:

We're going to do what we can, when we can, we're going to divide and conquer. And we are going to let whatever happens....go (P3 L 805)

By focusing on the current moments, mothers avoided overwhelming themselves with worries about the future.

The challenges of a kid like this in high school and in college. And when I'm like, oh, I can't go there yet. (P7 L 1033)

[researcher: how did you manage?] [participant sighs] That's a good question. [starts laughing] I don't know. It was, yeah, I don't know. Day at a time, sometimes it was a minute of time. (P6 L 1067)

Mothers balanced focusing on the "now," trying to keep a positive outlook by riding out the highs and lows that came with raising a child with ED. One mother said she would "try to focus on the good times, when things are going really well," (P1 L 332). Another mother was

advised to "ride the wave," because "one day it might be one thing, and the next, it's completely

different," (P8 L 553). The lows got very bad for one participant, who shared she was so full of

despair that she considered suicide. When asked what stopped her from harming herself, she said

the love of her spouse and her oldest son.

> P: My husband and I have a great relationship. And I couldn't do that to my
> oldest son, ..it wasn't going to be fair to him for me to check out because I
> couldn't handle their behaviors anymore.
> Researcher: You didn't want to abandon your husband or oldest child?
> P: right. right. [voice very quiet here] (P6 L 1077)

These mental adaptations reduced the stress and increased mothers' sense of purpose.

A few participants reduced their stress by getting mental healthcare themselves or with

their religious faith. Three participants discussed getting professional therapy for themselves, and

another also started anti-anxiety medication when she was particularly overwhelmed, which she

said helped tremendously (P4 L 1088). Group therapy was helpful for an adoptive mother,

because she found other adoptive parents going through similar situations (P6 L 635). Therapy

wasn't always available, and mothers needed someone to provide childcare while they attended.

Two mothers relied on their faith in God to sustain them.

> I believe in God. So, I know, it's what He's planned. And I know, my
> girls are exactly the way He wants them. Sometimes, I'm not sure that
> He equipped me with what I needed. [researcher chuckled] We talked
> about that occasionally in my heart of hearts. (P1 L 328).

The participants' faith in their children and in life was strong. One mother reminded herself that

"life takes us in weird directions," (P7 L 922). Lastly, another mother held on to her

"constant belief…that my girls can do whatever they want. I just had to keep finding that

environment for them to be able to do that," (P1 L 996).

Finally, a few participants dove into research, set up personal safety measures, and

occasionally, used unhealthy coping strategies, such as alcohol or obsessive cleaning. Mothers

researched using published books and articles, as well as social media such as TikTok and

Facebook.

> I tried to read and get as much information as I can, you know, parenting
> type stuff. And honestly, it's kind of helpful to know that you're not alone
> in it, by... by reading these books, and by watching these different like
> TikTok's, and Facebook things and videos. Because while I'm not
> personally engaged with these people, it is helpful to know that wow,
> like, other people are dealing with this stuff, too. Because that's actually
> reassuring...it's hard to be the one with the kid who's the problem child, if
> you want to call it that. (P4 L 1113)

Finding anyone, even strangers, dealing with similar behavioral problems reassured the mothers.

Mothers complained of a lack of organized groups or accessible information for parents like

them, "because everyone wants privacy, they don't want people to find out [that] my kid's in the

hospital right now," (P1 L 255). Finding other parents in the world with similar experiences was

personally affirming. Participants with violent children equipped their home with cameras and

alarm systems (P6 L 1687). Two participants admitted they relied on unhealthy habits at times.

One mother would dive into hours-long deep cleans of her house, leaving her exhausted (P8 L

1040). Another mother overused alcohol at times.

> I'll be honest with you; I did drink a bit. That was not the best coping, but
> it was the coping I could deal with at the time. (P6 L 1354)

Both of these mothers stopped these habits and found other ways to deal with their tremendous

stress.

For the siblings

Finally, any siblings living in the home were greatly affected by the child with ED's

outbursts and reactions. Six of the participants had other children living in the home with their

child with ED. Participants spent so much time and energy dealing with their ED child that there

wasn't much energy left to give to any other child in the home. Participants created ways to

make time for the siblings to get much needed <u>individual attention</u>. Participants had to <u>protect the</u>

<u>siblings</u> from harm from the child with ED. Participants knew just because one child had a lot of

needs, their other children's needs weren't diminished.

Participants knew with all the actions they were doing for their child with ED, their other

children might feel forgotten or shoved to the side. Participants tried to prevent this as much as

possible, which was hard to do when one child takes up so much attention.

> We would try to take our oldest son out, to just give him one-on-one time
> because it felt like we're so busy dealing with behaviors, that he kind of
> ...(paused) got shoved to the side. Not shoved to the side. That's not the
> way...(talking faster, trying to explain)... He was good. So, we didn't have
> to give him all that time and attention. So, I guess he kind of felt like he
> got shoved to the side. We would really try to make sure that we gave him
> the extra attention when he felt like he wasn't getting attention at all from
> us. (P6 L 664)

Mothers took the siblings out for special events. One mother did specific tasks with her other

children that the siblings enjoyed, such as cooking and building projects (P7 L 867). Another

mother knew "it can't be all about her" (P4 L 981).

> So, we really tried to give him [her younger son] his moments, which is
> good, because, you know, we don't want him to get lost in the in the
> wayside of stuff. (P4 L 988)

Despite the participants' best efforts, they knew the other siblings did not always get the attention

they needed and deserved.

> "T" often flies low under the radar, which is a thing. Because I like find
> things out later. And I'm like, oh, well, you would have been in a lot of
> trouble for that, but I didn't have any idea. [that it happened] (P7 L 722)

Participants also had to physically <u>protect</u> their other children from the child with ED.

One participant had to send her younger child to live with relatives for a few weeks.

> for C's safety...we ended up sending her ("C") to my sister's [home] for a couple of weeks, just to try and get everything back to some level of calmness. (P1 L 752)

Even though it kept "C" safe, she lost the comfort of her parents and her home during the emotional chaos. Another child was angry because she had to wear a bike helmet, when her younger brother didn't have to wear one- because he wasn't riding a bike. Instead of understanding the difference in their situations, she retaliated by attacking her five-year-old brother. Her mother was very angry her daughter hurt him, and she gets "protective of him…especially since he's younger than her," (P4 L 497).

One mother's oldest son was in a different type of danger from her daughter with ED. Her daughter had accused her younger brother, 11, of sexually molesting her. When she confessed the accusation was false, the participant was very worried her daughter might do the same to her older son, 15. To protect him, she never allowed him to be alone in the house with her again.

> We made sure they weren't ever alone. We were never gonna get in a situation where she could accuse him of doing anything like that. He was in his preteens, but we had to sit him down and say, "Hey, bud, just FYI, you can't be alone with her, ever." We had to [paused] kind of take away some of his naivety, and say she made accusations like this against her brother who's 11...so we can't let you be...just don't be around her. (P6 L 1162; 1171-75).

Not only did the participants worry destructive acts their child with ED could do to others at school or at events, but also worried their other children could be in danger from the ED child. Participants adapted themselves and their home environment to suit their ED child's needs, but also had to protect their other children's safety from the child with ED.

To manage the challenges and situations which participants faced due to a child's emotional disturbance, the participants had to adapt every aspect of their personal lives, their

child's environment, and even their other children's lives. Although the actions and adaptations weren't perfect, these approaches were definitely more successful than traditional parenting methods. However, the actions and adaptations required enormous energy and time commitments from the participants. Participants were asked how well these actions and adaptations continued to work as the child grew older, leading to Research Question 2b.

Research Question 2b: Do these child's situations and parent's responses change as the child ages?

Changing over Time

During analysis of the transcripts, the participants' stories indicated both the situations and participant responses changed as the child grew older, but interesting details emerged that the participants themselves also changed internally over time. The ongoing journey of internal change became **Category 3**: **Changing over Time.** Erlandson et al. (1993) state "bridging" of categories is appropriate when two or more categories or data pieces suggest a link which was not originally considered during early data collection. As this category emerged, the data suggested a continuation of adaptation and coming to terms, as the mothers adapted their own thinking and perspective as the child grew older. Therefore, **Changing over Time** was bridged with Category 2, **Responding to the Challenges**, under the second construct, **<u>Actions and Adaptations</u>**. This transformational journey was only partially present in the two participants with five-year-old children but was most obvious in participants with the oldest children, especially those whose children were late teens and early twenties.

Changing over Time consisted of five subcategories of internal change and adaptation: 1) *seeing through the child's eyes*, 2) *perspective changes*, 3) *seeing child's positives with the problems*, 4) *past reflections: I did my best,* and 5) *future thoughts: no longer a child but not yet an adult*. Although the progression through the five subcategories was not linear, all of the participants realized their child views the world in a much different - and unexpected- way compared with themselves. Mothers changed their own perspective by seeing the child's displays of defiance as a front for the child's internal struggles. Mothers then gained an increased understanding and compassion for their child. Participants focused on who their child "is" in the present time, and they focused less on who the child "could be" without the emotional problems. Some mothers saw how the child's challenging behavior could eventually translate into valuable adult characteristics. Reflecting on their own experiences, all of the mothers felt they had always done the best they could do. Lastly, the children in their late teens and early twenties still required significant support, time, and energy from their mothers. The mothers of these children worried about how -or when- their child would become a truly independent adult.

Seeing through my child's eyes

Just as a photographer can completely change a photograph by changing lens, the participants' children viewed the world through a very different lens than their mothers did. All participants eventually realized their child viewed the world in a vastly different way than they did themselves. When participants saw "through their child's eyes," they understood their child's thinking. Participants started seeing the isolation and ostracization their child experienced. Participants recognized the difficulty a child with impaired social skills has navigating situations with nuances. For instance, when does "self-advocating" become "arguing" or "disrespectful?" Who determines where the line is? The speaker, the recipient, or someone else? How does that

mesh with the need to "respect and obey" adult authority figures? Participants realized their child was often <u>unable to stop their behaviors</u> or control their reactions. Furthermore, their child was <u>suffering in silence</u> from harsh treatments from others. In addition, their children were genuinely <u>unaware of implicit social rules</u> but were still very sensitive to failing their parents' expectations. Rarely, the mothers saw a magical moment where their child came into their own and saw their own worth. Although this realization usually emerged over time, seeing through the child's eyes was a significant point for adaptation within the participant.

Several participants' children exhibited extremely rigid thinking, especially regarding the concept of justice. A mother said her child was "very preoccupied with the notion of "fairness" (P4 L 367). The children were incapable of forgiving any transgression that violated the child's sense of right and wrong.

> Look, whenever somebody does something that she feels is against
> the rules and not doing something right, and there's nepotism or
> something like that, she's just like, passionate, and she just loses it.
> And she doesn't' understand it. (P5 L 350)

> Her peer said, "Well, I'm just going to do it." And it just, it's almost
> like you can see the wires crossing. Or just like her inability to deal
> with someone's doing something that I don't' want them to do. I can't
> stop them. So, she hit them. (P4 L 389)

Mothers realized how many times the "rules" they struggled to teach their children had caveats and exceptions. Even a basic rule, "be quiet in class and listen to your teacher," has nuances when the teacher is not following the child's IEP accommodations in class.

> They [kids] are taught that the teacher knows exactly what they need and
> will provide that for them. And that's true up to a certain point. (P3 L 632)

> You're asking for a kid who has no wins in that class, who can't visualize
> what you're actually talking about. You want them, after being completely
> kind of stuffed back and they don't know anything, to come up to
> [teachers] & say, " I would like 10 extra minutes on this test." (P3 L 616)

This mother realized her child, who doesn't read social cues well and has been punished for arguing or misbehaving in class, is now being told he must independently ask the teacher for his accommodations. The teacher already knew about the accommodations, which are the child's legal rights. The line between "asking for" his rights and "challenging" the teacher's method is often determined only in the eyes of the teacher.

Other mothers saw beyond their child's outbursts to their child's pain from being excluded or hated. When a mother became very sad after her child's psychiatric report detailed how her daughter felt hated and misunderstood by friends and teachers. She could read her daughter's pain in the print (P4 L 260). Another mother experienced the same exclusion herself at her child's school. She noticed her child's desk was pushed into the corner of the classroom far away from the other desk, as the other parents grouped themselves away from her, on the other side of the classroom.

> And just like my kid's literally get pushed into a corner, so do I. I get how they feel because that's how you're treating me. (P1 L 409)

> Her psychologist said she felt hated by her peers. He said she has these negative self-thoughts about herself…she'll perceive any kind of little thing as reinforcing what she already believes. (P4 L 908)

Mothers of adopted children knew their children received poor early childhood care, and how this inconsistent care left lasting marks on their children.

> I think there was a lot of confusion for her during that period before we were able to adopt her because she was like, "Where do I belong? Who do I belong to?" (P6 L 478)

> She just could never forgive the biological parents for not coming back. (P6 L 771)

> I don't know if she was, you know, remembering what it was like living with her and she has some built up resentment about you know, being kind of dumped off all the time while mom went out and partied for …because that's what she [child's mom] would do. She

dumped her off with whoever would watch her and then, you know,
take off for three days at a time. (P2 L 716)

When the mothers looked at the world from these vantage points, flawed as they may be,

mothers saw their child weren't able to control their own reactions, versus a child who could

control themselves but is deliberately defying instruction.

People think they have control over things. And I'm like, yes, but no.
It's not that they were trying to do things. It's just what...happens, you
know? And they both feel bad when they say things and do things. (P1
L 751)

Kids, you know, sometimes, they really do kind of black out and they
don't realize how hurtful some things could be. (P8 L 1127)

Mothers learned their child was suffering internally or being mistreated but not telling

anyone. One participant learned her child's teacher was hitting her child in class, but her child

hadn't told her: "because 'D' felt that she was doing wrong." (P1, L 482). This mother's younger

child, (who also had ED), was repeatedly berated for being dyslexic by her teacher. Her teacher

yelled that dyslexia was not a "real" problem at the child and the mother didn't find out about

until the final day of the school year. Her child didn't say anything "because throughout the

years, all of these things have happened to her. And she's like, "well, people don't believe me,"

(P1, L 938). Another participant learned her child thought it was normal to be anxious every

minute of every day.

She didn't know it wasn't ok to feel like that….we found out that in
her mind, she had been struggling her whole life. And so, she just
knew how to mirror it, to look happy and do what she needed to do.
(P5 L 204).

Participants noticed their child wasn't just not following implicit social rules but didn't

seem to even realize there *were* social rules. One participant's child loved to play basketball, but

then spent all his time on the court chatting with other kids, not even those on his team. Children

with ED struggled to make peer friendships and successful social interactions.

> She doesn't do a great job of making friends. She thinks everybody's
> her best friend from the minute she meets them. She can be an over-
> sharer and a clingy kind of person…she can be mean and doesn't
> understand why people don't feel better the next day. (P7 L 625)

However, even when the children didn't know social rules, they did know they were failing their

own parents' expectations.

> They already feel like they're disappointing you. They already feel
> like they're not in the pocket. Because they *see* everybody else going
> past them [emphasized "see"] They see everyone else enjoying
> homecoming or doing the thing. (P3 L 825)

In public, the children tried to adhere to social conventions as long as possible, but then exploded

when they reached their limit.

> They're holding it together as best they can at school, and they come
> home, and they just let loose [gestures like an explosion] ...they know
> this is how we're supposed to behave, so we're trying really hard to
> conform. (P1 L 635; 644)

Two participants expressed joy when their child started coming into their own and

believing in themselves.

> This is the first place he's ever really been comfortable. Like kind of
> being himself and his friends accept him as well. (P8 L 659)

> In 7th grade, we're all talking, and you know, actually things are
> extremely positive, which is very unusual for us. So, it's like, wow,
> this is kind of cool… and at one point, "D" was like, you know what?
> I'm smart. And we all busted out laughing. [that was] when she kind
> of hit her stride. Like, yeah, I got this, I can figure this out. (P1 L 838)

Perspective changes

When participants stepped into their child's shoes and saw life through their child's eyes,

the experience changed their reactions toward their child. Participants started to seeing rationales

for a child's behavior, even when they did not agree with the child's overall view. By seeing a

rationale - any rationale- participants felt more <u>understanding and compassion</u> for their child's

problems. Participants stopped seeing the child's behaviors as just defiance or <u>a lack of</u>

<u>willpower</u> to control themselves. The change in perspective led many participants to search for

<u>the best environment</u> to suit this specific child, given the child's unique viewpoint, preferences,

and reactions.

Seeing through their child's eyes caused mothers' *perspective to change*, because they

saw the reasons and rationale behind a child's reactions. One mother originally thought of her

child as a "high needs infant" who always needed more attention, but she realized her child was

reacting to physiological inflammation and genuine pain stemming from repeated infections and

Pediatric Autoimmune Neuropsychiatric Disorders associated with Streptococcal Infections

(PANDAS) (P7, L 158, 176).

> Looking back with more data and more reflection time, I do think
> some of that was POT's [postural orthostatic tachycardic syndrome]
> related… at elementary school, there was a lot of P.E. that was
> outside and running. (P7 L 404)

Another participant was called to the principal's office after her child hit another student.

The week prior, her child had been taunted by a boy during at a field trip. At the office, the

mother confirmed with her daughter that this was a continuation of the previous week's

problems. She then told the principal, "I'm not saying what she did was right. But I'm just

saying.. that's why she did it." (P1 L 958). Other mothers wondered if their child's anxiety was a

reason for the child's overreaction.

> I was like, just thinking back, what if she has anxiety? (P5 L 372)

> Looking at things as not the behavior itself, but as to the why of the
> behavior. Because I think that with sensory kiddos, it's a lot of okay, what is

causing the problem? You see the behavior, but you don't sometimes really know [the problem.] (P8 L 1106)

When participants discovered there were rationales behind their child's outbursts -even if the rationale was from a warped perspective- participants viewed the outbursts as outward signs of struggles, and worthy of compassion. One mother felt that "sometimes, she (her child) can't control it, she's not doing it consciously" (P4 L 1183). Participants shifted their emotional response away from thinking their child lacked willpower or self-control, and toward thinking it was a sign of their child struggling. One child realized she was "lying" whenever she filled out depression screening forms.

> When she got older and filled out a thing about depression and how she felt. She goes, "I just thought it was normal to feel the way I felt. I didn't know I was lying." I just wish I had known so that when we had these battles, we would have been a little softer with her. (P5 L 1061)

> I wish I would have known earlier to maybe, you know, think about it from her perspective and start with compassion. Rather than start with authoritarian. (P4 L 1232)

When one mother linked her child's emotional reactions to a physical manifestation of inflammation, she explained to the teacher that her child wasn't being defiant or unwilling but was incapable of completing the assignment due to her inflammation.

> [Her teachers said] she's being willful. Well, yeah, but the problem is, when her brain's inflamed, she can't write. Because that's a hand-eye-brain coordination thing that she sometimes has a hard time doing. (P7 L 1167)

For this child, reducing inflammation reduced the behaviors, so she prompted her child to take breaks, cool down, hydrate, or even take Advil, for its anti-inflammatory property. Her daughter would show behavioral improvement with these measures in 20-30 minutes (P7 L 683).

As participants' *perspective changed*, participants looked for a <u>better fitting environment</u> for their child, rather than trying to get their child to fit in their current environment. One mother said her child was "wicked, scary smart. That's never been the issue. It's always been finding the environment for you to thrive in," (P1 L 843).

The right environment was hard to find. When one child had numerous problems at a commercial daycare, his mother tried opening a home day care. She thought this could be more comfortable for him and allow him to meet smaller groups of children. Although he adjusted to the infant, he did not adjust to the toddler, and his outbursts increased.

> [after starting a home daycare] Our toy room would just be destroyed. And it just wasn't working out. And that's when I realized, maybe I should go back to work. [outside the home] (P8 L 902)

Another mother thought she'd found a possibility with music and being part of the school band. He took private lessons for years in preparation for the high school marching band. The noise, the crowds and the excitement were exciting and a huge draw for him. But after starting summer band camp his freshman year, the school district enacted a schedule change. This change placed his required math class (with six total enrolled students) in the same period as marching band for all four years of high school. Years later, the mother was still frustrated and angry at the lost opportunity. Although she protested the change and tried to find a compromise with the school, ultimately her child never played in the band again.

> How do you take away band, that's one of the cornerstones where it's proven… music helps [math]! Where's his win? …Why can't you delay math? Honestly, there's six kids in that classroom. You tell me you can't find another slot? For six kids. You could, but it's a lot of work to do. (P3 L 552)

Some mothers did find environments which were better suited for their children. One mother had a revelation about alternative pathways for education. She realized "there's other

ways to do school. And so that's when my mind opened up with online school," (P1 L 1136). She found online school's flexibility to allowed for class adjustments, such as doing class on the weekend, in response to her child's emotional state. She emphasized "it's always been finding the environment for you to thrive in," (P1 L 843).

This does not mean everything was easy for participants now. One mother and her spouse were "struggling with [the idea that] we have to parent her differently than we were parented" (P4 L 685). Children with rigid thinking patterns tend to struggle with nuances. A mother struggled to explain why it is unacceptable to be hit and kicked by the teacher or have one's desk secluded in a corner, even if the child would accept the treatment in order to stay with her friends at school. Some children may not know social rules, and may not want to learn them, either. One teenager wanted to play guitar like Jimi Hendrix but refused to learn how to even tune the guitar. Participants struggled to decide when they should teach, and when they should let go.

Child's positives with the problems

As the participants continued sharing their experiences, participants made comments that "this is just who my child is." In addition, mothers identified their child's strengths. Some of the child's strengths were directly related to the characteristics which created such difficulty now. Participants could see the "whole package" of their child, good and bad. Some mothers believed there was a higher, spiritual reason or power that intended this child, with these characteristics, to be a member of their family.

Mothers made definitive statements that this was their child, "warts and all." One mother described herself as a parent with "a child that might struggle in some social aspects," (P8 L 660), while another said her child "marches to her own drummer" (P2 L 966). One mother received social push that although certain problem behaviors were acceptable, but her child's

behaviors were not. She shrugged, saying, "It's what my kid does, I'm sorry," (P1 L 446).

Another mother "came to terms" about her child's needs after her child's residential stay.

> It was also the point where I was like, ok, I have a special needs kid
> that needs a lot more and a lot different parenting then my other kids.
> (P7 L 566)

When participants spoke of their children like this during the interviews, they also

described the unique and positive attributes their child possesses. Some children's assets seem to

grow out from the most challenging aspects of their persona. While one child coped with

constant anxiety by striving for perfection and overachievement, this striving and

overachievement drew others in toward her. Her mother described her as:

> She's vivacious. She's just got this personality that just sucks you in.
> And you just want to know who she is. She walks into a room, she's
> beautiful. She's smart. [speaking proudly, gesturing to pull you in]
> (P5 L 617)

Another mother sees how her child's bravery, independence and fierce nature could help her

child achieve great things.

> It just wasn't in my mind to defy, which can be detrimental in your later
> life, when you just going to...blindly follow and maybe get pushed
> around…The one thing I can say about "L" is that she's not going to get
> pushed around. And she's her worst critic, but she's also pretty
> ferocious. (P4 L 1316)

Positive attributes might be hidden by the child's behaviors, but participants were quick

to point them out. A participant told her child, "Honey, we've always known that you're smart.

You are like, wicked, scary smart," (P1 L 989). Another mother proudly pointed out her child 's

enthusiasm for children's sermon time, and how she always knew the answers to the preacher's

questions despite wriggling throughout the sermon.

> And she'll answer all the questions, she's not dumb…she's absorbing
> what she's being taught. But it doesn't seem like she is because she's still
> wiggly and distracted. (P2 L 1100; 1106)

The participants' parenting journey was marked with tough challenges due to their child's emotional disturbance which other parents simply don't encounter. People who travel harder roads in life often ask, "Why me?" Participants searched for a purpose to explain why their child had the problems they did, and why their parenting journey was so different from what they had expected.

Some mothers found a sense of meaning that their child was created as they were, and placed in their home, as part of a higher purpose.

> I got the kids I got for lots of reasons. And they wound up in this family
> because it's where they're supposed to be. (P7 L 945)

Another mother felt her daughters were created by God exactly the way they were supposed to be, which gave her a sense of peace regarding her children's strengths and limitations, even if she wished her journey was not quite so hard.

> I believe in God. So, I know, its's what He's planned. And I know, my
> girls are exactly the way He wants them. Sometimes, I'm not sure that
> He equipped me with what I needed. We talk about occasionally, in
> my heart of hearts [chuckles] (P1, L328)

An adoptive mother had a difficult conversation with her spouse about whether or not to proceed with their children's adoption. The children had been placed with her as a temporary foster placement and were expected to stay for six weeks. Her daughter had overt hypersexual behavior right after moving in. She was surrounded by emotional turmoil from both children's ED behaviors as well as court drama and threats from the biologic parents. The foster children

lived with her for more than two years before their biological parents' rights were terminated. She and her spouse had to decide whether to adopt the children.

> We did decide to go ahead and go with it…We really sat down and kind of ..talked it through. And we decided that even though he [spouse] wasn't 100% sure that this was the right fit, that he did [agree]. There was love there and we should go ahead. They've been with us that long, to disrupt them again would really cause a lot of problems for everybody. (P6, L 508)

The parents proceeded with the adoption despite the numerous early challenges because they felt the children had been placed with them for a reason.

One mother eloquently summarized her internal conflict. She was torn between wishing her child was easier to manage and the belief that her child should be accepted for who she is, not who she might want her to be.

> If I could wish away all of the things about "L," I would wish she was more compliant, if I could wish she was more this or wish she was that, then she wouldn't be *her* anymore, she would be somebody else. And that's not fair…don't get me wrong- I still sometimes wish she was compliant and happy and not so difficult, but I try to remind myself that then she wouldn't be who she is. And I have to try and love her for who she is. (P4 L 1072)

Reflections: I did my best

Parents often wonder if they were a "good" parent, and what things they should have done differently. The study participants were no exception, and all eight participants had specific parenting <u>regrets.</u> Despite all participants having regrets, the vast majority of participants also believed <u>they did everything they could have possibly done</u> for their child. This belief allowed participants to view their past mistakes with forgiveness, knowing that despite any mistakes, they had <u>always done their best</u> for their child.

Parenting <u>regrets</u> may be a near-universal experience, and this was certainly the case among the study participants. Sometimes, participants regretted specific decisions such as not homeschooling their child or not placing their child in a residential home. Participants wondered if things would have been better if they had not been a stay-at-home mom or had not used fertility medications. But above all, participants wished they had known about their child's issues earlier, so they could have adjusted their parenting strategies sooner.

> When in the beginning of it all, I just was like, oh my gosh, is everyone's kid like this? You know what I mean? Like, is this like, a stage? Is that normal? [questioning, doubtful voice] I do wish I would have known that [not every child is like this] sooner. (P8 L 1109; 1117)
>
> I wish we would have known these things. (P5 L 1059)
>
> I wish…that we were able to have identified stuff and kind of got more proactive. I don't know that that would have changed anything. But yeah, I think I wish that I would have been able to…other people would have been able to notice it. And maybe we start working on some of these self-regulation issues earlier. (P4 L 1206)

One mother of a young child denied having any regrets and was a negative case in this regard. When the researcher asked if she had any regrets or wished she'd handled something differently, she said no.

> There's not really anything I wish I would have tried differently. Because I don't know what else I could have tried differently. You know, we were just everyday… you just do the best you can. (P2, L 1172)

However, these regrets did not mean the participants judged themselves harshly. In fact, mothers in the study were confident <u>they had done everything they could possibly do</u>. A mother said, "We tried everything," and "My husband and I just feel like there's nothing more we can do," (P6 L 131; 1722). Another mother knew that "we're.. really trying [our] hardest with what [we've] got," (P4 L 1275).

One participant made deliberate decisions to let some parenting expectations and dreams

go. She could only accomplish so much when managing a child with ED, her other children with

learning needs, and crises such as her mother's dementia diagnosis.

> There was] a lot of negotiation about what we're able to
> do…Everything gets a little smaller, right? There aren't the big
> family trips. You're not doing extra things because it's very home
> oriented, there's just no time. (P3 L 743)

One participant struggled with deep regrets, even knowing she had tried everything. At

the time of the interview, her two adopted children with ED were both in legal trouble. One child

was in juvenile detention for robbery and assault, and the other child had run away to another

state.

> You know, because at that point in your life, you feel like, did I even
> make any difference? Has this just all been a failure for all of us? (P6,
> L 1217)

She had not "come to terms" or found any sense of purpose in her parenting journey. The bonds

between her and her adopted children were broken, and she, her spouse and oldest child had been

violently threatened by them. At one point, she was in such deep despair that she thought of

committing suicide.

> Participant: I'll be honest with you, they got me to a point where I was
> suicidal. And I felt the only way out was to... go out. (sounding tearful,
> got very quiet)
>
> Researcher: What made you hang on? ..When someone has those kinds
> of thoughts, there's often something that makes them say, "Okay, I'm
> not going to do it."
>
> P: My husband and I have a great relationship. And I couldn't do that
> to my oldest son…it wasn't going to be fair to him for me to check out
> because I couldn't handle their behaviors anymore (P6 L 1068-1079)

 Despite all her efforts, she did not know if she had made a "difference."

> You know, because at that point in your life, you feel like, did I even make any difference? Has this just all been a failure for all of us? (P6, L 1217)

Even within her despair, she knew that she had always done her best, even if it failed.

> I honestly…[paused, sighed] I felt like we went above and beyond. We reached out to the therapist. We tried every kind of therapy that they can throw at us. We even had respite care that would take her for a little bit, like a couple days off, to give us a break. I literally think back and think, I can't think of anything else we could have done to support her. (P6 L 766)

The researcher asked every participant if there were any questions that she should have asked, and this participant replied, "Would you do it again?" (P6, L 1757). Her therapist had asked her this question, and she said it took her a long time to answer.

> No, I completely regret. And that's, that's really hard to say… It was hard for me to say it out loud, that I regret adopting them. And I regret bringing them into my life. Because it's been, it's been just chaos after chaos...[her therapist said] you don't have to feel guilty about that. (P6 L 1757)

In fact, all of the mothers realized <u>they had done their best</u> for their children. Mothers seemed to forgive themselves for their short comings. Two mothers knew that beating themselves up over past decisions was not helping them to raise their child now.

> I can't blame myself that for the first 12 years of her life, I let her eat gluten every single day, not knowing she was allergic….for a long time, I was like, great. I just poisoned my kid for 12 years. Well, I had to let that go. Because, how do you know what you don't know? (P7 L 954)

Another mother forgave herself for not knowing her teenaged child was staying up all night from anxiety. Her daughter "wasn't telling us all of the stuff that was going on," and given her age, the mother let her daughter have privacy in her room (P5 L596).

Some problems cannot be "fixed" by parents. Mothers in the study did not hold themselves accountable for things beyond their control.

> Because I could never fix the behavior. There's no fixing the behavior, right? (P3 L 1052)

> We can't…I can't make them care. And I could never make them care…if they don't want to change, they will literally tell me, "I don't care." And I'm like, I know. I can't make you care. And I can't care enough for the both of us. (P6 L 1723)

As time passed, the mothers consciously worked toward self-healing and forgiveness. One mother reaches out to other struggling parents because it is a "healing thing for me," (P1, L 1498). This self-forgiveness was an ongoing, intentional effort. At the conclusion of the interview, one mother became very quiet and pensive. She was clearly frightened her child, now nine, might one day harm someone badly. She tries to comfort herself that if this happens, she has tried everything possible to prevent it.

> [after the recording was stopped, she whispered, "if my child does something….[long pause] …really bad, it will not be because I didn't try. I did everything I could. (P4 L 1430)

Future: No Longer a Child, but not Yet an Adult

From the time a child is born, parents work toward raising their child to be an independent adult. However, the study participants questioned when – or if - their child would become a "fully fledged" adult. This concern was not mentioned by the participants with the two youngest children (both five years old), and only briefly mentioned by the participant whose child was in elementary school. But for the remaining participants, (whose children ranged from 15 to 23 years old) all of them worried if their child will become an independent, self-managing adult. Mothers said the "game changed" as their child grew older. This change meant the participants must adapt and shift parenting strategies again. Lastly, the mothers desired a more balanced, mature connection with their older children, or grieved broken relationships. Mothers

saw their conversations and bond to their child went one-way- from mother to the child. For

these mothers, their child is clearly *no longer a child in years, but also not yet an adult*.

As children age and mature, society's behavioral expectations rise. Parents face new

challenges, and this is no different for parents of children with ED. Study participants learned

after they finally found some successful methods for their child, the "game changed" again.

> You think when they're little and you're going through it, it's really
> hard. And you're like, oh, this is the end of the world. And then they
> get bigger. And you realized, I don't have any [ideas.] (P1, L 1158)

Participants of older teens and young adults must cope with job or budgeting problems, such as a

young adult who forgets rent must be paid before buying new shoes.

> He's coming over…to learn about budgets…his decision making
> isn't great. He's very live in the moment. He does not understand
> why he should have to work…He works a 40 hour a week job….he
> is consistent, and he goes to work and makes a good wage. But boy
> howdy, he wants to run with the craziest girl, and he wants to live in
> the heart of the city, which is super expensive. And he wants to
> spend every dime he has on flashy shoes, and the latest place and the
> best food…so the conversations are "that's great, but you can't have
> $800 shoes AND live in that apartment because it's kind of one or
> the other"…(P3 L 963)

Mothers hoped their child will just "mature out of it" (P3 L 1057) or protected themselves

by not pre-planning for future problems, such as college or moving out of the house (P7 L 1032).

But the participants of older children with ED realized what the ideas they used before were no

longer working.

> I thought it was really bad when they were little but, its' worse as
> they get bigger . You know, the game changes…everything that you
> thought you knew…like, holy crap, I don't know what to do now!
> (P1 L 1170)

Most of the participants of older children saw improvement in their child's self-

management as their child grew older. Study participants saw marked improvement in their

child's communication with others and emotional self-management. However, their children still

did not think or react as a typical teenager or young adult would. One mother was frustrated that

her child needed reminding for items not normally needed for a 15-year-old child:

> "P" gets picked on sometimes because she's 15, physically and age-
> wise, but emotionally, she's more like, 12, you know? (P7 L 705)
> This is a kid who could sleep 20 hours a day if we let her… she's 15
> and I still say things like, what are you taking for lunch today? (P7 L
> 664)

For the participants' children, reaching age 18 is not the measure of a successful adult

transition. Mothers worried if their child will ever become an independent functioning adult, who

doesn't need constant watching.

> Even though, you know, they're adults…[but] they not…not adults
> like others, per se. (P1 L 335)

> Then my brain also starts thinking like, is this going to be our life?
> Like we won't be able to have a vacation and alone time and we won't
> be able to just leave her with someone because we're always going to
> be worried about her? (P4 L 848)

At the time of the interview, none of the participant's children were fully independent, but

some of the children were capable of parts of adulthood. Participants with older children focused

on which supports their child needed in the unmastered areas of adulthood.

> Just trying to help them so they have a good foundation so they can at
> this point be functioning adults and live their best life. (P1 L 120)

Almost all of the participants of older children said they wished they had a more mature

connection and relationship with their children. The children with ED seemed incapable of

typical give-and-take conversations between adults, regardless of their physiological age. One

mother adapted her communication, because she knew when her child calls to talk, her child

wants to talk about her own world and her own problems only. Although the mother realized she

is supporting her daughter by being her sounding board, she wished the conversations were more

balanced.

> It's hard for me not to say something like, aren't you gonna ask how
> my day was or how your brother is or how your sister is? She just
> calls and she's complaining… but I know, I'm kind of her sounding
> board….she doesn't ask (about me), she's just in her world. (P5 L
> 523; 536)

Another mother felt the bond was one-way between her and her son. She actively sought ways to

connect to him but didn't feel he was connected to her.

> I wish I knew how to connect him to me in a way that I felt
> connected (voice is quiet, sad). [researcher: that's meaningful to both
> sides?] Yeah. I still do not know that….I still feel like at any point,
> he could just kind of fly away (speaking slowly and sadly). (P3 L
> 1192; 1199)

The difference in parent-child bond was even more obvious for mothers with additional children

without ED. One mother had strong relationships with her other children, but not with her child

with ED. Despite all of the counseling, research, and residential stays, her bond with her

daughter with ED was still weak comparatively.

> She and I have a hard relationship just because she's a hard kid…I'm
> super close to "M." I'm super close to "T," all in very different ways.
> [but] "P" and I still have a very touch and go relationship (P7 L 649; L
> 779)

Sometimes, the family relationships are permanently broken. False accusations and

ongoing criminal behaviors broke the basic bonds of trust for one family. One participant had

two children with ED staying at a residential facility. During the stay, her son (11) was sexually

molested by his roommate. When this assault was discovered, the older child (also with ED)

accused her younger brother of sexually assaulting her. A subsequent investigation found the

accusations were false, but the accusations destroyed the family.

> She said that because [her brother] was getting extra attention, because
> he had been sexually molested….that's where I think I kind of got
> colder to her, because it just really hurt everything when she said
> that…it's when my husband kinda gave up, too. Because it's like,
> "when is she gonna say it about me? When is she gonna say it about
> our oldest child?...[if] she's gonna say that about her biological
> brother, when are we next?"…that's really the point where the ..whole
> base of trust crumbled, and we never recovered from that. (P6 L 1130;
> 1142; 1198)

Her son engaged in more criminal behavior as he got older. After he was arrested for robbery
(age 15), he threatened to kill her and her spouse while on video tape at the police station. This
threat permanently broke the bond between the participant and her son. She refused to bail him
out of juvenile detention and refused to allow him in her home. However, even with she still
despaired over the broken bonds between them, saying "I could never make them care," (P6, L
1732).

Summary of Construct 2: Actions and Adaptations

Once participants' suspicions about their child's behaviors were confirmed, they engaged
in ongoing **actions and adaptations** of their parenting methods and themselves personally in
order to manage the challenges which arose from their child's ED. The construct, **actions and
adaptations**, bridged two categories: **responding to the challenges (Category 2)** and **changing
over time (Category 3)**. **Responding to the challenges** included subcategories of responses for
the child with ED, *for the parent: self-care*, and *for the siblings*. For the child with ED had
themes of parenting using past experiences, using outside expert assistance, and switching to
intentional responses. **Responding to the challenges** posed by the child with ED required
enormous expenditures of time and energy. The diversion of such large amounts of time and
energy resulted in additional needs and responses for the participants' self-care as well as other
children living in the household. Subcategory *for the parent: self-care* included themes of

connecting with others, time away, consciously changing their reactions, using therapy or belief

systems, and researching. For some mothers, self-care also included personal safety measures or

unhealthy coping habits. *For the siblings* had themes of protection/safety and provisions for

individual attention for the siblings.

As the child grew older, the situations and participants' subsequent responses changed.

The ongoing challenges resulted in an internal transformation of the mothers. This process

became **Category 3: changing over time**. **Changing over time** included *seeing through the*

child's eyes, which lead to *perspective changes* in the mother. As mothers started seeing the

world as their child does, mothers started to realize the struggles their child was having, even as

their ED was causing problems. Mothers could *see their child's positives* and inherent strengths

that were in spite of – or because of - their child's challenging nature. All of the mothers had

parenting regrets, but they all believed *they did their best* for their child. The future is still

uncertain for mothers of older children with ED, which was reflected in the final subcategory,

Future: no longer a child, not yet an adult.

Research Question 3: How does raising a child with an emotional disturbance impact the

family as a whole?

Raising a child with ED impacted every aspect of the participant's family life and each

family member was affected personally. The breadth of the responses in **Construct 2: Actions**

and Adaptations alludes to the depth of the child's impact on the family. The child's behaviors

and emotional reactions created a constant state of turmoil in the home. The adaptations required

to manage the turmoil and ensuring aftermath altered the entire family, although individual

family members were affected in different ways. **Construct 3: Altered Families and Advice for**

Others describes the magnitude of the impact imposed on a family raising a child with ED and how other families might reduce this impact.

In this study, the participants were all mothers and the primary caretaker of the child with ED. As expected, these mothers were greatly affected by raising a child with such emotional or behavioral problems. In most cases, the mothers were responsible for implementing the majority of **actions and adaptations** outlined above. However, these actions and the ED child's own behaviors significantly impacted the spouse and spousal relationship, as well as any siblings living in the home. No family member was unscathed by the experience. Category 4 emerged as **Altered Families**. Qualitative research can give a voice to groups who are hidden or suppressed. Participants wanted to share their experiences so other families raising a child with ED might learn from the participants and experience less negative impact. Erlandson et al. (1993) reminds the naturalistic research that "analysis of data interacts with the collection of data," (p. 130). The participants wanted to help other families from being as "altered" as they themselves were. Category 5 became **Advice for Other Families** and was bridged with **Category 4: Altered Families**.

Altered Families

The parent, their spouse and any siblings were all altered because of the challenges stemming from a child's ED**.** Participants described their lives as being in constant turmoil, lasting for years at a time. In this study, many of the children's behaviors got markedly worse between the ages of seven to eleven years old. Residential stays were rarely beneficial for the child with ED, but the participants said the residential stays did provide a reprieve from the volatility for their families. One mother said even though her daughter actually got worse while at the psychiatric hospital, "we all really needed a break, like 'P' was destroying our family," (P7

L 537). Another mother said any reprieves from a residential stay were temporary at best, with a

constant cycle of escalating problems, residential stay, promises to do better after discharge, then

reverting back to the original behaviors (P6 L 869).

Participants felt their child's outbursts were like explosions going off, and completely

unpredictable.

> They come home and just let loose [hand gestures like an
> explosion]…[and] letting loose sometimes is…[pauses] yeah, it's real
> hard. (P1 L 635; 651)

> Like, she would just all of a sudden [big hand gestures, like an
> explosion] like she almost…sometimes she controlled our house with
> her emotional outbursts. (P5 L 284)

> We'd just be sitting at dinner and all of a sudden it just like…When she's
> sitting at dinner, we want her to tell us about her day. But when it's
> negative, negative, negative, my husband would be like, I'm tired…just
> like complaining and complaining" And then she'd lose it on him (P5 L
> 660).

Another child's volatile emotions created palpable tension throughout the house. Her mother said

and there were "years and years where none of us slept through the night," (P7 L 340). When the

researcher asked why no one got any sleep, the participant said her daughter would just wake

everyone else up, "because if 'P' wasn't sleeping, nobody was sleeping," (P7 L 275).

Sometimes the explosions were violent and dangerous. One mother with two ED children

both worsened at the same time, around age 11 and age 9, respectively.

> Researcher: Seems like they both kind of blew up at the same time?
> P: Right at the same time, and the aggression towards each other in
> the home was off the chart, just literally, it was like they hated each
> other. (P6 L 969)

This mother had to physically intervene in these fights, and even called the police.

> One time she came out with a knife, and I was like, Oh, no! So I stepped
> in between that. And obviously, you know, I'm like, "I'm sorry, but you're

> not going to come out with a knife with anybody in this family!"… And that was an automatic, well, we call the police right away and then they did do a psych hold on her that night. (P6 L 991-1008)

Living with emotional turmoil impacted everyone in the household. In addition to the emotional turmoil, the **responses to the challenges** as described Category 2 affected all members of the family, not just the child with ED. A mother explained that her family knew "pulling a hard line with her means that it's going to be a disturbing day for everyone," (P7 L 310). Even though individuals were affected in different ways, all of the participants' families were altered as a direct result of the child's emotional and behavioral problems. **Category 4: Altered Families** describes the impact on *the parent*, *their spouse,* and *the siblings* in the home.

Impact on the Parent

All of the mothers spoke extensively about the impact upon themselves as a result of their child's emotional and behavioral problems. This impact was emotional, social, and economic. There were eight major themes under the subcategory, "*Impact on the parent*." Themes included feeling constantly "on alert," stressed, frustrated, and guilt-ridden. Mothers grieved the loss of their personal dreams of motherhood. Mothers were fearful of what might happen to their child, as well as fearful of what their own child might do to others. Mothers were stigmatized and judged by others, and felt socially isolated, rejected, and embarrassed. Some mothers had employment problems or had to sell their home to meet their child's needs. Some mothers were plagued with self-doubt and a feeling of being lost. Individual participants spoke of their own anxiety being triggered by their child's behavior, and of feeling hurt by their child's general lack of empathy. In all, participants bore emotional scars and traumas directly related to their child's emotional disturbance.

All participants were stressed and felt they had to be "<u>always on alert</u>" for the next crisis. Living in this heightened state left mothers overwhelmed and exhausted. Mothers instantly tensed up every time the phone rang, worried there was another problem, a crisis, or a fire they needed to immediately leave to smother.

> Because if things go wrong with "C," then I'm back on-call 24/7. And just to make sure I keep her safe. That's always the top priority is safety. So, I feel like, you know, for 23 years, I've been kind of in this waiting for the next crisis. (P1 L 343)

> Whenever I see the... whenever I see the elementary school caller ID on my phone, I'm always, you know, kind of deflated or panicked because I'm wondering, you know, did she walk away? Like, did she hit somebody? Do we need to go pick her up? (P4 L 795)

Even when a child was doing a little better, "if anything happened, I was right back there in my head ," (P7 L 554). A mother said because she "was always in this crisis management," (P1 L 675), even trying to plan a break was stressful, because she had to repeatedly scrap her plans.

> I don't want to plan anything because it's gonna change. So, to actually plan something is hard, because for so many years, I would try and plan things. And then be like, "oh, sorry, I can't do it. I'm sorry. I can't come." So, there's that kind of a toll. (P1 L 353)

<u>Stress</u> was a major theme for many of the mothers. Mothers had "lots of stress, lots of overwhelming things," (P3 L 715) and being "really overwhelmed, and having a lot of crying," (P4 L 1100). Mothers got "so overwhelmed with everything, we didn't know what else to do," (P6 L 130). The stress came from all directions. Participants had to juggle their jobs, finish their own schoolwork/ university degree, their household and their child with ED.

> Sometimes it's hard, because I mean, I'm a therapist, and it's hard to be your kid's therapist. (P7 L 744)

There was no break from the emotional volatility or turmoil in their house.

> And I'm a quiet person by nature. So, to be yelling, or screaming, or something happens, and I get upset. Well, I don't shake that very well.

You know, it.. it affects me, not only probably for that day, but probably for a few days. And then when you're constantly getting it day after day after day, there's never any time where you're just like, Okay, now I can just [sighs] relax. (P1 L 656)

Gaslighting me is one of their favorite things to do. They're very good at gaslighting. (P6 L 1552)

One mother said she secretly wanted to just run away.

It was harder when they were in high school. Because there were times when I was just like... when it was like, okay, I do believe I would like to live in an apartment by myself. [in a funny voice] Because this is a lot. [emphatically & loudly, then laughs] But I never left! [laughs] (P3 L 1029)

The end result of constantly living in turmoil was complete exhaustion.

She wears me out a lot. There's times when, like, when she's at preschool, it's like, do I take a nap? Do I hurry up and try to get housework done? What do I do? Because I have that X amount of time when she's not here. It is. It's...tiring. (P2 L 973)

I was like, "I am so defeated, like, I've tried anything and everything to help them and I just can't." (L 247) It was a, like, the mental exhaustion on my part was just... depleted at that point. (P8 L 388)

Participants were <u>frustrated</u>, and understandably so. Participants were frustrated when they couldn't teach their child basic social rules or when the child did not remember a lesson (or a consequence) for any length of time. Participants were frustrated when after trying other parenting techniques or after consulting experts, they got limited benefit, if any effect at all. Mothers were frustrated because they were constantly reminding their child to not do certain things, but could not find a way for the message to sink in.

It's frustrating because everything is turns into this big...you know, World War Three over something..[pauses] …small. (P2 L 518)

And so, it's little things like that, that if I'm in like, more of a rushed, frustrating or a frustrated mood, I'm like, Dude, what is going on? Like, just calm down. (P8 L 468)

Frustration came from all directions: their child, their child's teacher or school, their job, and even family and friends. In addition, the participants were frustrated by the barriers they encountered to getting assistance. One mother passionately exhausted all avenues within the school district to allow her child to continue in band, the only class he actually enjoyed in school.

> And this is it. This is the only time marching band is offered. And you have decided through your school, that the special ed kids that are coming in, can't participate in band. That's what you decided by [scheduling math] at that time. You know better! [very angry, lecturing] But you've decided that those kids aren't worth.... because they can't do it. You've just......you've just other'ed them into a place where no special ed kid at "K" High School can be in band. (P3 L 476)

Despite having high ranking contacts and personal connections within the school district administration, she was powerless to make the schedule change for her child. Additionally, this was personally painful because she had had all positive memories and experiences from this same school, but the same environment she had adored in childhood was now a tremendous source of friction and frustration for her and her child.

Participants' jobs and work productivity suffered from the time and energy spent taking their child to appointments or responding to crises caused by the child's behaviors. Schools called the mothers for outbursts and problems and wanted the child picked up immediately. Depending on the mother's job, this might not be possible. One mother was a nurse working swing shifts. If she was not able to pick her child up immediately, the school would simply walk her child to her home and deliver him to her. Another mother knew her work suffered due to her child.

> That's the hardest part is when you're a parent with a child who has needs to be met, your work suffers...everyone's fighting for that five o'clock therapy appointment. (P8 L 270)

Mothers also dealt with frustration stemming from family or friends, as well as their own child. One mother's family told her to just give her children up.

> Then a lot of other family members were like, why didn't you just give up already? And just send them back? And I'm like, send them back where? They're not dogs! I can't just take them somewhere and drop them off. That would be very frustrating to hear. (P6 L 1411)

Another child's anxiety caused her to relentlessly ask about upcoming plans, usually multiple times in an hour for days leading up to the event. ("What time will we leave?" "Who's going to be there?" "How long will it last? "What should I wear?") Her mother got so frustrated with the obsessive questions, she would "see red."

> We are very close, and then we have moments where I'm like, I... like I will always love this kid. But there are days when I'm like, I really f***ing hate you. [slowly, emphatically] ..right?... where you just go red in your head, and you're like, oh, my God, I just want to murder this person. Okay, I am seeing red, and I'm done. You know, and so now where do I go with that? I mean, she gets me to that place, because she just ....is relentless. [slowly, emphatically... "relentless"] (P7 L 781; L 797; L 816)

In addition to constant crisis management and frustration, many participants faced <u>social isolation</u> and stigma. Participants were judged and rejected by others, causing the participants embarrassment and isolation. Sometimes the judgement was bluntly overt, and came from strangers, family members, or even close friends.

> I felt judged a lot…by my father-in-law especially, [who said] "Gee, can't you do a better job?" (P6 L 1402)

> They're looking at me, like, "Do something with your kid!" (P2 L 846)

One mother sensed some judgement as a gender stereotype from her spouse.

> And my husband is engaged, like thank God. But at the same time, there is a little bit of... this is probably a generalization but based on my experience…I feel like there is definitely like a default to the

mom when it comes to certain things, certain parenting things. And
because I'm a nurse, although I've never been a pediatric nurse, or
mental health nurse, it's almost like, oh, well, don't you know what to
do? Like, don't you know? (P4 L 703)

One child's emotions were always dramatic, so during a sad movie, he might sob and

wail loudly, even as a teenager. He also didn't really like being hugged, so his mother was at a

loss about how to comfort him or even respond in public.

Then people are looking at you. And he's… then someone who doesn't
like hugging, and so how do you comfort, you know? He's 17, doing
this in public and you're just like, "I'm a good mom!" [pleading voice,
then laughs] (P3 L 327)

Several mothers lost friends. One mother said, "People have walked away from us

because "P" is difficult," (P7 L 978). Years later, the memory still pains a mother deeply.

I… thought… the lady was my friend. [paused, emphasized "thought"]
And she's like, "well, what's going on?" And I would tell her, and
because [my child] was acting out. And [my friend] looked at me, and
she's like, "wow, well, she looks really normal." [paused, looked away,
eyes tearing up] (P1 L 207)

The mother wondered if her child had a physical deformity, if "that would make it ok? [her

child's behavior]. And you'd be sympathetic?" (P1 L 217)

Losing friends caused severe isolation for some mothers. After the above encounter, the

mother knew she should not talk about her child to other parents and was alone in the world.

When she volunteered at school, the other parents stayed away from her. She was being treated

like her child, whose desk had been pushed into the corner by her teacher.

So, I think at that point, that's when I realized, I'm, I'm alone. You
know? So it was hard. [whispers "hard," tears in eyes, looked very
sad]… And so that's what I knew is kind of like me, and "R" against
the world. (P1 L 219; 236)

Even if friendships survived, friends might avoid the mothers in order to avoid their ED child.

> Some people, even friends, will prefer not to hang out with us just
> because.. it is harder. Some people just don't have the patience. (P8 L
> 568)

Mothers didn't only experience external stigma and exclusion by others, but also internalized stigma themselves. Mothers were embarrassed by their child's behavior and lack of social awareness. It was very difficult for the mothers when their child had loud, angry, emotional outbursts in public or at school. One child would bark and crawl on the wet floor at school or stand on her desk and scream at her teacher. Her mother, by nature a quiet and soft-spoken person, said that "things like that are embarrassing, because it's so inappropriate and mean! It's not the way to talk to anybody!" (P2 L 867). Another mother painfully admitted how hard it was to be "the mother of the troublemaker kid," (P4 L 1058). She described the internal conflict of being the mother of "that kid:"

> [To] have the kid who's the one that's getting (in trouble), you know,
> the one who hits other kids, and the one who's defiant. And maybe
> what some people would say is disrespectful. You know, you don't…
> you didn't want that kid, you didn't want to be the parent of that kid.
> And before you have kids, you're always like, "that's never gonna be
> my kid." [whispered judgmentally]. And then you're in that situation.
> (P4 L 1059)

An interesting negative case involved the mother whose child was barking and screaming. She was surprised to find more support and less judgement than she expected to receive. After she revealed her daughter's tumultuous background to friends at church, they said they had noticed her behavior, but weren't bothered by it (P2 L 1139).

> And so, I sometimes I think some of the stigma is more my
> perception and my expectations than, you know, other people's.
> They're not as bothered as I think they should be. (P2 L 1141)

She wondered if her embarrassment was more internalized stigma than true criticisms from others.

In hindsight, parents often feel <u>guilty</u> for decisions they made or how they handled situations, and the study participants had similar feelings. Mothers had different reasons they felt guilty, including how they handled their child or for not being "good enough" parent. Mothers regretted treating their child harshly before they knew their child had an emotional disturbance. One mother wished she had not followed the "rules" as much but been a fiercer advocate for her child at school. She wanted to request a specific teacher for her younger child, because they had been great with her older daughter. Unfortunately, her younger daughter ended up in a terrible school situation.

> I play by the rules, and they always said, "Well, don't request [your child's] teacher, blah, blah, blah, [in a mocking voice], [the school will] fit them with who we think is best." I went along with that. And I found out that she was mentally abusing "C." (P1 L 1208)

Other times mothers felt guilty for still wanting a career or vacation, instead of "just" being a parent.

> Part of me feels a little guilty, that I have been doing this degree for so long and trying to work and I want to work, and I want to have a career. And so of course, I feel a little bit guilty about that.. If I was able to like, you know, really read all those parenting books and really become the, you know, absolute best mother, I could have been without the competing career "slash" degree "slash" school interests (P4 L 1215- 1220)

> But it's, (the job) you know, it gets me away from.. from that and from her. Which sounds terrible. (P2 L 998)

One mother wondered if she caused the ED due to her use of fertility interventions.

> Is this related to IUI [intrauterine insemination]? Is this like, should I have taken that as a sign that I wasn't supposed to be here in this role? (P7 L 913)

However, none of the mothers dwelled on guilt during the interviews. In fact, mothers said even if they felt guilty about certain things, dwelling on the past was not helpful for the present.

> I try not to think like that, just because, you know, what good's that gonna do? (P4 L 1224)

The mothers were often <u>fearful</u>. They <u>feared</u> for their child with ED, and potential bad things that could happen, but they were also <u>fearful</u> of their child, and potential bad things their child might do. Mothers were worried their child might never become an independent adult, and how this will impact their own future. One mother was frightened her child might not finish school and her child's future: "how's their life going to change [then]? They've got to pass the grades." (P1 L 1135). Another mother worries wondered if everything always be about her daughter with ED's needs, and if this situation will continue for "years and years," (P4 L 1006). Mothers worried if their child would make friends, or "going to be that kid that everyone is like, 'I don't want to be friends with him,' " (P8 L 662). Parental worries about their child's future may be common. However, given these children's severe behavioral problems and the high risk of poor adult outcomes, it is difficult to say these mothers are being overly anxious.

Several mothers were <u>frightened</u> their child's unpredictable behavior might lead to violence or self-harm. Mothers were worried their child might abuse alcohol, run away, or become institutionalized. A mother with two children with ED was violently threatened by both children, and her spouse and older son were afraid to be near her daughter, due to the daughter's prior history of making false sexual assault allegations.

> He said that he's going to shoot us in the head, [while] in the police station. (P6 L 1534)

> I've had knives come at me. Scissors come at me. Fists come at me. Feet come at me. (P6 L 1696)

Another child would have bursts of rage. If she was angry, simply hitting another person once wasn't enough, but she would hit them over and over. Her mother worried "what if "L" grows up and becomes a serial killer?" (P4 L 1096). This mother's fear was palpable as she whispered if her child does something "really bad," it wouldn't be because she didn't try to prevent it (P4 L 1430). But even as she works to prevent a "really bad" event caused by her child, there is deep-seated fear it could be beyond her control.

With all of the negative impacts of constantly being alert, stress, frustration, fear and social isolation, the reality of the participants' parenting experience was very different than the experience they thought they would have. Among the mothers, "the loss of their dreams of motherhood" was a common theme.

> So, it's hard. I mean, parenting isn't what I thought it was going to be.
> (P1 L 327)
>
> That makes me sad that I feel that way. Because then my brain also starts thinking like, this is going to be our life? Like we won't be able to have a vacation and alone time and we won't be able to just leave her with someone because we're always going to be worried about her. (P4 L 848)

Mothers were sad and disappointed because their child was not fitting in, bonding with peers or bonding with other family members, even with the mother herself.

> I still feel like at any point he could just kind of fly away. [spoken slowly and sadly] (P3 L 1199)

Mothers spoke eloquently about milestones they had dreamed of, such as attending their child's fifth grade graduation or having their child graduate from their own high school, which did not occur because of their child's ED.

> I feel like a lot of those special moments that I should have had as a parent were ripped away…[graduation] should just be a happy day (P1 L 1230)

 Another mother's prior happy memories of school were now painful because of her child's

experiences.

> School was not pleasant for "L." And it wasn't pleasant for us. For
> someone…I loved my school district, I grew up in my school district,
> my mom worked for 30 years for that school district, I love school. [said
> "love" emphatically, passionately] And to have it be someplace
> that....gave me a panic attack, was difficult to navigate as a person
> [speaking reluctantly] But also knowing all those people for my entire
> life and knowing them on a personal level, and on a professional level
> was [pauses]
> Researcher: because this is your hometown- your family- and your child
> isn't doing well?
> P: Right. [sadly] (P3 L 401)

One mother said a therapist taught her to mourn the death of a dream, and "you have to grieve

the loss of what you thought something was going to be," (P4, L 1051). Mothers hoped their

parenting journeys would have included some of those dreamed moments, and they deeply

grieved the loss of motherhood ideals.

> You have to kind of mourn the loss of what you thought, what, what the
> vision was going to be. (P4 L 1066)
>
> And so, attending those performances, and just letting go of our
> expectation that we're going to be everything, everywhere. (P3 L 774)
>
> It would be nice, because this is quote, "what I think of," you know, what
> I thought "motherhood" would be like with my kids. [emphasized
> 'thought'] And well, I thought we would be doing those. (P1 L 1060)

All of the mothers were significantly impacted by raising a child with ED. Each mother

bore a high personal price from fulfilling their child's needs. Mothers lived on constant alert and

were overwhelmingly stressed and frustrated. Mothers were judged harshly or rejected by others

and were subsequently isolated and embarrassed. Guilt and fear were also major experiential

themes. Participants were sad that they didn't get to experience motherhood as their friends and

family did. Mothers essentially grieved the loss of their motherhood dreams. Even bearing all of

these burdens, the mothers were not the only ones impacted by the child's needs. Taking care of a child with ED meant every member of the family was affected and must adapt to the child with ED.

Impact on the Spouse/ Primary Relationship

As described above, the ED child's behavior greatly affected the participant themselves, but also impacted the participant's spouse. All of the participants said their spouse or partner was negatively affected by their child's ED, and their relationship suffered as a result. Living in a tumultuous home, observing the strain on their wife/partner, and having to change parenting styles was not any easier for the spouse than it was for the participant. The stress from living in so much turmoil and change affected the relationship between the two parents, especially if the two parents did not agree on the best parenting approach. Although two of the participants were unmarried, they also had relationship problems which were directly related to their child's ED. The subcategory of *Impact on the Spouse* was comprised of five themes: 1) did not see the problem, 2) rejection, 3) tension, 4) unbalanced load, and 5) best friend.

Because the participants were all mothers and the child's primary caretaker, their spouses did not observe as many outbursts as the mothers did, especially in the early years. When the spouse did not observe the meltdowns, they did not see the problem and the level of emotional turmoil from the child's reactions as strongly as the mother did. Spouses rationalized the concerns regarding the child's behaviors for a longer time than the participants did.

> So, he drives, he's on the road [for] three to three and a half hours a day, five days a week plus his day at work. And so, I spend the majority of the time with the children naturally... And I'm the one who deals with it all. So, I think a lot of times, he just wasn't there to see it or hear it from himself. (P5 L 898)

> I was noticing a lot of things. He, for a long time, chalked it up to virtual school, or her age, or what have you. (P4 L 734)

As the problems escalated, the spouses observed more problems. Spouses started thinking

the mothers' suspicions could be correct.

> As things just kept getting progressively worse, and it was impacting our
> life, our work, and things like that, he was like, "She needs something.
> Like we can't, what are we doing?" (P4 L 281)

> And I don't want to say it's only because it started impacting him in a
> greater way. But that could be it as well, like when she started getting in
> trouble at school, and he would have to go pick her up or when she was,
> you know, when it started impacting, you know, [him more].. her
> behavior and stuff like that, he definitely realized it was more of a...
> more of a thing. (P4 L 766)

Spouses were definitely impacted by their child's behaviors, as well as by the various

adaptations the participants used to manage the child with ED. One participant's partner moved

in to provide childcare while the participant worked. Their spouses saw the toll being taken on

the mothers. Spouses felt helpless watching the stress but unable to fix the problem. Another

spouse felt rejected and frustrated when he watched his son struggle to learn to play guitar,

which the spouse had played for years. However, the child had no desire to learn from his

father's expertise.

> "M" (participant's spouse) said, "Well, I'm classically trained
> musician. Didn't ask me a thing about music, or theory or anything."
> "M" took lessons for years on the guitar. "L" doesn't even know how
> to tune the guitar. But he'll post pictures of himself on Instagram,
> tagging, "super star!" (P3 L 1088)

One participant saw the pain and rejection her spouse went through due to their children

with ED. Her daughter made false allegations that she had been sexually assaulted by her

younger brother (11). Her spouse (the child's father) decided it was unwise and unsafe for him

to be alone with her, because he was frightened of an accusation leveled at him.

> Because it's like, "When is she gonna say it about me? When is she
> gonna say it about our oldest child?" He's like, "[if] she's gonna say that
> about her, her biological brother, when are we next?" He was really,
> didn't really want to be around, or he didn't want to be in the same room.
> He made sure that he was never alone with her because he was like, "I
> just can't, I can't risk my life and my livelihood, professional license,
> because she's saying these lies." (P6 L 1142; 1144)

Later, he was betrayed when his son walked out on him.

> He and "A" were closer. And when my husband, when[he] found out
> about the [son's] robbery, my husband said to him, "if you walk out that
> door, it's over." (resigned voice). And he walked out anyway. And my
> husband felt like that was a huge betrayal (emphasized huge) to him,
> because he was excited about the sports, excited about the fact that he
> was doing well academically in the public school. (P6 L 1574)

Tension was high between spouses. Some spouses refused to adapt to the child with ED

or did not believe the child had a "real" mental health problem. Other spouses simply lacked the

patience to deal with the level of emotional explosions from a child with ED.

> He doesn't have the patience. He, you know, he expects her to sit and
> be quiet, like the other kids. [while at church] (P2 L 1060)

One participant's spouse felt strongly about the value of exercising, and did not think this should

change for the child with ED. This family lived in a very warm climate in southern regions of the

U.S.. This child's emotional disturbance worsened whenever she had an increase in

inflammation, so excessive exercise, especially outside, caused her to have a physiologic

reaction which manifested as behavioral outbursts.

> It took him a really long time to understand that, like, he can't send
> her out to ride her bike when it's 90 degrees out for half an hour. (P7 L
> 352)

Another spouse thought his daughter's problems were not "real," but just a female

teenager being melodramatic and seeking attention. Early on, he frequently confronted his

daughter's emotional behaviors in a classic "old school parenting," telling her to just stop being

dramatic and spoiled. This mother had to mediate battles between them, while still suspicious

that something was truly wrong with her child.

> He was very, very much against it, very much against [evaluating child
> for depression]. And then we got the diagnosis, and he still didn't believe
> it. He just felt like, I guess, somehow they skewed... she skewed it (P5 L
> 381)

The participants' problems were worsened when the spouse didn't see the child's behavior as

abnormal or refused to adapt to the child. Life was harder for the participants before their spouse

"came on board."

Even when spouses were completely "on board" with the mothers' concerns, they still

struggled to raise their child with ED. Because the mothers were around the child more often, the

mothers had more insight about how this child's mind "works." Mothers saw their partner trying

their best to help but the spouse didn't know what to do during a meltdown or when traditional

methods or consequences failed.

> So, he tries. You know, and sometimes it's great, and it works. And
> other times, it's like, you know, I get the call, okay, "you got to come
> home." Or you know, "This is what's going on.. I don't know what
> to do. How do I make it better?" (P1 L 704)

She knew her partner was sincerely trying, but he genuinely did not know how to respond to

their child's emotional reactions. For these participants, the imbalance of knowledge between the

parents unwittingly created a pattern which continually placed more and more burden on the

mothers in the study, with fewer and fewer options for respite.

There was an unbalanced load of responsibility in almost all of the participants' stories.

The mothers were responsible for nearly all of the appointments, adjustments to the home,

researching new parenting options to try, teaching others how to communication with the child

with ED, and bore the largest brunt of the emotional upheaval from the child's outbursts.

> So, kind of when the poop hits the fan, so to speak, it's me, and that's
> why I feel like I'm kind of always in this crisis management. (P1 L 673)

> And he never wanted to help me with "C." There was like, one time
> when I was like, "Hey, can you just pick him up from daycare really
> quick and feed him before we have to go to therapy? So that way I know
> that he's fed and he's okay?" And he refused to do that. (P8 L 1181)

> It really put a lot of stress on me, because he was traveling all the
> time and put a lot of.... I carried the burden of…the childcare while he
> was trying to find his nook and niche with a job.. I was the default
> person (the school/ daycare always called) (P6 L 589; 601)

The participants carried a heavy and unbalanced load of parenting responsibility raising the child

with ED. Mothers are often the primary caretakers of children in U.S. culture, but the extreme

challenges a child with ED presents made the role of "primary caretaker" much more difficult.

There was one exception to this unbalanced load between parents. One participant and her

spouse made a series of very deliberate decisions to balance the load of responsibility between

them. This couple delineated which jobs each parent was responsible for.

> We divided by who was responsible. So, at a certain point, I did not go
> to IEP meetings...I'm not doing math. I'm doing social studies…I'll do
> language arts. And I'm not attending sporting events [but she attended
> musical performances]…Just letting go of our expectation that we're
> going to be everything, everywhere. We're going to do what we can,
> when we can, we're going to divide and conquer. And then, we are going
> to let whatever happens....go. (P3 L 765; 774; 805)

These hard boundaries allowed each parent to focus on their assigned responsibilities instead of

trying to manage everything.

Even though only six of the eight participants were married at the time of data collection,

all of the participants had relationship problems stemming from their child's ED. Participants'

relationships bonds became strained from dealing with the child's behaviors and all of the

adaptations they tried to use manage the behaviors. One couple actually divorced, partially

because of the conflicts they had about how to handle their child with ED.

> The kids' dad and I got divorced. That was definitely like, there were
> a myriad of issues, but that was one of them. That she was a hard kid
> to parent, and we definitely had disagreements about how to do that.
> (P7 L 326)

Spouses blamed the participant for the ED child's behavior or thought adapting their reactions

was akin to "caving in" to the child. One partner said, "She's going to end up being a spoiled

brat!" (P2 L 946). Other times, the mother's fatigue and stress made her "snappy" at her spouse.

> There are times when it's just, it's stressful. And it's like, I can't handle
> anything else. And I can't... He'll be like, "Well, why don't you go try
> and do this?" And I'll just be snappy and be like, "How's this gonna
> work? You know, how can I do this? (P1 L 819)

Although one participant had been single from her son's birth, his unpredictable reactions and

emotional meltdowns made it hard to date or find a new relationship. She has struggled to find a

partner who accepted both her and her child.

> It has impacted like dating life. It was hard. Like [in] that last
> relationship, it was constantly an issue. (P8 L 566)

Tension erupted when one spouse did not believe the child had "real" depression and anxiety, but

rather that her diagnosis was an "excuse for her to be on medication," (P5 L 374). The family

eventually staged an intervention.

> We had to do like a family intervention with her therapist. And he was
> still pissed off about that because he felt like the therapist was blaming
> him. (P5 L 1095)

However, despite all of these issues, the six married participants spoke highly of their

spouses, and were very grateful to have their spouses' support. Participants called their spouse

their <u>best friend</u>. Relationship tension often lessened once the spouse experienced the child's

outbursts themselves, especially if they were alone and the participant was not there to handle it.

Tensions eased when the spouse accepted the child's mental health problem was "real," and not

just circumstantial or simple defiance. One spouse was shocked when he learned the depth of his

daughter's depression, and this realization eased the tensions between both parents and from this

father to his child with ED.

> And so, we went as a family [to therapy] and they were having some
> talk and she said something about how she didn't know it wasn't
> normal during high school to not wake up and not want to be alive.
> And he's like, "Excuse me?"(surprised voice) and I think he's like,
> "you felt that way?!" (P5 L 893)

The participants said their spouse was their <u>best friend</u> and strongest supporter. The

participants were extremely grateful for their spouses and cherished the strength of their

relationship.

> It took him a little bit longer to get there. And, you know, thankfully,
> now he is. (P4 L 741)
>
> My husband and I have a great relationship. (P6 L 1077)
>
> We've been [married] 26 years. We've been together 31 [years]. So,
> you know, he's, he's my best friend [whispered, with tears in her eyes]
> So, you know, we always work our ways back. (P1 L 816)

Despite the numerous legal and criminal problems of one mother's children with ED, she

was proud that she and her spouse kept their bond strong. She never wanted to jeopardize her

relationship.

> We had date nights to keep our relationship strong, we didn't want to
> jeopardize that.. we stayed strong. (P6 L 653)

Now that their children with ED were not living with them, the participant and her spouse are

focused on healing themselves.

>My husband and I will definitely... we make time for each other. We
>have our date nights. We have times where we just sit and talk with
>each other. (P6 L 1609)

Another couple made a pact to always back each other's decisions.

>Basic agreement is whatever decision you make, you've made the best
>decision you can make, we will never argue about a decision
>somebody else makes. And that conversation happened with my
>spouse. (P3 L 786)

This couple has been together for 38 years, and "we know the heart of what each of us are," (P3 L 1022). They treated each other intentionally by dividing responsibilities and agreeing to believe each parent is doing their best. All of the six married participants drew great strength from their spouses and spousal relationship.

Raising a child with an emotional disturbance altered the spouse individually as well as the parents' relationship. Even though two participants were unmarried at the time of data collection, all of the participants had relationship problems which stemmed from their child's emotional disturbance. Spouses did not always see the problem as quickly as the mothers did and struggled to adapt to their child's behavioral patterns. This resulted in tension between the two parents. As primary caretakes, the mothers had more day-to-day responsibilities and dealt with more day-to-day behavioral problems. This created a cycle of more burden being placed on the mother, because she knew more about how the child "works," but rapidly decreasing options for respite. The unbalanced load of responsibility stressed the parents' relationship even further. However, participants felt their spouse was their best friend, and they were able to maintain their relationship bond.

Impact upon the Siblings

Six participants raised other children in addition to the child with ED. The needs of a child with ED does not negate the importance of other children's needs, regardless of how

extensive the ED child's needs may be. The subcategory *Impact on the sibling* contained themes

of stress, harmed sibling bonds, and feeling overprotective of the child with ED. Siblings were

personally affected by the ED child's outbursts and volatility personally, just as the participant

and the spouse was. Living in emotional turmoil stressed the siblings deeply and harmed the

bonds between the child with ED and their siblings. Sometimes, the siblings became

overprotective of the child with ED as they struggled to fit into the world.

The unpredictable behaviors of their child with ED created stress and havoc for their

siblings. Some siblings simply could not fathom why the child with ED acts like they do.

> Absolutely that [ED child's] behavior affected "T" [older brother]. "T" is
> much slower in his processing of what's going on. He does not like
> drama. He does not like noise… because "L" makes [long pause]
>
> Researcher: "L" loves the noise, the crowds, the screaming, it feeds him?
> And "T" needs quiet to center?
> P: Yeah (P3 L 891)

Siblings with innately calm demeanors might try to avoid the turmoil. One sister could not

handle the emotional outbursts of her sister with ED, so she would leave the vicinity whenever

her sister's emotions ran too high.

> [Daughter with ED would] lose it on him [her father] and they'd be
> at it, and then "M" would just get up and put her plate down. She
> goes, "I'm done." And she would just go away. (P5 L 664)

If the siblings attended the same school, the outbursts from one child would embarrass the

sibling or impact school relationships just due to association.

> And it was hard for him because you know, they were in the same
> school. And when she would like, misbehave, I mean, they have to
> "room clear." The cops would be called, and it was embarrassing to
> him because here, here, everybody knows that his sister's having a
> breakdown and getting the cops called. And it was pretty mortifying
> for him. (P6 L 680)

Siblings learned their own coping mechanisms, but these were not always healthy methods. One

child felt the need to be "perfect" to make up for all the drama (P7 L 876). Another mother said,

"her brother and sister spent a lot of time sort of placating, [hesitated] because it was easier than

arguing [with their sister]," (P7 L 300).

> I think that they both have taken like these roles in our family that
> are really intense because of "P"... even now that I'm like, "What do
> you guys want for dinner? And they're like, "Well, what do you think
> "P" will eat? [Researcher: they always defer rather than state their
> thought?]. yeah. (P7 L 317)

The constant turmoil and vastly different innate personalities <u>harmed the siblings' bonds</u>.

> She has a hard relationship with her brother and sister and her
> brother and sister are super close to each other. And none of them are
> super close to "P." (P7 L 651)

Some bonds went beyond harmed to completely broken. A mother said when her sons

come home for dinner, they no longer speak to each other because the "relationship is broken,"

(P3 L 895). For one sibling who experienced abuse from his younger brother and sister, he

decided it was better for him emotionally to cut his siblings out of his life.

> He doesn't he feel, he says to us he doesn't have a sister. And the fact that
> his younger brother did what he did, with all the criminal crap. He's like,
> "I don't even feel like I have a brother, either." He's like, "They've just
> been nothing but stress and trouble for all of us." (P6 L 904)

Vast differences did not always break sibling bonds. Sometimes, the other children

became <u>overprotective</u> of their sibling. These siblings tried to shield the child with ED from

negative consequences of social stigma. Even when the siblings were not close, one child's twin

sister tries to protect her sister with ED from peers who mis-treated her in school (P7 L 698).

Another sister takes special efforts to keep up with how her older sister with ED is doing. When

things happen that might flair her sister's anxiety, she checks in to make sure her sister is ok (P5

L 751). Even after his sister hit him, her younger brother stood up for his sister and did not want

his sister to get into trouble with his mother (P4 L 443). Participants were warmed by these lasting bonds of sibling love.

Siblings struggled to cope with the turmoil that emanates from a child with ED. <u>Sibling bonds were harmed</u> or even destroyed by this <u>stress</u> and havoc. This was especially true in the cases of physical or emotional abuse from the child with ED. Some siblings decided to acquiesce every decision to the child with ED, simply to keep the peace. However, other siblings responded with innate compassion toward the child with ED, even if they would prefer a less dramatic home. These siblings would try <u>to protect</u> the child with ED from being mis-treated.

Advice for other families

The final category was **Category 5: Advice for other families**. As the researcher described the study to potential participants, many potential participants wanted the chance to tell their own story to hopefully help other families like their own. Potential participants felt other families as well as professionals could learn from their experiences. In turn, this could lessen the burden for other families in the future. Naturalistic design qualitative research can give a voice to people whose voices have been hidden by sharing participants' stories and experiences with the world.

To directly capture this opportunity, the final interview question was: "If you had a personal bullhorn, and could give other people or the world a message, what would you want to say?" Some participants seemed surprised at the question and took a pause before responding, but every participant was eager to share their personal messages. Three subcategories emerged from this advice, including *Kids really are all different!*, *We need help, not blame*, and *Survival tips for families*. Participants reminded other families that the phrase, "children are all unique" means…children will learn and react differently. Families with children who have emotional or

behavioral disorders require individualized plans for their children. Children with ED cannot be measured with the same "yardstick" as typical children. Participants strongly felt other people did not understand how difficult it was to find support resources or information about parenting a child with ED. Participants wanted the world to know how hard they were working to raise their child into a productive member of society. Lastly, participants offered compassion and survival tips for riding out the chaos that comes with children who have an emotional disturbance.

Kids really are all different!

The subcategory, *kids really are all different*, was comprised of three themes: 1) <u>typical parenting fails</u>, 2) <u>school focus on speed, not success</u>, and 3) <u>ignore differences; address the disruption.</u> Participants pointed out the incongruency of saying "All children are different and unique!" but then expecting all children to learn and react in the same way, especially in school.

Parents of children with ED need to know that mainstream educational methods and <u>typical parenting strategies usually fail</u> when used with children with an emotional disturbance.

> And not every kid is going to be the same and walk the same path. I think I've really realized that kids are very different....[we need] recognition that the kids can't all be measured with the same yardstick. (P4, L 1260; L 1272)

All of the study participants said the traditional or "old school" parenting methods they grew up with failed when used with their child with ED. One mother learned her child with ED did not respond to anger or punishment as she herself did when she was a child. Parental anger did not inhibit the child's behavior but made the child worse. She explained this thought further when she felt others judged her parenting.

> But saying to other people who are very much like, "well, if your kid's a jerk, you just punish them...that's what you do." Like, that's not how that works. It doesn't work for her, I'll tell you that, it doesn't work for her. (P4, L 1299)

Similar to this mother's belief, another mother strongly felt underline{school systems are focused

on speed and curriculum, over the success of individual learning and progress.

> Did we forget what teaching is about? Did we forget what the point
> it? (speaking quickly) What would I love for teachers to know?
> Damn,…that its teaching! That it's not that they (children) come
> fully formed, that it's a process and that they forget what a bell curve
> was? That not everybody knows the same crap at the same time?!
> (P3, L 1360; 1391)

> What we're (schools) looking for now is not necessarily success, but
> expediency. They just want to get the child through…this thing. (P3,
> L 1548)

Participants had suggestions for to improve school accommodations. Children with

school accommodations should have individual levels of schoolwork and grading expectations

and should not be measured by standard benchmarks. This way, a child is measured by their

individual level of work, progress, and productivity, rather than assigning all children the same

work graded with the same rubrics. Schools may suggest giving extra time to complete

schoolwork, but the "additional time" kept her child perpetually behind, in a homework deficit

he could never resolve. By measuring a child on accommodated levels of work and rubrics, they

have a greater chance for higher grades and personal success.

> There's no reason for kids to have to do extra homework when they
> are already on an IEP…please use your time wisely and figure out
> what the most important thing is for them to know, to be careful about
> how you set your goals for that student. If it's an individual education
> plan, you should know what goal you individually have for that
> individual student, and that should not match any other students. And
> I know that's extra work, and I know that's really hard (speaking
> slowly). But by partnering with parents, you could do so much more
> than what you're able to, but by exhausting them with...busy work,
> you're destroying families. (P3, L 1267)

Another idea which flowed from accepting *all kids are all different* <u>included ignoring</u> <u>behaviors</u>. This mother advised that every odd behavior does not require correction, and to differentiate between unusual actions and actions that truly disrupt other children's learning.

> Even teachers, you know, if she gets up on her desk and starts barking, okay, let her do that. Unless she's disrupting class and ..let her go somewhere else and back. Or she needs to stand up to do her work. Let her stand up and do it. You know, you really have to tell yourself, is she really bothering somebody by doing this? …if it's disruptive, then…just take her somewhere else, let her do it. (P2, L 1240)

We need help, not blame

Mothers said they often felt lost, but instead of finding help, they found blame. The subcategory of *We need help, not blame*, was comprised of the themes <u>it's not our fault</u>, <u>we need</u> <u>tools</u>, and <u>healthcare needs a wider view</u>. Participants struggled raising their child without professional guidance yet were blamed for their child's poor behavior. Participants pleaded for others to understand it is <u>not our fault</u> and to stop blaming parents for "bad kids." Some participants discovered new ideas through social media and personal research. These discoveries offered new helpful <u>tools </u>and strategies to try. Mothers were comforted by the knowledge that other parents were having similar issues with their children. Participants strongly advised other families to seek parenting tools and relieve personal isolation. Participants felt <u>healthcare needs a</u> <u>wider view </u>of potential causes of a child's problematic behavior. Participants advised other families to prompt their own pediatricians to take a wider view. Lastly, segments of society still treat mental illness as a simple lack of discipline or will power, rather than a "real illness."

When asked what she would like others to know about her experiences, one mother shouted:

Stop blaming the parents! Stop blaming us because we ***tried*** ["tried" said emphatically]….their biological parents did drugs while they were in utero…they didn't show up again when they were supposed to. So now [the children are] diagnosed with reactive attachment disorder, ADHD, and other things…my husband and I have done our job…(P6 line 1707)

Researcher: for others to know you have exhausted everything that can be done?

Participant: Yes, yes! More than a lot of other people would… I just feel like there's nothing more we can do (P6, line 1722).

Another mother echoed these statements, wanting to "scream" her message to the world.

And just if I could just scream it to the world, it's not the parenting...You know, it doesn't mean someone's a bad parent just because their kid might be, quote, "bad." I assume other parents are really struggling to find the right path. So, I would say, it's not the parents. These kids need help and not necessarily punishment, suspension, and expulsion…There's no one telling us what to do, what the right path is…(P4, line 1262)

[We need] more awareness that… it's not the parents' fault, that something is going on here. (P4, Line 1275)

Mothers floundered around, seeking information specific to their child's problems.

Participants offered several ideas for improvement.

Trying to get sort of a little think tank, you know? Where you can have more resources that are free. And you know, there can be more 24/7 vs what my next appointment is in…three weeks kind of thing. (P1 L 1529)

I would have loved a workbook. Something that stepped me. If you're dealing with 504's, IEP's, the different things that you're trying to put together for a child, to be like, "here's some questions we can write down."… The concepts of [elder] care, there are books for caregivers you can fill in. (P3 L 1681)

We need more accessible intervention, interventions and resources for child who are struggling with, you know, who are different…trying to figure out how we can start this even earlier…I would say, more resources and more counseling available. (P4 L 1258; 1272)

Another participant pointed out healthcare and mental health professionals need to be

willing to look further afield for potential causes of a child's problems. In her experience,

healthcare providers were narrowly focused on the parents or the child's behavior in the moment.

> PANs and PANDAs go so underdiagnosed that I just wish there was
> more education around it. I know that there's more kids out
> there…talk with your medical professionals about it…it's like,
> education, education, education…recognizing when we were kids
> and…got strep throat, you always went back…for a recheck after
> your antibiotics. And they don't do that anymore. (P7 L 1282)

Lastly, segments of society still stigmatize childhood mental illness as a lack of self-

discipline or blame it on poor parenting. Two participants focused on changing that lingering

perception.

> I think some people think it's… oh, ADHD, that's not a real thing.
> Yeah, it is. You know, just like diabetes is, or any kind of mental
> illness. A lot of people think that's not a thing. That its' just,…just all
> in your head. No! I mean, it is in your head, but it's a medical
> problem. I guess the ignorance of some people really kind of bothers
> me. But education that yeah, this is a real thing. (P2, L 1205; 1215)

> [Researcher clarifying: the social idea that you could just will
> yourself out of it, if you had discipline, you could?]

> Participant: Yes! "it's just in your mind!" and I look at people and I'm
> like, *exactly*. It's in their mind, that it's a part of their body. The
> problem is there. (P1, L 1391)

> The thing that is frustrating to me [is] it seems to be the big thing to
> talk about mental health, and it's so important, and we need to work
> on this as a society (mock serious voice) But when it comes down to
> it, it's not really happening…I feel there's a lot of lip service right
> now in society, that it's the thing to talk about, "let's work on mental
> health" and "we need more services"… but when it comes down to it,
> I don't feel like it's happening. (P1 L 1376)

However, this stigma may be dissipating. One participant saw the shame and instinct to hide mental illness decreasing with her daughter's generation.

> I think as a society, we are getting more open about it…I think back in our days, you never knew why or what was going on (when someone committed suicide). And I think as a society, we're getting more tolerant of that… [when a neighbor said] "more kids are just taking their life nowadays," I'm like, they were doing it back then. And people didn't talk about it. It was kept hidden, and nobody said anything. (P5, L 1333; 1358)

Survival tips for families

The final subcategory within **Category 5: Advice for other Families** was labeled "*Survival tips for families.*" Mothers shared tips and messages of hope to other families raising children with ED. Themes included being <u>open to learning</u>, <u>connecting with others,</u> that the <u>child may be suffering,</u> and to <u>ride the wave</u>.

The participants encouraged families to <u>open their minds to learning</u> from other parents' experiences. One mother found her daughter's teachers were a wealth of knowledge and support, and she advised other parents to tap into those resources.

> When I meet parents, if they have a three- or four-year-old [with behavioral problems], and they don't have them in the [preschool special education program], I'm like, why aren't you using these professionals there? (other parents say) "well, I just don't think that it's the right place for him or her. I'm just like, you have free help! Use it! (P5, L 1428)

This mother encouraged other parents to be open to teachers' observations of their child. Teachers interact with the child for hours daily, observing them with peers, other adults, and in different situations than parents will observe in the home.

> I have always been very open because I have another child with special needs. I know that there's other parents that don't even want that diagnosis, but I was like, something's wrong. We need to find out what's wrong. (P5 L 1279)

Parents, you just have to be open. And it's not scary. It seems scary.
But the more you know, the more you can help them [your child]. (P5
L 1286)

Another participant advised parents to be consciously open to listening to others, even if

they don't think the specific idea will work. She found listening to one idea may spark other

ideas. If a specific technique failed, the idea could be "tweaked" into a success.

What works for you, may not work for them, but just have that
openness to be like, you know what, I'm just gonna listen. Or…I
don't think that'll work, but I could do this and tweak it a little and
that might work. (P1 L 1511)

Connecting with others, especially other parents, was vital. Participants explained making

those connections reduced their isolation and help banish thoughts that "no one else has ever had

deal with this before." Participants struggled with feeling ostracized and lonely.

I wish there was more help for the parents. Some way to connect…I
guess my advice would be is to try to find others who are similar…
so you don't feel so alone. They have to have someone to talk to. It
can be hard to open up, because I had that experience of "oh, she
looks normal." Oh, I couldn't imagine anything worse to me…keep
trying to find others that you can talk to…you need to be able to
vent. Trying to find some of those people, so you are not alone. (P1
L 1335)

Other parents should know even though it may not be obvious from their behavior, their

child could be suffering, too. When one child attended an out of state university, students from

other regions were surprised how little her daughter knew about mental health. This mother

learned her daughter truly didn't know that her overwhelming anxiety and feelings of

worthlessness were not normal feelings.

I guess mental health is not talked about to young children, or high
school kids, like it is up north…there's no way for them (children)
to know it's not right to feel sad every day. It's not right for me to

> feel this way about myself. I should love myself. I should be happy
> with my life. (P5 L 1313)

A mother reminded other families that these children still want to love, to be loved and be

accepted.

> At the end of the day, these kiddos just…they just want to love and
> be loved…'cause he'd be like, "do you still love me?" and I'm like,
> Oh, [when] you have good days, bad days, rough days, sad days.
> And he's like, "You really do?" [mimicking excited child voice] (P8,
> L 1223)

Lastly, participants encouraged other families to keep searching for their own pathway

for success as they ride the waves of change which go along with raising a child with ED.

> You can't give up. I mean, there's resources out there…some people
> are blessed with more resources, more finances. But there's still
> resources out there. And you just, you can't give up on your kids,
> you've just got to keep being their advocate (P1 L 1331; 1346)
>
> There's no right or wrong way. You just have to find your one. And
> whatever that path takes you on. And you may see light in the tunnel
> and then be like, oh, but we're gonna have to veer off that way. And
> we'll get back to it…It can take longer. It can be a different path
> from what quote "the norm" is and there's something that'll
> work…there are lots of options. Don't ever think that, well, this was
> it. That's all there ever was. No, you're limiting yourself, keep
> going. Keep figuring it out. (P1, L 1449; 1466; 1483)

One mother was advised to "ride the wave," and this phrase became a mantra for her.

Individual situations are fluid and temporary, but by viewing them as shifting waves, she could

focus on her path to the other side of the wave.

> The one thing that sticks with me is just "ride the wave." Everything
> is so temporary. Everything is so fleeting, really, with these moments.
> Take the good ones when you have them. We don't know how long
> the wave is. We don't know how short the wave is. Just… ride the
> wave. (P8. 1221; 1236)

Summary

In conclusion, three overriding constructs were derived from the data gathered in this study: 1) **concerns and suspicions**, 2) **actions and adaptations**, and 3) **altered families/ advice for others**. All aspects of the participants' lives were impacted by the behaviors, emotional volatility, and the needs of their child with ED. Participants experienced growing **concerns and suspicions** about their child's behaviors. **Realizing my child is different** describes the experiences which eventually lead to the participants' child being identified as having ED by a professional. The journey to discovering their child did have ED was difficult, but then mothers began the tough work of finding methods to manage the child's ED.

Once the participants' suspicions were confirmed, they engaged in ongoing **actions and adaptations** to manage the situations, outbursts, and reactive behaviors of their child with ED. **Category 2: responding to the challenges** outlines the vast array of responses that participants used managing the challenges and turmoil related to their child's ED. Responses included those *for the child with ED, for the parent: self-care*, and *for the siblings*.

Responses *for the child with ED* included parenting using their past experiences (usually authoritarian) which failed to change their child's behavior. All of the participants sought expert assistance from mental health experts and education experts from their child's school. Sometimes these professionals were very helpful, but participants struggled to find effective and well-fitting professional care for their children. Participants' experiences with schools were widely varied. Some participants received wonderful support through their child's schools, but others encountered extreme difficulty or worse, discovered their child was being physically or emotionally abused by their teachers. Participants adapted themselves and their child's environment to better suit their child's needs, instead of teaching the child to adapt to others. The mothers stopped reacting to challenges and switched to intentional responses by adapting

themselves and the environment surrounding the child with ED. Individual actions might be viewed as "nice to do" or "good parenting." However, these "nice to do" actions became absolutely necessary due to the severity of the child's outbursts.

Responding to the challenges of the child with ED required significant time and energy. The diversion of this time and energy caused additional needs for *the parent's self-care* and *for the siblings'* care. Mothers described the vital need to connect with others and get time away, even if that time was their employment. Researching, therapy, belief systems and purposefully changing their internal reactions enabled mothers to continue responding as their child with ED needed. Mothers also had to ensure the siblings' safety. The responses needed for the child with ED impacted the available individual attention left over for siblings, which mothers tried to mitigate as much as possible.

As the child grew older, the situations and mothers' responses changed. The ongoing challenges resulted in an internal transformation of the mothers' perspective. The internal change became **Category 3**: **changing over time**. Mothers realized their child with ED *sees the world* in a unique way. When the mothers saw the world from their child's eyes, they could see rationales behind their child's reactions, even if the rationale was from flawed reasoning. This allowed the mothers' *perspective to change* and their child's behaviors as signs of internal struggle instead of simple displays of defiance. Mothers saw their child as ***struggling*** with a problem, rather than just ***being*** a problem, especially as the child suffered in silence or was unaware of social rules. Most mothers started *seeing strengths within their child* in spite of- or even due to- their child's view on the world. Participants felt regardless of the outcome, they personally *had done their best* for their child. There was a tenuousness about their child's future from mothers of older children with ED. mothers knew their child was *no longer a child, but also not yet an adult*.

Mothers wondered if their child will ever become a "true" adult, as none of the children were independent.

Category 4: Altered Families describes the aftermath of turmoil brought into the family because of the behaviors of the child with ED. Many of the adaptations used for the child with ED altered the entire family as well. Participants met their child's needs but at great personal cost to their family and themselves. Mothers were constantly <u>on alert</u> for the next crisis, leaving them <u>stressed</u>, <u>fearful</u>, <u>frustrated,</u> and <u>isolated</u>. Spouses were impacted by ongoing strain and relationship <u>tension.</u> For some mothers, this tension included divorce and difficulty finding a supportive partner. Participants had to provide <u>safety</u> for their other children, as well give these other children <u>personalized attention</u>. Sometimes siblings had to live elsewhere to ensure their safety, but these siblings may have felt pushed aside or unfairly punished because of the actions of the child with ED. When a family had to move, change schools, change employment, or otherwise adapt the environment for the child with ED, their siblings had to change also.

Participants were offered the opportunity to share personal messages about their experiences. **Category 5: advice to other families** emerged from these personal messages. The participants wanted others to understand children *really are different*. Measuring every child by the same yardstick ignores the idea that "everyone is unique." Participants wanted the world to know the child's ED is <u>not their fault</u>, and that parents desperately <u>need tools</u>. Participants also offered *survival tips* by encouraging other families to <u>connect with others </u>and to<u> be open to learning. </u>Participants encouraged other parents to consider their child with ED might be <u>suffering silently</u>, even if the child's behavior does not reflect this distress. Most importantly, participants wanted other families to realize they are not as alone as they may feel, and parents should <u>ride the wave</u> of daily challenges.

The study findings illustrate the far-reaching impact a child's ED has upon everyone around them. The findings demonstrate how the child's emotional reactions, outbursts and behaviors deeply affect the parents and siblings living with the child. No single description can capture all of the challenges and impact experienced by parents of children with ED, but every attempt was made to create a rich and nuanced picture of the parenting journey experienced by these eight mothers. The data was selected to allow readers to interact with the challenging situations as well as the emotional responses of the participants undergoing this journey. It is hoped readers will gain a sense of what parenting was like for these eight participants, as well as to provide a basis for healthcare and educational professionals to improve practice and supports for parents raising children with an emotional disturbance.

The final chapter, Chapter 5, will discuss the study's conclusions and recommendations. Chapter 5 will provide an overview of the major findings and how these findings relate to previously published literature and Orem's Self-Care Deficit Theory. Chapter 5 will discuss what implications for nursing practice can be derived from the study. Lastly, the chapter will present the limitations of the current study and recommend directions for future research.

CHAPTER 5: DISCUSSION AND CONCLUSION

This study used naturalistic inquiry to explore the experiences and challenges faced by parents who are raising children with an emotional disturbance (ED). The study describes how the parents managed the problems related to their child's ED as well as the barriers or facilitators the parents encountered. In addition, this study describes how profoundly each family member was impacted by the problems which stemmed from the child's ED. This closing chapter will review the major findings of the study, relate the findings to the current body of knowledge, and present implications for nursing practice. Finally, the chapter will discuss the study's limitations and recommendations for future research.

Overview of Major Findings

During data analysis, three constructs emerged describing the experiences of the participants in this study: **concerns and suspicions**, **actions and adaptations**, and **altered families/advice for others**. The constructs address the study's three research questions:

1) What are the parenting experiences of parents of children with emotional disturbance?

2) How do these parents respond to the situations & challenges that arise due to their child's ED? Do these situations and responses change as the child ages?

3) How does raising a child with ED impact the family as a whole?

The three constructs were developed from five categories which emerged from the data: 1) **realizing my child is different**, 2) **responding to the challenges**, 3) **changing over time**, 4) **altered families**, and 5) **advice for other families**.

The first construct, **concerns and suspicions**, encompasses the participants' internal reactions to their child's unusual behaviors. Participants' children behaved in very unusual and worrisome ways, causing their parents frustration and confusion when the child did not respond

normally to parental guidance, discipline, or even comfort. The first category, **realizing my child is different**, describes the journey most participants experienced as they realized their child was not developing and maturing emotionally as other children for their respective age.

The participants, all mothers, were *concerned* about their child's behaviors at an early age, sometimes even as infants. Their child with ED was unable to read social cues from others, like barking in a store or leaping at strangers for a hug. The children were very rigid thinkers, lacking awareness of anyone else's needs, wants, or point of view. A child with ED might be wildly emotional, reacting completely out of proportion to the situation, like when a six-year-old sobs and wails because the plane has landed, and he must de-board. Many of the mothers *rationalized their concerns* at first, thinking the behaviors were circumstantial or a personality quirk and would resolve with time. The mothers' *suspicions escalated* when their child did not respond to any parenting method they tried. Many of the children's behaviors worsened around age seven to nine, and mothers *decided something was definitely wrong*. Some participants' children with ED were aggressive and violent. One child's rage went from "zero to sixty" when a friend did not follow the rules of a make-believe game at recess, so she violently hit him over and over again, as if to get her anger "all the way out."

All of the participants *consulted* with experts, and each participant's **<u>concerns and suspicions</u>** were *confirmed:* their child did have an emotional disturbance. However, participants faced many barriers getting to this step. Participants were delayed getting a consultation for several reasons, included other simultaneous family crises, siblings with more obvious needs, children with physical health issues in conjunction with their behavioral problems, or when the participants' spouse did not believe the child's behaviors were truly abnormal. Once the participant decided to get an expert evaluation, they faced additional barriers from experts. There

were long waits for appointments, consultations might require payment out of pocket instead of from insurance, appointments meant time away from work or long travel, and some educational or healthcare experts rationalized the child's behaviors. In a pre-interview recruitment conversation, a mother recalled bringing up her concerns to her child's pediatrician several times. The pediatrician responded, "Well, she's only two," then, "Well, she's only three." The mother exclaimed, "Well, now she's five and it's worse, not improving!"

The second construct, **actions and adaptations**, describes how the participants actually managed their child with ED. This construct bridges two categories: **responding to the challenges (Category 2)** and **changing over time (Category 3)**. **Responding to the challenges** describes the methods, resources, and adaptations participants used to manage the situations and challenges caused by their child's ED. **Changing over time** describes the participants' internal changes over time, which occurred as the child grew older and the participant was able to better understand the child with ED.

Participants engaged in numerous courses of action to raise their child with ED. Early on, participants saw that traditional parenting methods were not working well for their child with ED. These methods were based on the participants' past parenting experience which were generally reactionary, consequence-based or "old school parenting." Some participants continued to try "old school" methods, but these methods were never successful for any of the participants. All participants used outside expert assistance, including healthcare, legal assistance and school-based assistance. "Healthcare" included therapy, occupational therapy, speech therapy, medications and residential care. Five mothers tried medications to regulate their child's behaviors, although some were very reluctant to use medicines and the medicines were not always effective. Mental health residential housing placements were used by some participants.

Unfortunately, none of the participants found residential facilities helpful for their child, but these placements did give the families respite from the emotional turmoil which came from the child with ED.

Mothers faced significant problems accessing healthcare, especially therapy and residential care. One child's speech therapy was delayed for more than six months. In **response to this challenge,** the mother taught herself speech exercises from the internet. Another mother had to push physicians to order a full neuro-psychiatric evaluation for her child, such as a Q-EEG. The physicians were focused on treating or reducing the current behaviors instead of looking with a wider view to find a physiologic root cause. Financial impact was variable among the participants. A few participants experienced high financial impact, including a $35,000 residential admission fee, maxing out multiple credit cards and hours spent away from work. However, other participants found resources to cover the financial aspect of their child's care without serious impact to their family. These participants denied any significant financial difficulties relating to their child's ED.

All children with ED (who were enrolled in school) received special education services from school. Participants' interactions with schools and teachers were widely divergent. Schools. were the strongest ally for half of the mothers, and the biggest battleground for the other half of mothers. All the mothers were appreciative of those teachers who made extra efforts to connect with their child, especially those teachers who actively reached out to the mother to discuss their concerns. An Individualized Education Plan (IEP) and school accommodations could ensure a pathway for their child's education, but some mothers could not get their child a realistic IEP, or make the schools follow the IEP. A few children suffered physical or emotional abuse from their teachers. The participants were horrified to learn about the abuse much later, because their

children simply <u>suffered in silence</u>. For a child with rigid thinking, being "respectful" to adults might equate into withstanding any treatment they are given, without discerning that being kicked or called a racial slur by one's teacher is *never* acceptable.

Most participants switched from a reactionary, consequential parenting style to an <u>intentional, pre-planned parental response</u>. The mothers' <u>intentional responses</u> might not prevent outbursts but were used to mitigate the emotional turmoil or search for the root cause of the outburst. Mothers found acting with "intentionality" was much more successful for communicating and managing their child with ED. In addition, this approach helped mothers manage their own emotions during a child's outburst. One mother could not convince her child of anything using logic or past experiences. However, if she was a "sounding board" only, and focused on affirming her child's feelings, she had a better chance of getting her child to see things from another point of view. Mothers adapted their own communication styles, their expectations, and their emotional responses to arguments and battles with the child with ED. Defusing the child's emotions became extremely important. Many participants stopped imposing extra punishments for bad behaviors, but consciously allowed the child to feel the natural consequences of their actions independently, without parental reaction or judgement. For instance, if a child threatened to throw something away in a fit of rage, the mother simply said, "it will get yucky in the garbage, because there's old food in there," instead of yelling or trying to convince the child to change their mind.

Participants adapted the environment around the child with ED, rather than trying to teach the child to fit into their environment. Participants adapted the environment by changing jobs, schools, living arrangements, and even changing their child's diet. Participants focused on keeping the child safe and adapted school assignments as much as possible. Participants also

spent significant time and energy directly teaching their child about the world. The children with ED lacked social awareness, but still knew they were "different" and struggled more than their peers. Participants had to verbalize implicit social rules to their child repeatedly. A mother might try to teach their child these implicit rules by explaining them: "if your friend is turning away from you or crying, they don't want to play with you anymore, even if you still want to play." Children with ED needed to be explicitly and repeatedly taught the rules of social play and interactions, because they could not recognize these social rules by themselves.

The child with ED caused a constant state of emotional turmoil in their family's lives, and the above adaptations impacted everyone who was living with the child. The actions taken for the child with ED had a ripple effect, which created new needs for siblings in the home and for the participant themselves. The participants' other children could not get the same parental time and attention because the child with ED required so much of the participants' energy and time. Some siblings were in danger because the ED child's outbursts were explosive and violent, and participants needed to provide physical protection for them. Participants themselves dealt with exhaustion and isolation from all the crises stemming from their child's ED. Participants had to find ways to connect with other people, including their spouse. Any time away from their child was respite; even going to their own jobs was a break from the chaos at home. It was hard for participants to consciously change their reactions, especially when focusing on natural consequences instead of traditional punishments. Mothers worried they were being "soft" and second guessed themselves often. Mothers learned to focus exclusively on the "here and now" problems and tried to ride out the storms of their child's emotional reactions. Mothers let go of their ideas of "normal" experiences, such as attending all their children's performances or their child attending regular school, in order to consider other options that might work better for this

specific child. Mothers spent a lot of time researching their child's ED as well as other parents'

experiences for managing a child with ED. Mothers found comfort in believing this was part of

God's plan or got mental healthcare for themselves. It was hard for participants to engage in self-

care, even when they knew they should. Friends and family were not always supportive or could

be outright judgmental, or their child's behaviors could be too difficult for other people to

handle, even for just a lunch with friends. Some of the ED children were so violent, the mother

herself needed physical or police protection.

As the child with ED grew older, mothers **changed internally over time**. Mothers

realized <u>their child viewed the world</u> in a very different way than themselves. The mothers saw

that their child <u>could not always stop their reactions</u>, and <u>suffered mistreatment silently</u> because

the child thought they deserved the treatment (or that no one would believe them). When the

mothers *saw through their child's eyes*, the mothers' *perspective changed*, and allowed them to

see their child as **struggling with a problem**, as opposed to **being a problem**. Participants were

heartbroken to learn their child felt hated by others, even when their child behaved in ways that

pushed friends away. Participants saw their child's behaviors could be an asset someday, such a

child who was difficult, but also "brave and ferocious." Mothers <u>believed there was a reason</u> this

child came into their family. Even with reflection, mothers knew they had <u>always done their best</u>

to raise their child well. Overall, these internal changes helped mothers find some peace within

themselves. One mother had not yet found a purpose to her experiences. This mother, whose two

children with ED continued to engage in criminal activity and violence, never found her "reason"

for these children to come into her family. The lack of reason or meaning left her in despair over

the lack of purpose for all of her and her family's struggles.

None of the children with ED were independent adults at the time of data collection. Participants with older children with ED worried if their child will ever become a "true" adult. This heavy burden left these mothers worried about their own future. As their children grew older, the game changed with new adult challenges, such as budgeting. Mothers wished they had a more balanced, mature connection with their older children. The participants' parent-child attachment or bond was one directional: from the parent to the child, not a give-and-take, reciprocal interaction. One mother wished she could connect to her child so that she felt connected to him. This one-way attachment meant the mothers were always "on duty" with their child, and never relaxed into their authentic self. A mother who works as a counselor noted that "it's hard when you are a therapist, and you are your child's therapist," because there was no time or space for the mother to be…herself.

The participants' **actions and adaptations** required a relentless search for information, support, resources, and ideas. The mothers constantly searched for the right environment, the right therapist, or the right communication style, regardless of how much they struggled to find it. Mothers said, "we tried everything!" and "we were screaming for help!"   Any of the individual actions could be viewed as just "good parenting," but the severity of the child's outbursts and behaviors meant actions that are *helpful* for any child, become *essential* for a parent raising a child with ED. However, the time, energy and adaptations spent on the mothers' **responses to challenges** left the mothers completely drained.

The challenges which arose due to a child's ED impacted the family so profoundly that the **families were altered,** the fourth category**.** As the primary caregivers, the mothers were significantly affected, but their spouses and other children were also impacted by the behaviors and needs of the child with ED. The participants themselves were stressed and exhausted from

constantly advocating for their child, adapting for their child, and constantly <u>on alert</u> for the next crisis. The mothers battled <u>isolation</u>, self-doubt, social stigma and <u>frustration</u>. Mothers <u>feared</u> what might happen to their child with ED, but also feared what their child with ED might do to others. Respite was hard to obtain because of the turmoil which revolved around the child with ED. Mothers constantly adapted to manage the turmoil. Other people, often not even the spouse, did not know the adaptations or how to manage the child's outbursts, which meant the mothers felt like they could never get respite safely. Having lunch with a friend would get interrupted by a crisis. Mothers felt guilty for having to run out on their friends: "I know we haven't gotten our food yet, but I have to go."

Participants grieved the <u>loss of their dreams</u> of motherhood. Mothers sadly missed milestone memories because of problems from their child's ED. Typical memories like a fifth-grade graduation or enjoying a field trip with their child were luxuries these mothers did not have like mothers of more typical children. One mother was terrified her child might kill someone someday. She was <u>frightened </u>her life would always revolve around keeping her child safe - and the world safe from her child. Participants with wonderful memories of their childhood school grieved that school was now a battleground for their own child. Mothers <u>desired a two-way, adult connection</u> with their older children with ED, and grieved because their child could not relate to them in that way. The mothers spent so much effort enforcing schoolwork assignments that the child with ED resented her for enforcing the constant, hopeless grind. Mothers grieved the loss of spontaneity and family fun.

It was not just mothers who were affected, but **every family member was altered** by the challenges and necessary adaptations related to a child's ED. Many participants' spouses were not concerned about the child's behaviors at first. As the primary caregivers in these families,

mothers experienced more of the child's outbursts and reactions first-hand. Some spouses did not see the child's behaviors as a serious problem or lacked the patience to adapt to the child with ED. In these cases, tension would grow between the two parents. Eventually, all of the participants' spouses came to see the child's behaviors as abnormal, especially if the child's behaviors affected employment. Because the mothers had already adapted so much to fit with their child's needs, fathers struggled to handle the child's explosiveness without the mother present. This imbalance of working knowledge meant that mothers carried even more responsibility for day-to-day childcare. This created an unbalanced load of responsibility and stress within the family. Despite this unbalanced load, the participants treasured their spouses' support and considered their spouse as their biggest supporter and best friend. Participants felt it was "us against the world."

The siblings living at home were also affected by the chaos and challenges which accompanied the child with ED. The siblings were stressed by the volatility of the child's emotions and outbursts, often simply leaving the area to get away. Mothers saw their other children acquiesce to anything the child with ED wanted, not even stating a preference for dinner. Siblings found it easier and more peaceful to defer everything to the child with ED than it was to give an opinion, much less draw a boundary line. Many times, the bonds between siblings were harmed or broken due to the stress and chaos. Even-tempered siblings could not understand why their brother or sister's reactions were so disproportionate to the situation. Siblings might need protection, requiring they live with relatives or to stay away from the child with ED, causing additional stress and fear. Lastly, some siblings became overprotective of their sibling with ED, and tried to mitigate the problems their brother or sister faced.

The final category was **advice for other families**. During recruitment, mothers indicated the chance to potentially reduce other families' burden was a compelling reason to participate in the study. Mothers emphasized that *kids really are all different*. Mothers noted the fallacy of saying "everyone is unique," but teaching and measuring everyone in the same manner, with the same "yardstick."   Participants warned other families that typical parenting methods discussed by child development experts or in books may fail when applied to a child with ED. Some schools prioritized expediency of finishing the curriculum over successful learning. If the child could not achieve the curriculum check points quickly (or at all), they were given more "practice" homework, but not more *teaching*. Children might then lose the parts of school they truly enjoyed. Mothers felt schools were grinding down their family due to unrealistic expectations. Mothers cried out, "*Don't blame us*!" and "*we need help*!" Mothers desperately wanted others to know how hard they tried to raise their children well, but that they needed tools to use. Healthcare providers tended to focus on reducing the immediate behaviors or stricter use of traditional parenting techniques, rather than taking a wider view for underlying causes. Mothers found there is still a stigma that mental health issues are not "real," but just a lack of will power or discipline. A mother said society needs to understand that mental health problems are in your head- because that's where the brain is located!

Lastly, participants shared *survival tips for other families*. Connecting with other people is vitally important for parents of children with ED. Isolation was a major problem for many of the mothers. Mothers tried to relieving isolation as a priority for self-care. Mothers advise other families to look everywhere for connections. Mothers explained as they started sharing about their child's problems and researching online, they connected with other parents who experienced similar issues. Mothers wanted others to realize their child with ED may be

suffering, too. Being surrounded by emotional chaos, parents might not consider that the child causing the chaos is also hurting, perhaps more deeply than a parent might imagine.

Mothers encouraged other parents to see the chaos and situations as temporary waves, and to ride the wave through the storm. Mothers encouraged other parents to keep searching for their own pathway, and to be open to pathways they had not previously considered. Participants encouraged others to enjoy the good moments when they happen. Parents cannot know if the next problem will be a long-term or short-term problem, so parents must "ride the wave" to the other side.

Relationship to Literature and Conceptual Framework

The findings of this study fit with Orem's Self-Care Deficit Theory (SCDT) as well the supporting theories of family- and dependent-care deficits, which were derived from Orem's original SCDT (Taylor, 1989; Taylor et al., 2001). Orem felt nurses should anticipate and assist patients to find solutions to their self-care barriers (Meleis, 2018). Although Orem's original theory centered around an individual patient's needs, Taylor (1989) extended the theory to include dependents' needs. Taylor (1989) also viewed the family as single unit with needs and requirements in order to function properly. This extension is highly relevant, because although the family is comprised of individuals with individual needs, a family is also a "multi-person unit" and must function as a whole (Smith and Parker, 2015; Taylor 2001).

The findings demonstrated that the mothers' self-care and dependent-care demands were very high. Mothers faced difficult situations due to their child's ED, which were often highly intense, atypical, and could be violent or dangerous. Participants relayed a number of areas where they did not have the resources to properly care for themselves, their child with ED, or their other children. Participants' families struggled to function properly and were often

consumed with chaos. Taylor (1989) advises nurses to consider if they will be providing nursing service to a caregiver, to the dependent person, or to the family as a whole. The findings indicate there were deficits in all three realms for these participants.

The findings also suggest specific nursing actions that could increase a parent's ability to care for themselves and their children. School nurses could partner with parents and teachers to address issues and individualized interventions for the child with ED. Nurses could teach parents new communication approaches for their child with ED, or ways to modulate the parents' emotional reactions to a child's outbursts. Nurses could share professional knowledge of school accommodations and childhood ED to guide parents and teachers when Individualized Education Plans are being created. Lastly, nurses and other healthcare providers can support parents of children with ED by sharing information about the variations of ED within children, as well as showing these parents that they are not alone with their struggles.

Mothers in the study desired affirmation they were "a good mom," and worried their child's problems were due to something the mother did. In fact, Hinshaw (2005) reported throughout most of the 20th century, the predominant child development view was that any child mental disturbance was related to faulty parenting. This means healthcare personnel must overcome potential biases they may have (or have been taught) regarding parents being responsible for their child's mental health problems.

Stigma

Study participants encountered stigma often. Hinshaw (2005) stated "stigmatization that surrounds mental illness is increasingly recognized as a central issue, if not *the* central issue, for the entire mental health field," (p. 714). Stigma is a "mark of shame or discredit," (Merriam-Webster, n.d.) and persons with mental illness are often blamed for their condition, as though

they could control it if they simply chose to do so (National Alliance on Mental Illness, 2017).

Similarly, parents of children with emotional disturbance have been blamed for their child's

condition, as though it would not exist if the parent simply "tried harder." Hinshaw noted mental

health stigma occurs in multiple spheres including individuals, families, schools, and

communities.

In this study, mothers were shunned, excluded, or directly blamed by others because of

their child's emotional disturbance and behavioral outbursts. Mothers saw other parents clustered

in groups away from them, were accused of using their child's behavior as an "excuse" for poor

work performance, or were directly told, "can't you do a better job [parenting]?" This social

judgement was tough to receive when the mothers were exhausted from the efforts expended to

raise their child with ED. Mothers were shunned and increasingly isolated, even by friends and

family. One mother was deeply wounded when a close friend said, "but she looks normal," as

though only children with physical characteristics of a disability were worthy of forgiveness and

kindness. Other times, mothers worried educators displayed a negative bias against their child.

Societal stigma regarding mental illnesses has persisted for decades (Bhurga, 1989; Segal, 1978).

Although a 2006 review of literature indicated social stigma has somewhat diminished in recent

times, a 2020 research study found stigma was still the most commonly identified barrier to

mental health treatment (Angermeyer & Dietrich, 2006; Lavingia et al., 2020).

Stigma is not limited to social experiences but can also be internalized when an

individual (or parent) agrees with the negative bias themselves. The National Alliance on Mental

Illness (n.d.) states internalized stigma causes people to shift from feeling bad to believing *they*

are bad people (or parents). There were a few indicators that study participants struggled with

internal biases against mental health problems. Mothers commented how hard it was to be the

mother of the "troublemaker kid," and worried they were being a "soft" parent when they implemented adaptations to accommodate their child's reactions. One mother noted her generations' view of mental health was much more negative and secretive than her daughter's, and how that shift in attitude was difficult for her assimilate at times. Occasionally, mothers made statements such as "I caved in and took him to therapy," or "she uses it as a crutch sometimes," which may indicate the participants themselves harbor internalized biases, even as they valiantly seek assistance for their children.

Stigma from society, parents themselves, and healthcare professionals may indicate why so many participants had difficulty confirming their child had an actual emotional disturbance. Liggins-Chambers (2023), in a recent parent-oriented article, described the resistance parents receive when their family members downplay possible signs of a child's disability. Mothers in the present study found their spouses did not see or acknowledge their child's reactions were abnormal for a long time, leading to increased maternal stress and delayed intervention. Pediatricians are the first line of healthcare for parental concerns about a child. However, Weitzman et al. (2015) reported pediatricians themselves lack confidence when screening or even advising parents concerned about a child's emotional or behavioral problems, so they defer a thorough investigation of a child's behaviors. Study participants experienced deferred psychological examinations when they were told that "she is too young to diagnose," or "[boys] are just slower to mature." This deferred examination practice was also noted by Liggins-Chambers (2023). The examination delays found by Liggins-Chambers and this present study cause increased stress and turmoil for the entire family living with a child with ED.

Orienting the Results within Prior Literature

This study's findings correlate with previously published literature regarding parental stress and parental involvement in their child's school. Prior studies demonstrated parents of children with ED experienced higher levels of stress (Duppong Hurley et al., 2017; Green et al., 2016; Kelson et al., 2005; Taylor-Richardson et al., 2006; Tahhan et al., 2010). The participants in this study reported high levels of stress from multiple directions. These findings expanded on previous research findings (Duppong Hurley et al., 2017; Green et al., 2016; Kelson et al., 2005; Taylor-Richardson et al., 2006; Tahhan et al.,2010) by providing the context of the participants' stress, including being "on alert" constantly, partner tension, isolation, and living in constant turmoil at home. These reported experiences also support a Canadian study that mothers of girls with ADHD committed their entire lives to helping their daughter (Wiener et al., 2016).

In addition to parental stress, the study participants reported mixed experiences with their child's school. A large, national study found parents of children with ED were highly involved with their child's school when their child started school, but parents' involvement dropped off dramatically as the child reached middle and high school (Liu et al., 2018). Participants of older children with ED had some successes with their child's special education accommodations, but other mothers had a very difficult time working with their child's teachers and schools. McCrory Calarco et al. (2022) examined the relationship between homework inequalities and teachers' perceived bias. The study found teachers assign homework that they know students cannot complete independently, but teachers expect students to receive help from their parents or self-grade their own work. Unfortunately, this type of educational system only works well for the students whose parents can tutor them. McCrory Calarco et al. reported teachers believed students who did not complete homework were "irresponsible," without considering why the student was not completing the homework. Direct comparisons between this study's findings and

McCrory Calarco et al.'s results are beyond the scope of this study. However, study participants reported that their child with ED did not have the capacity to complete high-level work independently, after expending all their energy trying to maintain self-control in public. Parents of children with ED may not have the ability to manage their child's learning with such challenging assignments. As school system academic standards rise, teachers rely on parents as home tutors to meet the increased academic rigor (McCrory Calarco et al., 2022). However, parents of children with ED may be unable to tutor their children to this level due to the chaos the parents face at home from the child's ED.

Implications for Nursing Practice

This study has illuminated several key needs of parents and families who are raising children with emotional disturbances. The findings suggest implications for nursing practice to directly improve the health and well-being of these families and by extension, the children with ED. The findings indicate nursing practice changes are needed to improve identification and management of children with a suspected emotional disturbance, supporting views stated by Lipkin et al. (2015). Parents of children with ED desperately need guidance for new parenting approaches, personal support, and community partnerships. School nurses are ideally positioned to strengthen partnerships between parents and educational professionals in schools as part of a "hidden system of healthcare," (Lear, 2007, p. 410). School nurses must be valued as an established specialty which encompasses healthcare and educational systems so that school nurses can practice nursing to their fullest capacity (Robert Wood Johnson Foundation, 2010). Lastly, the findings indicate nursing practice needs to advocate for policy changes to address (1) school systems' lack of support and disparate distribution of resources, (2) gaps in knowledge

regarding children with ED, and (3) the absolute need to employ nurses at schools to support the educational achievement of children with ED.

Healthcare

The participants reported many barriers to accessing and utilizing healthcare, including evaluation and identification of possible ED in their child and a lack of ongoing information and support. Nurses and other healthcare providers should respond realistically to parents' concerns. However, this study's findings indicate that healthcare professionals may over rationalize parents' concerns when parents described behaviors which could indicate emotional disturbance.

Participants struggled to convey the severity of their children's outbursts and reactions to anyone who did not observe the outburst. By rationalizing the child's behaviors repeatedly, the child required multiple healthcare visits before the concerning behaviors were thoroughly evaluated. Nursing practice must balance being overly suspicious and unduly dismissive. Study participants reported that healthcare erred on the dismissive side when discussing their child's behaviors, which corresponds with other researchers' findings (Liggans-Chambers, 2023; Weitzman et al., 2015). Prior literature indicated pediatricians lack confidence when assessing emotional or behavioral problems, which could explain the tendency toward over rationalizing the child's behaviors (Liggans-Chambers, 2023; Weitzman et al., 2015). Nurses should adjust their assessment to include a more concerted effort regarding parents' concerns about their child's behaviors. Healthcare practices should develop guidelines to improve clinician confidence when evaluating unusual emotional reactions or behaviors. Offering repeated assurances that a child is "just slower to mature" may inadvertently dismiss legitimate concerns.

There is power in a diagnosis. Although the term "emotional disturbance" is fluid and overlaps many mental health or developmental diagnoses, the language itself represents

acknowledgment and understanding. Identification of an emotional disturbance gives parents the realization that this situation is not unusual, and the parent is not alone. Once the participants' child was identified as having an emotional disturbance, they used the terms to research ED, gather new parenting ideas, get accommodations at school, locate services, and find support groups. Without a diagnosis, children do not "qualify" for services, regardless of the necessity, and parents are dismissed.

There can be stigma from a mental health diagnosis, even from healthcare professionals (Riffel & Chen, 2020). Healthcare providers may be slow to identify ED in children for this reason. Study participants did report social stigma due to their children's ED, but found having a name, a term, or an identification gave them options to research and learn about that diagnosis. Nursing practice must battle mental health stigma and refute the beliefs that emotional problems are a sign of weakness or a lack of willpower. The findings demonstrated a child's diagnosis can give legitimacy to parents' concerns. The implications of not properly identifying a child affects the child's ability to get assistance and can preclude the parents and family members from receiving support, information, and relief from isolation.

Family Well-Being

Nursing practice encompasses the well-being of the entire family, not just the patient. Nurses' code of ethics states a nurse's "primary commitment is to the patient, whether an individual, family, group or community," (American Nurses Association, 2015). In the U.S., healthcare often focuses on curing or resolving individual health issues instead of managing the complexity of interacting family issues over time. These are social determinants of health factors that until recently were not addressed in health care delivery. Every member of the participants' household was profoundly impacted by the behaviors and the adaptations required to manage the

child with ED, and all of these family members have needs which are often unaddressed. The data supporting **Construct 2**: **Actions and adaptations** and **Construct 3: Altered families and Advice for others** offer several suggestions for nursing practice to improve parents' ED literacy, such as sources of information, possible school-based supports, and connections with other parents. When nurses support the parents of children with ED, the entire family's well-being can be improved.

Improving parents' ED literacy

This a qualitative study with a small sample. Therefore, the specific actions used by these participants have not been rigorously tested and may not apply to other families raising children with ED. However, nursing could teach parents the value of adaptation and "letting go of social norms" when working with parents struggling with their child's behaviors. Nursing practice guidelines should consider that "typical parenting" methods may fail when applied to children with ED. Parents of children with ED live in emotional chaos and turmoil. Nurses can assist in improving parents' ED literacy by guiding parents to respond to chaos and behavioral challenges with intentional, planned actions. Nurses could help parents see situations through their children's eyes. For these mothers, this view allowed them to see their child was also struggling with the problems caused by ED.

The child's behaviors put the study mothers on constant alert for the next crisis. Encouraging parents to deliberately divide responsibilities between spouses can strengthen marital bonds strong and relieve partner tension. Parental division of responsibilities can also help to ensure all of their children's needs are being addressed, not just needs of the child with ED. Parents of children with ED experienced years of ongoing challenges, with changing nuances as the child grew older. Parents should be prepared that the game changes as a child with

ED grows older. If nurses proactively prepare families for this possibility, future families may not be as surprised when the sand shifts under their feet.

The study's findings painted a vivid picture of how parents of children with ED are isolated and emotionally drained, reinforcing previously published findings (Johansson et al., 2010; Leitch et al., 2019; Wiener et al., 2016). Participants grieved the loss of their dreams of motherhood. Study mothers also grieved the lack of a two-way connection between themselves and their child with ED. Without this two-way attachment, parents do not receive positive emotional feedback from their child.

Participants lacked positive recognition for their extraordinary efforts to raise their child with ED. Society has isolated and excluded these participants due to their child's behavior, as previously described by Hinshaw (2005). Mothers in the study wanted to be recognized for their efforts, with one mother crying out, "I'm a good mom!" The interviews ranged from 53 to 95 minutes and averaged 76 minutes. The long length of the interviews alludes to the mothers' strong desire to be heard and valued. Participant self-care was difficult to achieve due to the constant needs of the child with ED. Participants found connecting with others, dividing parental responsibility, and consciously changing their own emotional reactions were vitally important to maintaining their own emotional health during this parenting journey.

The study participants reported deep emotional and social needs which were unmet. Nursing practice should respond to parents' need to be heard, connected, and supported. Nurses should encourage parents to utilize similar self-care actions by providing parents with guidance, direction, and potential ideas for self-care. Nurses are highly trusted advisors (Advisory Board, 2020). This study indicates parents of children with ED are in dire need of emotional support and

advice through this difficult journey. As trusted advisors, nurses are in an ideal position to assist these parents.

Schools

School nursing practice could utilize the study results to demonstrate the need for school nurses' involvement in the special education process. Although all of the participants' children received special education services in school, participants struggled to create and utilize an effective, realistic plan for their child's education. The participants' child may have been offered additional time to complete assignments as part of their Individualized Education Plan, but participants did not find this accommodation helpful. Mothers found if their child with ED had the same work with the same grading rubric, the child just got further and further behind. Accommodations may include preferential seating or give detailed homework instructions, but without the necessary background about the child's condition, a teacher may not know what a "preferential seat" or "detailed instructions" look like.

School nurses should be able to provide expert information about the condition of emotional and behavioral problems in children to school administrators, teachers, and counselors. This information could assist educators to create effective school accommodations for children with ED. Nurses' increased knowledge of childhood mental health problems could be used to educate teachers. Unfortunately, school nurses themselves may not receive adequate educational preparation to handle the myriad of physical, emotional, social and mental health issues that are present in the school environment (Wilson, 2020). In order to provide quality care in the school setting, school nurses need additional education or perhaps specialty certifications to complement their university or college training. With proper education and training, school nurses' knowledge and expertise could assist educators greatly. Nurses are highly trusted

professionals, and as such, school nurses can improve partnerships between teachers and parents as members of a "hidden" healthcare system (Lear, 2007, p. 409). School nurses are ideally positioned to bridge educators' knowledge gaps about the child's condition with the extreme efforts the parents are exerting at home.

Policy Implications

This study's findings indicate potential policy implications that could be led by nursing practice. Policy implications include a need for continuing teacher and nursing education regarding the law and rights of children with disabilities, distribution of support resources and screening information for parents. Participants' reported experiences indicated there are knowledge gaps in schools, and potentially within nursing, regarding the laws surrounding the rights of children with disabilities. Nurses and educators must obtain ongoing education about legally required school accommodations. Educating nurses and teachers once about a legal topic is not adequate. These professionals need continuing education about the laws and updates on changes within the legal system regarding children's rights, so they are not practicing with outdated knowledge. Policies should be enacted which require continuing education for school nurses and teachers about children's legal rights and requiring schools to employ nurses on their campuses.

Healthcare in the U.S. tends to be centrally distributed from "hubs," such as through employment, religious faith-based care, and schools. Grisso (2008) identified four hubs which focus on children: child protection agencies, juvenile justice systems, pediatric mental health, and schools. Schools are an intuitive hub for distribution of information and support because children are physically in school for many hours of the day. Schools were set as the main location for children's mental healthcare by the 2003 Presidents New Freedom on Mental Health

Commission (Kutash et al., 2011; New Freedom Commission on Mental Health, 2003). Nurses are the providers of healthcare for medically fragile children as well as children with ED in schools. To accomplish this care, school nurses must be employed in all schools, receive ongoing education, and be involved in special education planning.

Schools in the U.S. are run by state governments, not from the federal level. As such, schools are subject to fluctuations in funding and political shifts in each of the 50 states. In order to educate children with ED (or any disability), school nurses and teachers need education and funding to provide the service. The participants in this study were geographically widespread throughout the U.S. Some participants found very little education and support for their child's mental health problems while other participants were well supported. Participants' access to resources was widely divergent. This inconsistency indicates problems with the distribution of resources, screening processes, and school supports.

Limitations

The findings of this study should be interpreted with caution due to limitations related to the size and composition of the sample. Participation was limited to biological or adoptive parents. Other primary caregivers' experiences, such as grandparents or foster parents, were not captured. Parent participation was not limited to mothers, but informational redundancy was achieved with the first eight participants, who were all mothers. Fathers' parenting experiences were not explored. Seven of the eight participants were White, and six of the eight participants were married. One participant was under 30 years old, but the remaining mothers ranged between 41 and 62 years old. The sample was small and homogenous in terms of age, racial background, and marital status.

Although educational status was not collected as part of the study data, within the course of pre-data collection conversations and the data collection session itself, it was apparent that most of the mothers were highly educated, possessing at least a bachelor's degree, and three participants possess healthcare graduate degrees. These participants may have had greater access to healthcare, educational supports, and home resources than the average U.S. parent.

The data collection method also created certain limitations. Interviews were conducted over Zoom (an online video meeting platform) or by telephone. Using these modalities for data collection allowed for greater geographical diversity of the study sample. The participants were geographically diverse, with participants living on both coasts of the U.S. as well as the far north- and south-central region of the country. However, the recruitment flyers were sent via email and posted on social media, which effectively self-selected potential participants who had access to the internet. In this sample, seven participants responded to a social media posting or recruitment flyer, and one participant was a snowball recruit from an earlier participant. Lastly, a single interview for data collection is more convenient for participants because this limits the time required for participation. However, a single interview also meant the data is reliant on participants' memory of events which may have occurred years before.

Despite these limitations, the study still expands the body of knowledge in this previously unexplored phenomenon. The above limitations provide guidance for areas for future investigations.

Recommendations for Future Studies

This naturalistic design study explored the reported experiences of parents who are raising a child with an emotional disturbance. A naturalistic design study does not attempt to reveal broad trends or generalizations, but expands contextual understanding about a

phenomenon, which can be explored by other means in the future (Erlandson et al., 1993). Although a naturalistic inquiry research study such as this one could never completely describe a phenomenon, the study findings do provide direction for future research.

As discussed in the limitations section, the sample size was small, homogenous, and highly educated compared with the average population of the U.S. In addition, the participants were all mothers. Research is needed to examine fathers' experiences as well as a wider range of ethnicities, family compositions and educational backgrounds. The participants' children ranged from five to nine years old, then from 15 to 23 years old. None of the children were aged 10 to 14. The findings could be used to develop a survey instrument to gather quantitative data to examine and verify the commonalities found here. This quantitative data could test the applicability of this study's findings. A larger sample population may have greater diversity to examine potential trends based on demographics.

The **actions and adaptations** discussed in Construct 2 were varied, but could be potentially useful interventions to teach parents or educators working with children with ED. An interventional study could examine the effectiveness and feasibility of utilizing some of the participants' **responses to challenges** on a larger scale. Participants requested "tools" and "workbooks" so they could try different approaches, but finding this information was very difficult. Research is needed to determine what "hubs" or methods are best for distributing information to parents.

The participants' changes in perspective, described as **changing over time**, may be useful for mental health professionals and counselors to actively teach parents who are struggling to raise their children. Interventional research is needed to see if these ideas might provide parents with ways to reduce their internal stress and frustration. Interventional research might examine if

helping parents "see through the eyes of their child" could lead them to switch from reactional parenting responses to <u>intentional responses</u> more quickly.

Schools face great pressure to improve educational outcomes, but with fewer resources and staff. Often, school activities like physical education, recess, and fine arts are being replaced with more strenuous curriculum, even in kindergarten. The increase in rigor means teachers do not have time for individualized teaching, especially for children who cannot sit still and stay quiet for long periods of time. Research should examine if school curriculum has become so rigorous that children who are different cannot be tolerated or succeed in the classroom.

Lastly, a number of other issues were revealed in this study that were not part of the original specific aims but warrant further research. Extremely troubling social justice problems were revealed in this study. Research is needed to deeply examine the problems of overt racism, bias against disabled children, and abusive teachers which are occurring in schools. This study was restricted to parents raising children with ED, but these social justice problems affect all children, and must be rooted out. Participants were very concerned about what originally caused their child's ED. Participants wondered if their child's ED was linked to infection and inflammation. Since healthcare no longer routinely re-tests children to verify a strep infection has resolved, research is needed to examine the prevalence of PANDAs syndrome more closely. Adoptive participants were concerned about damage in utero from exposure to drugs and reactive attachment disorder from the trauma of adoption, and the link to their child's ED. All of these social issues were outside the scope of this study's purpose but warrant significant attention in future studies.

Conclusion

Erlandson et al. state a naturalistic inquirer strives to expand the knowledge of "constructed realities," rather than identification of themes or generalizations that hold true over larger groups (1993, p. 45). The participants in this study shared vivid details about their parenting journey and the unique hardships they faced. The participants' reported experiences suggest a strong need for future research to validate the ideas unveiled in this study, along with the need to further examine the unexpected and disturbing social justice issues some participants experienced.

Three overriding constructs were derived from the data gathered in this study: 1) **concerns and suspicions**, 2) **actions and adaptations**, and 3) **altered families/ advice for others**. Mothers who participated in this study described how their initial **concerns** about their child's unusual or explosive behaviors escalated, requiring the participant to overcome various barriers to obtain expert evaluations and assistance for their child. All of the mothers' **suspicions** were confirmed when their child was diagnosed or acknowledged as having some type of emotional disturbance. Mothers in the study engaged in numerous **actions** to get outside help for their child with ED, including mental health services and special education support through their child's school. In addition, mothers had to **adapt** their own emotional reactions, responses and even the child's environment to align with their child with ED, rather than trying to have their child adapt to the world. Although any single action or adaptation might be *helpful* for other children, the **actions and adaptations** were absolutely *essential* for their child with ED, given the volatile nature of their child's behaviors. The volatility created by the child's ED meant the entire family lived in constant chaos and turmoil, generating great stress, tension, social isolation and outright fear within the participants and the other family members. The participants' families were permanently **altered** due to the behaviors and needs of the child with ED. Study

participants offered **<u>advice to other families</u>** to try to mitigate the negative impact and alteration for other families of children with ED.

In the face of these challenges, the study participants were fiercely committed to their children, despite their overwhelming exhaustion, stress, and isolation. Orem's Self-Care Deficit Theory (and Dependent-Care Deficit) guides nurses to assess a child's or family's care demands along with the parents' "agency" (ability) to meet those demands. Parents of children with ED have a tremendous gap between their child's and family's care demands and their personal agency. These parents desperately need nursing expertise.

Although the applicability of the findings may be limited due to the small, homogenous sample, several potential implications for nursing practice were suggested to improve the well-being of parents, families and children with ED. Implications include improved assessment of parents' concerns regarding their child's behavioral patterns, a need for education and parenting advise that does not rely on traditional authoritarian approaches, and assistance creating appropriate accommodations for children with ED in schools. Nurses should be cautioned that too much reassurance may be perceived as dismissing legitimate mental health concerns. A proper diagnosis can unlock avenues for parents to find assistance, accommodations, information, and support. Nurses can provide much needed support and affirmation to other parents raising children with ED for the tremendous efforts they are expending and emotional exhaustion they are experiencing for their child.

This naturalistic design study attempted to construct the realities of participants' experiences of raising a child with an emotional disturbance so the reader would have a greater understanding of the parents' needs, challenges and emotional impact that occurred due to their child's ED. The mothers who participated in study shared a wealth of intimate details about how

raising a child with ED impacted themselves and their entire family. Mothers searched for the pathway to effective responses, adaptations, and environments for this child's emotional reactions.

Although the findings resulting from this study cannot yield broad generalizations about a population at large, the findings did identify potential issues which warrant further research. This study's findings suggested there are barriers to finding support, advice, and information for the parents of children with ED. In addition, there are gaps in healthcare and educational experts' ability to identify children with a potential emotional disturbance, and in experts' ability to guide parents on potential response strategies to the challenges stemming from a child's ED. Parents of children with ED are desperate for assistance, information, support, and affirmation for their efforts. Nursing practice, which focuses on overarching themes of improving the health and wellbeing of the individual as well as the family, must heed these parents' calls for help.

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Appendix A: University of Texas Medical Branch Institutional Review Board Approval

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Working together to work wonders."

02-Mar-2023

MEMORANDUM

TO: Michelle Nighswander
                Grad School Biomedical Science GSBS9999

FROM: Alexander Duarte, MD
                Vice-Chairman, IRB #2

RE: Initial Study Approval

IRB #:   IRB # 23-0049

Submission Number: 23-0049.003

TITLE: Understanding the Journey of Parents of Children with Emotional Disturbance

DOCUMENTS: Research Protocol
                Demographic Form
                Fast Facts Sheet
                Interview Guide
                Oral Consent Narrative
                Recruitment Cards
                Recruitment Flyer
                Transcription Confidentiality Agreement

The UTMB Institutional Review Board (IRB) reviewed the above-referenced research protocol via an expedited review procedure on **02-Mar-2023** in accordance with 45 CFR 46.110(a)-(b)(1). Having met all applicable requirements, the research protocol is approved. The approval for this research protocol begins on **02-Mar-2023.**

Continuing Review for this protocol is not required, as outlined in 45 CFR 46.109. A Status Report is required to be submitted to the IRB every three (3) years. A reminder will be sent approximately 90 days prior to its due date. *Please be advised failure to submit a Status Report may result in the study being administratively closed. If the study is administratively closed, the project will require resubmission as a new proposal to continue.*

The next Study Status Report will be due on 02-Mar-2026.

The Principal Investigator is still responsible for:

1. Submitting amendments for protocol changes.
2. Reporting Adverse Events, Protocol Violations, and Unanticipated Problems, as outlined in IRB policies and procedures.
3. Closing the project once it ends, or when personal identifiers are removed from the data/biospecimens and all codes and keys are destroyed.
4. Compliance with UTMB Health Information Management Research Tracking and Accounting of Disclosure of PHI policy.

Written documentation of consent is waived in accordance with 45 CFR 46.117(c).

The approved number of subjects to be enrolled is **25**. If the approved number needs to be increased, you first must obtain permission from the IRB to increase the approved sample size.

If you have any questions, please do not hesitate to contact the IRB office via email at IRB@utmb.edu.

Appendix B: Recruitment Business Card

Front of Recruitment Card:

Understanding the Journey of Parents of Children with Emotional Disturbance

You are invited to tell your story!

Consider participating in a research study of parents of children with emotional or behavioral issues

Back of Recruitment Card:

Who can participate?
- Parents or stepparents of children with possible emotional or behavioral disturbance
- Parent must have raised child in their home
- Parent must be English speaking
- Child is less than 24 years old & has had emotional/ behavioral problems for 6 months or longer

For more information, contact:

Michelle Nighswander, MSN-Ed, RN, Principal Investigator

512-470-3147 (call or text) or minighsw@utmb.edu

Appendix C: Recruitment Flyer

Do you feel raising your child is *so much harder* than other parents' children?

Are your child's reactions *really different* than other children's?

Do you think your child might have an emotional or behavioral problem? Have you been told your child has an emotional disturbance or behavioral disorder?

You are invited to tell your story!

You are invited to participate in a research project exploring the experiences of parents raising a child with a possible emotional disturbance and how this has impacted you and your family as a whole.

Who can participate: Any parent or stepparent who is raising (or raised) of a child with a possible emotional disturbance or behavioral disorder in their home, & whose child is less than 24 years old (English speaking only)

What is involved: A one-on-one interview of 90 minutes or less, either online or by telephone, and possible follow up interviews

All information will be kept confidential

For more information, contact:
Michelle Nighswander, MSN- Ed, RN, Nursing Doctoral Student
512-470-3147 (call or text) or by email: minighsw@utmb.edu
University of Texas Medical Branch at Galveston

Appendix D: IRB Approval for Researchmatch.org Recruitment Letter

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Institutional Review Board
301 University Blvd.
Galveston, TX 77555-0158
Submission Page

27-Mar-2023

MEMORANDUM

TO: Michelle Nighswander
Grad School Biomedical Science GSBS9999

FROM: Dwight Wolf, MD
Chairman, IRB

RE: Amendment/Miscellaneous Request Approval

IRB #: IRB # 23-0049

Submission Number: 23-0049.005

TITLE: Understanding the Journey of Parents of Children with Emotional Disturbance

DOCUMENTS: ResearchMatch Participant Contact message

The **Miscellaneous Response** request to the above referenced study has been reviewed via an expedited review procedure on **27-Mar-2023** and approved by the UTMB Institutional Review Board (IRB) in accordance with 45 CFR 46.110(a)-(b)(2).

The approval period for this modified research protocol begins on **27-Mar-2023**. Amendment approvals do not change the approval period of the protocol. Therefore, the expiration date will remain the same as was determined for the protocol at the time of initial or continuing review.

If you have any questions, please do not hesitate to contact the IRB office via email at IRB@utmb.edu.

Description of Changes/Submission

Addition of the advertisement script for IRB approved recruitment site ResearchMatch.org.

Hi,

Our team is working on a new research study, *Understanding the Journey of Parents of Children with Emotional Disturbance*, and we need your help.

The purpose of this new study is to learn about the parents of children with emotional or behavioral issues, including the parents' experiences and management of situations related to their child's emotional or behavioral issues. In addition, the study will explore how raising a child with emotional or behavioral issues impacts the parents personally and the family as a whole.

The ultimate goal of the study is to increase our understanding of the needs and challenges of these parents and families so that the parents and families of children with emotional or behavioral disorders can be better supported.

Would you like to help?

- You will have the opportunity to share your personal parenting stories, which can be a very positive experience for parents who may not feel "heard"
- You will be helping to increase our knowledge about the challenges families with a child with emotional problems face as well as the coping strategies these families use
- Your information can help us create more supportive programs for parents, which may benefit other parents in similar situations in the future

Who Can Participate?

- Biologic parents, adoptive parents, or stepparents who believe their child may have emotional or behavioral problems, or who have been told their child has been diagnosed as having "emotional disturbance" by a healthcare or education professional
- The child must have had the emotional or behavioral problems for at least 6 months
- The child must be less than 24 years old at the time of the interview
- Parents who lived with the child during the child's pre-adult years and when the child was having the emotional/ behavioral problems
- Parents able to complete a recorded interview, lasting less than 90 minutes, either on Zoom or by telephone

If you fit these requirements and are interested in helping us, please respond to get additional information.

Thank you for helping to improve the lives of parents raising children with emotional/ behavioral problems.

Appendix E: Study Fast Facts Sheet

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FAST FACT SHEET   IRB#: 23-0049

Study Name:
Understanding the Journey of Parents of Children with Emotional Disturbance

Contact Information:
Principal Investigator: Michelle Nighswander, Nursing PhD Student   Phone: (512) 470 - 3147

Study Supervisor: Dr. Carolyn Phillips   Office: (409) 772 - 8234

What is the purpose of this research study?

The purpose of this research study is to explore parents' experiences and management of parenting situations related to their child's emotional or behavioral issues, and parents' perceptions of the family impact when raising a child with emotional or behavioral issues**.** The ultimate goal of the study is to increase understanding of the needs and challenges of these parents and families so the parents and families of children with emotional or behavioral disorders can be better supported.

What are the Research Procedures?

You are being asked to participate in a research project, *Understanding the Journey of Parents of Children with Emotional Disturbance*, because you are a parent who has lived with and raised a child who has had emotional or behavioral issues for longer than 6 months. Your participation will consist of one interview, conducted over Zoom or by telephone, which should be completed in less than 90 minutes. You also may be asked to participate in one or two follow up interviews, which will not exceed 30 minutes.

What are the Risks and Benefits?
There are no direct benefits to those parents participating in this study. However, for some parents, the opportunity to share their parenting stories can be a positive experience because it will allow the parents to feel they have been "heard." We hope the information learned from this study will benefit other parents in similar situations in the future.

There is very little risk to anyone who participates in this study. Potential risks include a possible loss of privacy or confidentiality, or possible feelings of fatigue or distress. To protect your privacy, you will be assigned an identification number, which will be used instead of your name on research materials. Furthermore, any information that could be linked to you or your family will be removed or masked. If you find the interview to be stressful or tiring, we can pause the interview for a break, reschedule for another day, or stop the interview entirely, as you prefer.

The researcher is a nurse and is required by law to report any suspected abuse or neglect of any children or any disabled or vulnerable adult. You will not be asked any questions about abuse or neglect, but if any information is revealed during the interview that raises the researcher's concern that there may be abuse or neglect, the researcher is legally obligated to report these concerns to the proper authorities. If this situation occurs, the researcher will inform you of her concerns and

immediately stop the interview. At that point, the researcher would be required to break your confidentiality in order to notify the proper authorities.

Cost:
There is no cost for participation in the proposed study.

How will my information be protected?
Any information you share will be identified only by a unique identification number, and any identifying details about you or your family will be masked or removed. Only the principal investigator will have access to the list of participant names with the corresponding participant identification numbers. This list will be kept in a secure, locked location and stored separately from any other study information. If we publish the results of the study in a scientific journal or book, we will not identify you.

How can I withdraw from the study?
You can withdraw from the study at any time, before, during, or after the interview, by notifying the principal investigator at the number above. Any information collected from you would be destroyed and not used in the study.

Who can I contact with questions about this research study?
This study has been approved by the UTMB Institutional Review Board (IRB). If you have any complaints, concerns, input or questions regarding your rights as a subject participating in this research study or you would like more information about the protection of human subjects in research, you may contact the IRB Office via email irb@utmb.edu.

For questions about the study, contact Michelle Nighswander or Dr. Phillips at the numbers listed above.

Before you agree to participate, make sure you have read (or have been read) the information provided above, your questions have been answered to your satisfaction, you have been informed that your participation is voluntary, and you have freely decided to participate in this research.

This form is yours to keep.

Appendix F: Narrative for Oral Consent

As we've discussed before, the purpose of this study is to gather information about the experiences and challenges that parents of children with emotional disturbance encounter, coping strategies parents have tried, and how parents managed those challenges.

I am asking parents of children with emotional or behavioral problems to share their experiences about how raising a child with these problems has affected you and your family. I am interested in researching this issue so healthcare providers and educators can better understand what parents raising these children deal with and need for support. I am conducting this study as part of my doctoral dissertation research at the University of Texas Medical Branch.

You have indicated you are a parent who is currently raising (or have raised) a child (or children) with long-term emotional or behavioral problems, and these problems have been present or lasted longer than six months.

Your participation in this study will consist of at least one interview, which will not last longer than 90 minutes, and potentially one or two follow-up interviews, which will not last longer than 30 minutes. This study is expected to pose very little risk to anyone who participates.

Potential risks of the study include a possible loss of privacy or confidentiality, and possible feelings of fatigue or distress.

Your privacy and confidentiality are very important. To protect your confidentiality, I will substitute a number for your name, and any information stored about you will only have that number as identification. I also will remove any names or other identifying information, such as the name of a school, from your information. No one will see or hear this recording except myself or my research team.

Some parents may find talking about or remembering challenging times with their child to be stressful or tiring. If at any time during this interview you feel fatigued or emotionally upset, please let me know. We can pause the interview for a break, reschedule for another day, or stop the interview completely, whichever you prefer.

I plan to ask you demographic questions about you and your immediate family, such as age, gender and grade level in school. Then I will ask you about the challenges you and your family have dealt with surrounding your child with the emotional or behavioral problems.

For some participants, the opportunity to share their parenting experiences raising children with emotional or behavioral disorders can be very positive event and allow parents to feel "heard." There may be a benefit to other parents and society in general to learning how parents of children with emotional or behavioral disorders, like yourself, cope and manage the day to day challenges these children present. However, there is no other direct benefit to you personally from your participation in this research project.

Your participation is entirely voluntary. You can choose not to answer any question at all, or stop the interview completely at any point, for any reason you wish, and I will respect your wishes. You can withdraw from this study at any time during the interview or even after the interview, and I will respect your decision and remove your information completely.

The following information is very important. As a nurse, I am required by law to report any suspected child abuse or neglect (or abuse/neglect of an adult who is disabled). In Texas, these reports must be made to the Texas Department of Family and Protective Services. I will not be asking you any questions about abuse, but if any information is revealed during the interview that creates a concern for potential or ongoing abuse or neglect of a child or disabled adult, I am required by law to notify the authorities. At that point, your confidentiality will need to be broken so that I can report the issue to the proper authorities. If that were to happen, I would let you know immediately.

Do you have any questions about this study or participating in this study? (Researcher will now pause and answer any questions the participant raises. Once all the participant's questions are answered to the participant's satisfaction, the researcher will proceed with the following question.)

At this point, I would like to directly ask you if you agree to participate in this study. If you say "no," I will not start the recording and your information will be not used in this research study. If you say "yes," I will begin the recording. I will ask you to repeat your agreement on the recording, and then start the interview by asking you the demographic questions.

Do you agree to participate in this study?

Appendix G: Demographic Data Collection Form

Participant ID: Date:
Session start time: Session end time:

Demographic Section:	
• Gender	
• Age	
• Marital Status	
• Ethnicity/ Race	

Family Information			
Does one or both parents work outside the home?	Yes, both parents	One parent/ which parent?	Neither parent
List all adults currently living in the household	Initials	Age/ Gender	Relationship
List all children currently living in the household	Initials	Age/Gender	Relationship
List any children no longer living at home	Initials	Age/Gender	Relationship

Child(ren) with Emotional Disturbance Only	
• Age	
• Gender	
• Does the child still live at home?	
• Does the child go to school? What is their current grade level? Are they homeschooled?	
• Does the child currently receive, or have they ever received special education services?	
• Does the child have any chronic illnesses, or been diagnosed with any developmental or mental health problem?	

Appendix H: Semi-Structured Interview Guide

Participant ID: _____   Date: _____
Start time: _____   Completion time: _____

Prior to beginning the interview:
After oral consent has been obtained, the researcher will turn on the recording. The researcher will say: "Thank you for meeting with me today. For the purposes of the recording, can you re-state that you consent to take part in this research study?"

The researcher will read the demographic form (Appendix F) for the participant to answer verbally. Once the demographic questions have been answered, the researcher will pose the "grand tour" question.

Grand Tour Question:
"As you know, I am interested in learning about the lives of parents of children with emotional or behavioral difficulties. I would like to hear your story."

If needed, the researcher will give an additional prompt: "When did you start noticing things about your child that caused you to think your child might have an emotional or behavioral problem?"

Additional questions to ask: (unless already discussed by the participant)

1- Did your child's emotional or behavioral issues create challenges for you and your family? If so, what are some of the common, "everyday life" problems or challenges that came/come up due to their emotional/behavioral issues?

2- How have your child's issues impacted you? (i.e.: emotionally, work life, financial impact?)

3 - How have your child's issues affected other members of your family?

4- How did the challenges you faced change as the child grew older?

5 - What are some of the things you (or your family) have tried to help yourself to cope with these effects?
        Follow up questions: What things helped you the most? Are there things you tried that did not help at all? Have you ever done anything to protect yourself legally due to these situations?

5 - What is something you wish you had known or had tried earlier when dealing with your child's issues and the impact they had on you and your family?

6- What would you tell the "system" if you could?

Clarification: it could be the educational system, healthcare system, or even society as a whole

Possible conversation topics (if more detail is needed):

    a. Was your child ever evaluated for an emotional/ behavioral problem or did they receive a diagnosis of an emotional or behavioral disorder?

    b. What actions does he/she do that makes you think they could have an emotional or behavioral disorder/ issue?

    c. Were there issues you had to manage with the child's school or with outside groups? (i.e.: sports, scouts, church)

    d. How did this affect your marriage/ relationship with your spouse? If still married, how did you keep your marriage together?

    e. How did you manage all your children's needs? (if there are additional children in the family)

Wrap-up question:
"Is there something else that you think I should have asked you?"

The researcher will recap 2-3 details of the participant's story to allow the participant to verify their own data. "Some of the important/ typical/ common situations that you discussed seemed to be (name 2-3 issues). Am I understanding you correctly?"

"Those are all of the questions that I had for today. Do you have any questions you would like to ask of me?"

Close of Interview:
"Thank you for sharing these experiences with me. If you think of additional thoughts you would like to share, please don't hesitate to email them to me, or you can call me. Please remember you can still withdraw from the study if you change your mind. [The researcher will verbally verify the participant has her contact information]. May I have your permission to contact you again if I have other questions or need clarification?"

The researcher will thank the participant again for assisting her in this research project, end the online meeting or phone call and stop the recording devices.

Appendix I : Code Book of Findings

<u>**Construct 1: Concerns & Suspicions**</u>

    Category 1: Realizing My Child is Different
      Concerning Behaviors: My child does this, but other children don't (ALL)
      Rationalizing Concerns (6/8; Not P1, 6)
          A. Early infant neglect, experiences or medical needs? (P2, P7, P8)
          B. Challenging Personality? [p2, p5, p7,P8]
          C. Circumstantial/ short term gap :covid, distant learning, needs to catch up: [P4,
              P3, P6]
          D. In my own head? [P4]
      Escalating Suspicions
          A. Nothing's working: Typical Parenting Fails [8/8]
              Barriers: spouse didn't see:P4, P5,   Others blamed parent, P6
          B. Problems in School [P1, P2, P3, P4, P7- verify timing]
              Barriers: child suffered in silence (P1, P5), Appeared successful (P5)
      Deciding something's wrong
          A. Catalyst [P6, p4, p5, p8]
          B. Concluding Something is Wrong Here [6/8; P1 & 6, never rationalized
              away]
              Barriers: other major issues distracted parent: (P1: abuse, health crisis,
              other sibling's issues more obvious (P3, P5,) obvious physical issues (P8)
      Confirming: Consulting Experts
          Seeking outside opinions (8/8)
          Barriers:
              i. Delayed care, access problems [7/8, P2 (youth, pre-interview notes), no
              P6]
              ii. Poor fit/ ineffective [P1, P4, P6, P7]
              iii. Cost [P1, P4]
              iv. Divergent opinions (P1, P8, P3)

<u>**Construct 2: Actions & Adaptations**</u>

    Responding to the Challenges
      For the Child with ED
          A. <u>Initial actions:</u> Reactionary/ based on past experience
              Rigid Rules/ "old school" [P1, P4, P6] ; Convincing Child [P4, P5, P8];
              Yelling [P4]
          B. <u>Seeking outside expert assistance</u>
            From Healthcare:
            1. Therapy: (psych, group, OT, speech -ALL)
            2. Medication [P6, P5, P5, P7]
               Barrier:. Parent reluctance [P4, P5, P8] ii. Ineffective [P6] iii. Developed
               allergy [P7]
            3. Residential/ placement [P1, P6, P7, P5 (temp hold)

Barriers: a. ineffective [P6] b: Child worsened [P6, P7];
Financial : High cost of care : P1,P3 P4; Negative cases: P5 & P6-
    negative cases

From Government agencies [P6- state agencies, courts, police]
Barrier: Ineffective, repeated criminal behavior

From Schools
Benefits:
    Supportive staff (7/8, not P7), Accommodations (7/8, not
    P2),Alternative schools (P1, P6)
Problems:
    Staff: Bad Teachers (P1,P3, P8); Uninformed teachers (5/8, not
    P3,4, 8); Harsh/ inflexible: (P3, 4, 8, 1), turnover (p5,8, 4, 3);
    excessive work/ unrealistic (P3, 1)
    System: Refused IEP (P3, 7, 8); communication (P7, 1, 8); Child
    suffered in silence (P1, 3), unsafe @ school (P1).
Time/ energy dealing with school: P3 adapted school to conserve time/
energy, Inflexible with curriculum, grading, scheduling

C.   Switching to intentional actions:
    Parent adapts self
    Parent Adapts (7/8, no P2): Praise (6/8: P2, 3, 4, 5,7, 8), Defuse (P2, 4, 6,
    8), Intentional actions/ not reacting (6/8, no P1, 7); Realistic
    Expectations (7/8, No P1), physical activity together (6/8, no P4, 5);
    Natural consequences (5/8, no P5, 7, 8); Avoiding battles (P2, 4, 8);

    Adapts the Environment
    Adapting School (P3) Calm house (P7) in home daycare (P8) work &
    home (P1,3,6,7,8); Connecting to peers (P3, 4, 8), Diet/ organic (P7, 8),
    Safety (P1,4, 5, 7), Changed living arrangements (6/8, no P4, 5)

    Teaching Child about the World (7/8, **Not P6**)
      Individual factors: divorce (P7), sensory (P8) Criminal behavior (P6)

For the parents: Self-Care
    Connecting with others (8/8- crisis interrupts, p4, 1); Friends & family: (p2, 4, 6,
        7, 8- letting some go (P8) judge-y advice (P1)
    Time away: driving, job (6/8, no P1, P3); others can't handle child: P1, 2, 4, 6, 8);
    Consciously changing internal emotional reaction (6/8, no P2, 6): Here & Now
    (5/8, no p2, 4, 8); Riding out (P1, 5, 6, 8); Letting go normal (P1,3, 7);
    Therapy/ Beliefs: mental healthcare (p3, 4, 6, 8); Belief in higher plan (P1,3,
    5, 7);
    Researching (P1, 4, 8- lack organized groups (P1,P3); group therapy
    overwhelming (p1, 7)

Unhealthy: ETOH (P6), obsessive cleaning (P8),
Safety measures (P6)

For the siblings:
Individual attention*:* P4, P5, P6, P7
Safety/ Sib needs protection*:* P1, P4, P6, P7

Category 3: Changing over time
Seeing through my Child's Eyes (**All**)
How child views the world *(***ALL***)*:
Unable to stop behaviors: P1, P2, P4, P5, P7, P8
Suffers in silence : P1, P3, P4, P5, P8
Unaware of implicit social rules *:* P3, P4, P7, P8
Child knows when failing parent's expectations : P1, P3
Coming into their own: P1, P8
Parent's Perspective Changes (all but P6)
Understanding Allows for Compassion: P1, P2, P4, P5, P7, P8
Finding Right Path/ Right Environment: P1, P3, P4, P7, P8
Not a Lack of Child's Willpower*:* P1, P4, P7, P8
Struggle with Nuances: P1, P3
My Child's Positives with problems (little from P6)
It's Who My Child Is*:* (all but P6)
My Child's Strengths : (all but P 6)
My Child for a Reason: P1, P3, P6 P7 (P6 searching for reason)
Reflection: I did my best
Regrets*:* (all)
I have done everything I could : (All but P5)
I did the best I could: (All but P2)
Future: No longer a Child, Not yet an Adult (None P2, P8 (children are 5yo); less from
P4, child is 9yo)
Game Changes: P1, P3, P7
Not Fully an Adult: Will they Ever Be? :P1, P3, P4, P5, P7
Desire for more Adult-Like Connection with Child: P3, P4, P5, P6, P7
Broken Relationships : P6

Construct 3: Altered Families and Advice

Category 4: Altered Families
On the parent:
Always on alert: [All] : on alert (P1, P4, P7) rollercoaster (P1, P6, P7)
stress (P1, P3, P4, P6, P7, P8), exhaustion (P1, P2, P6, P7, P8]
Frustration (All but P1)
Job problems (P4, P6, P8),
Social judgement (All but P5) : includes Feeling rejected: [all but P5)
Isolation: P1, P3, P4, P7, P8); Embarrassed (P2, P4, P6, P1,
Negative case: not always: P 2]

Guilt (All but P6)
Fear: **Of** the child: P4, P5, P6, P8; **For** the child: P1,P4, P7, P8)
Loss of dreams [all but P7: Grief (P1,P3, P4, P6), Sad (P2, P3, P4, P6, P8)
        Forced to change schools (P3)]

Less mentioned: self-doubt/ lost (P1, P3, P4); shock (P1, P5); Hurt (P5);
Anxiety (P8), Sacrifice (P8)

On spouse/ relationship (All)
    Didn't see problem- tension
    Personal: moved in (P2), rejected (P3, P6)
    Didn't see need to adjust(P2, P4, P5, P7),
    Lacked patience/ knowledge (P1, P2, P7, P8)
    Tension (P2, P4, P5, P6, P7, P8) ,
    Unbalanced load (P1, P2, P3, P4, P6, P8);
    Stress on bond: (All but P4)
    Best friend (P1, P3, P4, P6)

On the Siblings: stress of volatility (P3, P4, P6, P7), harmed bond (P1, P3, P6,
    P7) becomes protective (P4, P5, P7)

Category 5: Advice for other Families
Kids are really all different! (P2, P3, P4)
    Typical methods fail our kids (P4)
    Education focusing on Expediency over Success in learning (P3)
    Ignore differences, focus on disruptions (P2)
We Need Help, not Blame (P1, P3, P4, P6, P7)
    It's not our fault!: P4, P6
    Parents need tools: P1, P3, P4
    Healthcare needs wider view: (P7)
    Mental Health- Changing its "not real" thinking: P1, P2
Survival tips (P1, P5, P8)
    Connect with others : P1, P5
    Your child might be suffering, too: P5
    All Children want to love & to be loved: P8
    Ride the wave P1, P8

Vita

NAME: 2/2024

Michelle Nighswander, MSN-Ed, BSN, RN, AMB-BC
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PRESENT POSITION AND PHYSICAL ADDRESS

Lecturer (Adjunct), St. David's School of Nursing: Texas State University, 1555 University Blvd. Round Rock, Texas 78665, January 2020 – present

EDUCATION:

04/2024 (planned)	Doctoral Candidate, PhD in Nursing, University of Texas Medical Branch, Galveston, TX
05/2017	Master of Science in Nursing- Education, Texas A&M University, College Station, TX
05/1992	Bachelor of Science in Nursing, University of Iowa, Iowa City, IA

BOARD CERTIFICATION:

07/2010 to Present (Expires 07//2025)	Ambulatory Care Certified, Accreditation Board for Specialty Nursing Certification (ABSNC)

Prior certification:

07/1997- 07/2012	Oncology Nurse Certified, Oncology Nursing Certification Corporation

LICENSURE INFORMATION:

State	Status	Type of Licensure	Expiration Date
Texas	Active	Registered Nurse	02/28/2025

PROFESSIONAL WORK HISTORY:

Texas State University St. David's School of Nursing – Round Rock, TX
01/20 – Present   Lecturer
09/17 – Present   Affiliate Instructor

Concordia University
08/17 – 05/19   Adjunct Professor

Kaplan Nursing
09/19 – 05/ 20   Nursing Instructor

Baylor Scott & White
07/10 – 07/20   Telephone Triage Nurse
07/08 – 10/10   Rheumatology Nurse

American Cancer Society Information Center
07/1999 – 07/08   Nurse Supervisor
                             Oncology Nurse Information Specialist

Texas Oncology, PA, Austin, TX	Medical Oncology nurse, Chemotherapy infusion as needed
Austin Gastroenterology Assoc.	Office nurse
Capital Medical Clinic, Austin, TX	Cardiology office nurse
St. David's Home Care, Austin, TX	Staff relief nurse
Brackenridge Hospital, Austin, TX	Telemetry staff nurse

I. RESEARCH and SCHOLARSHIP

Research and Scholarship focus:

Improving the access, availability, and utilization of mental health care services in the outpatient setting, specifically focusing on parents and families of children with mental health problems. Healthcare providers and educators struggle to assist parents seeking help for their children. Regulations surrounding mental health and special education are convoluted, leading to further difficulties for professionals and families alike.

II. PUBLICATIONS:

A. PEER-REVIEWED JOURNALS

Nighswander, M. & Blair, P. (2024). From institutions to inclusion: How children with disabilities gained educational rights in the US. *The Journal of School Nursing*, *40* (1), 108-118. http://doi: 10.1177/10598405221105054.

B. OTHER:

Nighswander, M. (2022, July 8). "Looking beyond nursing education offerings can open   doors." *American Journal of Nursing, Off the Charts*. https://ajnoffthecharts.com/looking-beyond-nursing-education-offerings-can-open-doors

C. ABSTRACTS/POSTERS:

International Science Council. "Computer-aided depression screening: A literature review on optimal methodologies for mental health careening," Poster presentation. International Conference on Nursing Clinical Decision-Making, June 14-15, 2021

III. LECTURES/PRESENTATIONS AT SYMPOSIA AND CONFERENCES

Presenter:

Nursing care for patients with Lupus (1 hour CEU credit). Ambulatory care conference at Baylor Scott & White, February 2010.

Telephone Triage and Scope of Practice (Regional Education presentation for Baylor Scott & White), April 2017.

IV. TEACHING/MENTORING RESPONSIBILITIES

TEACHING/MENTORING RESPONSIBILITIES AT OTHER UNIVERSITIES:

Faculty Role	Course	Semester/Year	Institution
Lecturer/ Adjunct faculty	Community & population health	Spring 2024	Tx State University
Lecturer/ Adjunct	Essentials in Nursing	Fall 2023	Tx State University
Lecturer/ Adjunct	Health Assessment	Fall 2023	Tx State University
Lecturer/ Adjunct	Management of Nursing Care Practicum	Spring 2023, 2022, 2021, 2020	Tx State University
Adjunct Professor	Adult Health Theory 1	Fall 2018, Spring 2019	Concordia University

V. HONORS/AWARDS:

2022   Sigma Theta Tau International Honor Society chapters at University of Texas Medical Branch, Texas A&M University (2017), and University of Iowa (1992)
2022   John P. McGovern Chair in Nursing Award
2021   Jonas Scholar Nominee from University of Texas Medical Branch
2021   Baylor Scott & White Dixon-Galt-Lieberman Nursing Scholarship Award

VI. SERVICE/BOARDS/COMMITTEES: (* Denotes elected membership)

UTMB

PhD Student Liaison Representative with School of Nursing Faculty Committee

Other (e.g., Community)
*Round Rock High School Men's Soccer booster club- Treasurer

Round Rock High School Band Booster

Round Rock High School Project Graduation Committee

VII. MEMBERSHIP IN SCIENTIFIC SOCIETIES/PROFESSIONAL ORGANIZATIONS:

- Sigma Theta Tau International, Alpha Delta Chapter & Phi Iota Chapter

- American Nurses Association
- Texas Nurses Association- Area 5
- Southern Nursing Research Society
- Phi Kappa Phi
- Western Institute of Nursing