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DSM-5, Asperger's Syndrome Diagnosis, and Mothers' Experiences with Mental Health Services

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Abstract

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MA, Edinboro University, 2011

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Dissertation Submitted in Partial Fulfillment
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Abstract

Mothers who have children with a previous Asperger's syndrome diagnosis had to go through a process to maintain or obtain services for their child when the fifth edition of the *Diagnostic and Statistical Manual of Mental Health Disorders* (DSM-5) removed the diagnosis. Prior to and since the release of the DSM-5 in 2013, there has been an expression of concern in the literature about how this diagnostic change would affect services for children with a previous Asperger's syndrome diagnosis. Current research has not sufficiently explored the experiences mothers have had with this process. The purpose of this hermeneutical phenomenological study was to explore the experiences of mothers since this diagnostic change. Data were collected and saturation was reached at 6 participants using semistructured interviews. Interpretive phenomenological analysis was used to interpret the experiences of these mothers which produced 3 main themes related to the process of obtaining a new diagnosis, insurance-funded services, and educationally-funded services. The results included both subthemes and superordinate themes that highlighted the need for more stakeholder education, difficulty navigating systems, the need for advocacy, concerns about new diagnoses and loss of services, and the public's perception and the stigma associated with the Asperger's syndrome diagnosis both before and after this diagnostic change. Study results may assist with improving counselors and other stakeholder's knowledge about the importance of the mothers' experiences when there is a diagnostic change of this nature. Also, counselor educators can instill the importance of diagnostic accuracy and supporting all stakeholders when teaching new counselors.

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Dedication

I dedicate this research to all of the mothers with children who had a previous Asperger's syndrome diagnosis. I also dedicate this research to my deceased parents who did not get to see me accomplish my goal of obtaining my PhD.

Lastly, and with the utmost respect, I dedicate this to one of my best friends, my "fancy" Nancy DeLancey. You were the most "unfancy" and down to earth person I have ever known, but fancy rhymed with Nancy and DeLancey, so I found it funny and actually *my* kind of fancy. You taught me that it was alright to stand up for what I believed in and to never give up. You checked in with me more frequently than anyone about where I was in my dissertation process and when I would be done. You told me about your experiences at Harvard and being that "good Catholic girl who worked on birth control", and then, without fail, gave us that infamous Nancy devilish chuckle. There are no words to describe how much I already miss you, and I wanted nothing more than to complete this PhD process, and be able to say to you in person, "I'm, finally done". Rest in peace, my beautiful friend, I love you, and I'm finally done.

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Chapter 1: Introduction to the Study

Introduction

The Diagnostic and Statistical Manual of Mental Health Disorders (DSM) is published by the American Psychiatric Association (APA) and provides guidelines for the diagnosis of mental health disorders across a range of disciplines (Dailey, Gill, Karl, & Barrio Minton, 2014). The DSM, currently in the fifth edition, occasionally has updates, which can potentially add, change, or remove diagnoses (Dailey et al., 2014; Zwaigenbaum, 2012). The fifth edition of the DSM (DSM-5), released in 2013, replaced the previous autism, Asperger's syndrome, childhood disintegrative disorder, and pervasive developmental disorder (PDD) with an umbrella diagnosis of autism spectrum disorder (ASD) (Dailey et al., 2014; Zwaigenbaum, 2012). The rationale for this change had a scientific basis and reflected the understanding that all of these diagnoses have a similar set of behaviors, and a single diagnostic category was the best way to represent autism (Dailey et al., 2014; Grzadzinski, Huerta, & Lord, 2013; Lord & Jones, 2012).

Concerns about this diagnostic change began before the release of the DSM-5, and the current literature reflects ongoing concerns (Dailey et al., 2014). Many helping professionals view Asperger's syndrome as a distinctive diagnosis with its unique challenges and strengths (Dailey et al., 2014; Lord & Jones, 2012). Current research has reflected both positive and negative implications associated with this diagnostic change as it relates to Asperger's syndrome (Dailey et al., 2014). The primary concerns include stronger negative implications with an autism diagnosis including stigmatization by the general public who do not understand the diagnosis (Buxbaum & Baron-Cohen, 2013;

Dailey et al., 2014). Additionally, fewer children will meet the new criteria, which may result in a loss of diagnosis and services (Buxbaum & Baron-Cohen, 2013; Dailey et al., 2014).

Hoefman et al. (2014) discussed the impact on the quality of life for the caregiver as well as the entire family when a child in the family has an autism diagnosis. The care demands presented to these parents can often result in both physical and mental health problems for the parents (Hoefman et al., 2014). Gill and Liamputtong (2011) shared the experience of stigma of mothers with a child with Asperger's syndrome due to the invisibility of the diagnosis. Hoogsteen and Woodgate (2013) shared the challenges that parents encounter when trying to make this invisible diagnosis visible. Parents living in rural communities often have to advocate for the needs of their child due to a general lack of understanding (Hoogsteen & Woodgate, 2013). Without this parental advocacy, the child's quality of life may suffer due to not receiving the necessary autism-specific services (Lobar, 2016).

The trend for several years prior to the release of the DSM-5 was that the number of autism diagnoses was increasing each year (Bent, Barbaro, & Dissanayake, 2017). Bent et al. (2017) determined that the stricter DSM-5 criteria might have changed this trend of increasing diagnoses each year. Researchers who identify the positive aspects share that this is a more reliable way to diagnose, and it will assist with the utility of treatment planning (Buxbaum & Baron-Cohen, 2013; Dailey et al., 2014; Grzadzinski et al., 2013; Lord & Jones, 2012). Additionally, researchers expressed concern about the addition of social pragmatic communication disorder (SPCD) as a new diagnosis in the

DSM-5 (Dailey et al., 2014). The concern with SPCD is that many of those previously with an Asperger’s syndrome diagnosis may automatically receive this diagnosis, which represents those who do not have the restricted, repetitive behaviors and only struggle socially (Dailey et al., 2014).

This study is critical to counselors working with mothers because there have been no studies to date to about the experiences of mothers of children with a previous Asperger’s syndrome diagnosis. More specifically, this research examines mothers’ experiences with maintaining or acquiring services for their child who had a previous Asperger’s syndrome diagnosis. The focus on mothers in this research reflects their role as the primary caregiver for their child with an Asperger’s syndrome diagnosis (Gill & Liamputtong, 2011; Gray, 2002, 1993; Schrader, 2013). Schrader (2013) contended that mothers are more likely to be the main caregiver for a child with a disability. Mothers, as the primary caregiver, tend to have higher levels of stress, which affects their health and quality of life (Reed, Sejunaite, & Osborne, 2016). Mahmood, Saleemi, Riaz, Hassan, and Khan (2015) examined the coping strategies of mothers with children with autism and found that positive coping strategies included integration, networking, and religion, while negative coping included avoidance, ignorance, and isolation. All of these factors may contribute to the mother’s experiences with services since this diagnostic change.

In this chapter, I provide an overview of the background of my study including the literature background and the problem statement and purpose. I state my research questions and then identify my theoretical framework for the study. I discuss my rationale for the selection of a qualitative study and the chosen methodology. I provide the definitions of the key concepts and constructs in this study. I clarify the aspects of this study that I believe, but I cannot demonstrate to be true, and I will identify the boundaries of the study by sharing the included and excluded populations. Lastly, I share the limitations and significance of this research study on mothers' experiences and provide a summary of the main points of the chapter.

Background

Selected articles relating to the DSM-5 and mothers' experiences with services since the changes to the Asperger's syndrome diagnosis are described here:

1. Gill and Liamputtong (2013) conducted a qualitative study of 15 women aged 30-55 to capture their experiences as the mother of a child with Asperger's syndrome. This research assists with an understanding of the difficulties mothers with children with Asperger's syndrome endure (Gill & Liamputtong, 2013). Gill and Liamputtong (2013) also pointed out that the diagnosis phase for these mothers is difficult because these mothers tend to engage in self-blame for the child's diagnosis.
2. Kite, Gullifer, and Tyson (2013) conducted a mixed methods analysis of 547 health and education professionals on their perceptions Asperger's syndrome and autism and their view on the proposed diagnostic changes. Findings showed that the impact of having a diagnosis of autism was greater than that of Asperger's syndrome (Kite et al., 2013). The Kite et al. (2013) study relates to the current conversation about the DSM-5 changes because it explored the

health and education professional’s perceptions of both the diagnosis and the proposed changes.

3. Kite, Tyson, and Gullifer (2011) conducted focus groups with 51 people to determine perceptions of Asperger’s syndrome among health and education staff, parents of children diagnosed with Asperger’s syndrome, and community members. The Kite et al. (2011) study relates to the DSM-5 changes conversation because it was specific to Asperger’s syndrome and the perceptions of a broader group that included parents and community members in addition to health and education professionals. The data areas of focus are consistent with concerns expressed in other studies including stigma, services, diagnosis uncertainty, and confusion.
4. Kulage, Smaldone, and Cohn (2014) conducted a systematic review and meta-analysis of 418 studies to determine the effects of the DSM-5 changes on ASD and examine policy implications. The Kulage et al. (2014) study relates to the DSM-5 changes conversation because it was a comprehensive analysis of all studies since the first DSM-5 draft criteria. This study highlighted the need for an accurate diagnosis and that the diagnosis is the means by which those with ASD obtain educational, community, and medical services. Additionally, Kulage et al. (2014) highlighted the public health policy implications these changes may have on school-supported and insurance covered services.

5. Lord and Jones (2012) provided a comprehensive research review that included psychometric measures and clinical observations. Lord and Jones (2012) concluded that there must be a balance between clinical practice and the neurobiological associations in the social communication domains and the restricted-repetitive domains. The Lord and Jones (2012) research is useful because it crosses disciplines and included information about clinical and neurobiological research as it relates to diagnosis and ultimately experiences with services.
6. Matson, Hattier, and Williams (2012) conducted a study with two levels of relaxed DSM-5 ASD criteria modifications. This study was supplemental information to another study by Matson, Kozlowski, Hattier, Horovitz, and Sipes (2012) that predicted there would be a significant decrease in the number of children diagnosed with ASD under the proposed DSM-5 criteria. The Matson, Hattier, and Williams study is relevant because it points to the effects on prevalence rates that the proposed DSM-5 changes may have based on the rigidity of the criteria. Finally, the Matson, Hattier, and Williams article is important because it addresses the implications to services for some if they do not meet the new DSM-5 criteria.
7. Ruiz Calzada, Pistrang, and Mandy (2012) conducted a qualitative investigation into the utility of the PDD diagnosis by interviewing 22 people from 10 families with children with Asperger’s syndrome and high-functioning autism. Ruiz Calzada et al. (2012) determined that the utility of

the diagnosis is dependent on postdiagnostic services. The Ruiz Calzada et al. (2012) research relates to the current DSM-5 discussion because the ideas gathered have implications for improving care and services for those diagnosed with Asperger's syndrome.

8. Spillers, Sensui, and Linton (2014) conducted a phenomenological content analysis of discussion forum data. The discussion-forum data analysis of 76 people found that those with Asperger's syndrome and autistic disorder were concerned about services, community, identity, and the cure movement. The Spillers et al. (2014) study relates to the current DSM-5 diagnostic criteria change because it focused on the expression of two of the main concerns in much of the literature to date, services and identity. The main concern expressed was that the services would be more general and not meet individual needs. This research is pertinent to a study of mothers' experiences with services because it discusses both optimism and fear about the DSM-5 diagnostic changes and how that relates to services.
9. Taheri and Perry (2012) conducted a file review study of 131 children ages 2 through 12 to determine if they would meet the new DSM-5 proposed criteria. The Taheri and Perry (2012) research is useful because it discussed the goals of the DSM-5 workgroup and the intent for the new diagnostic criteria to be more broad and inclusive. Taheri and Perry (2012) stressed the importance of appropriate diagnosis for children to receive services.

10. Tsai (2013) reviewed 128 publications to compare DSM-IV Asperger's syndrome to high-functioning autism. The Tsai (2013) review is relative because it provided information on all of the comparative studies examining similarities as well as differences. The Tsai (2013) publication review is useful because it provided a comprehensive table of the articles, the author, demographics, and whether it is a qualitative or quantitative study. Tsai (2013) pointed to the fact that there was not enough research between the DSM-III and the DSM-IV to identify and define these mental disorders.

There is a gap in knowledge in the counseling discipline related to how the changes to the DSM-5 impacted mothers' experiences with services for their child. Researchers are calling for more research to understand the implications of this change. This research will contribute to counselor and counselor educators' understanding of how to better support these mothers.

Problem Statement

The fourth edition of the DSM (DSM-IV) included Asperger's syndrome as a separate diagnosis within the neurodevelopmental disorder category (Barahona-Corrêa & Filipe, 2016; Spillers et al., 2014). The release of the fifth edition of the DSM (DSM-5) brought significant changes to the previous DSM-IV edition. Of note, the PDDs category is no longer present, and Asperger's syndrome is no longer a separate diagnosis from the previous autism diagnosis (Barahona-Corrêa & Filipe, 2016; Spillers et al., 2014; Tsai, 2013; Taheri & Perry, 2012; Volkmar & Reichow, 2013). The DSM-5 presented the diagnosis of ASD on a continuum with three levels and required identification of the presence of an accompanying intellectual or communication impairment (Barahona-Corrêa & Filipe, 2016; Lai, Lombardo, Chakrabarti, & Baron-Cohen, 2013; Taheri & Perry, 2012).

Volkmar, Klin, and McPartland (2014a) asserted that the needs of children with autism typically correlate with severe cognitive, language, and social impairments, which include behavioral challenges and language delays and limitations. Over the years, parents of children with an Asperger's syndrome diagnosis have found it difficult to capitalize on available resources because the challenges and the needs of their children are very different from those with lower functioning autism (Feather, 2016; Volkmar et al., 2014a). Regardless, the mental health services provided for those diagnosed with Asperger's syndrome have advanced since the introduction of the disorder in the 1994 DSM-IV (Spillers et al., 2014; Tsai, 2013). Services that focus specifically on children with an Asperger's syndrome diagnosis include social and communication skills training, organizational skills, assistive technology, specialized curriculum, behavioral management, and psychotherapy (Feather, 2016; Volkmar et al., 2014b). The parents of children with Asperger's syndrome are key stakeholders and are responsible for their children's mental health services (Volkmar et al., 2014b).

More specifically, Ruiz Calzada et al. (2012) shared that mothers and fathers differ in the use of coping strategies and responses to their child with Asperger's syndrome. Fathers reported feeling disconnected from their child's difficulties and felt there was more impact on the mothers (Ruiz Calzada et al., 2012). Typically, mothers are the primary persons involved in advocating for children's services due to their role as the major caregiver (Gill & Liamputtong, 2013). Gill and Liamputtong (2013) asserted that the experiences of mothers differ from that of fathers. However, there are few studies examining the unique experiences of mothers of children diagnosed with Asperger's syndrome. Consequently, mental health clinicians must determine if children who previously had an Asperger's syndrome diagnosis meet the criteria for another diagnosis and if so, explain the diagnostic changes to the mothers. The children with a previous Asperger's syndrome diagnosis may or may not meet criteria for another diagnosis, and this change can impact the services the mother can acquire for her child (Gill & Liamputtong, 2013; Volkmar et al., 2014b; Volkmar & Reichow, 2013).

In recent years, there has been an expression of concern in the literature both before and after the release of the DSM-5 about changes to services for those who previously had a diagnosis of Asperger's syndrome (Barahona-Corrêa & Filipe, 2016; Spillers et al., Tsai, 2013; Taheri & Perry, 2012; Volkmar & Reichow, 2013). Recent literature focuses on the concern of meeting the new ASD criteria and the new SPCD diagnosis in various domains including home, school, and community (Barahona-Corrêa & Filipe, 2016; Spillers et al., 2014). The concern with the SPCD diagnosis is that its use may be a way for stakeholders, including schools and insurance companies, to avoid providing services (Volkmar & Reichow, 2013). There is also research that supports the addition of this diagnosis with the intent of more accurately describing symptoms and enabling a strengths-based approach to treatment (Dailey et al., 2014).

The problem identified for investigation is related to the scant information on the mothers' experiences with services since the Asperger's syndrome diagnosis merged into the ASD continuum (Gill & Liamputtong, 2013). This information is important because the medical necessity criteria for some insurance companies did not change when diagnostic changes occurred, thus this could have implications for the specialized services mothers can acquire for their children (Kulage et al., 2014). There is also concern about a possible reduction in diagnosis sensitivity to achieve a more specific diagnosis (Kulage et al., 2014); This diagnostic change could also potentially cause changes to services previously provided including a loss of supportive services in the school or community setting (Kulage et al., 2014). These diagnostic changes raise concerns about the ability of mothers to obtain future care, support, and services for their child who had a previous diagnosis of Asperger's syndrome (Gill & Liamputtong, 2013). Currently, there is no research related to mothers' experiences with services for their children with a previous diagnosis of Asperger's syndrome. This gap in the literature makes counselor educators and clinicians ill-equipped to understand the importance of diagnostic accuracy and how this can impact the experiences mothers have with services for their children. Additionally, this exploration will help stakeholders understand mothers' experiences and assist counselor educators and clinicians with understanding how to support mothers of children with a previous Asperger's syndrome diagnosis.

Purpose of the Study

The purpose of this hermeneutic phenomenological study was to understand mothers' experiences related to services since their child's Asperger's syndrome diagnosis merged into the ASD continuum with the release of the DSM-5. While information about the increases or decreases in services may be revealed in the interviews of this study, the purpose was solely to explore the experiences of the mothers. This research will inform counselors about mothers' experiences and how they were impacted by these diagnostic changes (Blumberg et al., 2015; Volkmar et al., 2014). Treatment and services must align with the medical necessity criteria so mothers can obtain adequate specialized services for their children (Volkmar et al., 2014b; Volkmar & Reichow, 2013). Additionally, this study may help to ensure that counselor educators are equipped to teach counselors to understand the importance of ASD diagnostic accuracy. Diagnostic accuracy is critical to ensuring that mothers receive adequate and appropriate services for their children (Volkmar et al., 2014b; Volkmar & Reichow, 2013).

Research Question

> RQ: What are the lived experiences relating to services and support of mothers with a child whose previous Asperger's syndrome diagnosis merged with Autism Spectrum Disorder?

Framework

When discussing the conceptual framework for a qualitative study, theory refers to the concepts and ideas and the relationship among them (Maxwell, 2013). The phenomenon under investigation in my study was the experiences of mothers with services since the elimination of the Asperger's syndrome diagnosis. The lens that I used for this study has a basis in phenomenology, hermeneutics, and idiography. Phenomenology is the study of experience, and I investigated the mothers' experiences of this phenomenon (Smith, Flowers, & Larkin, 2012). Hermeneutics refers to the theory of interpretation, and I related to my research subjects and the phenomenon under investigation as I attempted to make sense of and understand my research subjects' experiences (Smith et al., 2012). Idiography introduces the concept of detail and depth in my analysis as well as my commitment to understanding the experience from the perspective of my research subjects (Smith et al., 2012). I provide a more detailed analysis of phenomenology, hermeneutics, and idiography in Chapters 2 and 3.

Interpretive phenomenological analysis (IPA) aligns with my study approach because it has a basis in phenomenology, hermeneutics, and idiography (Smith et al., 2012). The hermeneutic circle recognizes the whole and the parts in data analysis, and this allowed me to have back and forth movement in my thinking about the data as well as my relationship to the data (Smith et al., 2012). As I investigated these relationships, I followed the IPA protocol, which I outlined in detail in Chapter 3 and in flowchart format (see Appendix A). Additionally, I used concept mapping as a visual to assist in understanding the various relationships and interplay among the concepts in my study (Maxwell, 2013). The concepts that had the potential for inclusion in my study were services, diagnosis, medical necessity criteria, individualized education plans, stigma, identity, and diagnostic criteria sets (Barton et al., 2016; Blumberg et al., 2016). The mothers' experiences with services was the main concept, and concept mapping throughout the IPA process assisted with a graphical display of the potential impact the other concepts had on services to enhance my understanding and interpretation (Maxwell, 2013).

While conducting the literature review for this study, findings illustrated a relationship between a qualitative approach and the use of social constructivism in data analysis (Creswell, 2013; Spillers et al., 2014). Social constructivism is inductive, and this aligned with the phenomenological approach to this research because the construction of realities occurs through the lived experiences of these mothers (Creswell, 2013; Kordeš, 2016). Social constructivism includes the use of methods such as interviewing and analysis of texts, which was the method of inquiry in this phenomenological research (Creswell, 2013; Kordeš, 2016). I provide a thorough explanation of this framework in Chapter 3.

Nature of the Study

For this study, I researched mothers' experiences with services since the change in the Asperger's syndrome diagnosis in the DSM-5. The best fit in a qualitative approach for this study was hermeneutic phenomenology because the researcher focuses on the lived experiences and attempts to garner the essence or meaning of the experience of the participants (Kafle, 2011; Pietkiewicz & Smith, 2012; Vagle, 2014). Smith et al. (2012) described hermeneutic phenomenology as an orientation toward the interpretation of texts of the lived experiences of humans. Hermeneutic phenomenology is a dynamic interplay that begins with the researcher's concern or interest and then progresses through identification and interpretation of themes (Finlay, 2009; Kafle, 2011; Patton, 2015). Smith et al. (2012) characterized that the interrelationship between the conscious and the underlying dynamics provides meaning that facilitates interpretation of the research subject's lived experiences. I followed the IPA approach to qualitative inquiry and interviewed mothers about their experiences since the change in their child's Asperger's syndrome diagnosis. Data analysis followed the IPA analytic focus in which I tried to make sense of my participants lived experiences by moving from the individual perspective to a shared perspective and from descriptive to interpretive (Smith et al., 2012).

Definitions

The key concepts and constructs in this research that may not be fully understood by the layperson include DSM-5, DSM-IV-TR, Asperger's syndrome, ASD, SPCD, and stigmatization. I provide definitions of each of the terms to ensure full understanding to a wide variety of consumers of this information.

DSM-5: The DSM-5 was published by the APA in 2013. DSM stands for Diagnostic and Statistical Manual, and the 5 refers to the fifth edition. The DSM is used by mental health professionals for diagnostic purposes and has specific categories that have gradually become more dimensional, which is evident by the changes in this edition to the autism diagnoses (Volkmar & Reichow, 2013).

DSM-IV-TR: The DSM-IV-TR was the edition of the DSM before the DSM-5. Similar to the DSM-5, the DSM-IV-TR was the manual for diagnosis for mental health professionals before the release of the DSM-5. The DSM-IV-TR was the last edition of the DSM to officially recognize Asperger's syndrome as a separate diagnosis (Volkmar & Reichow, 2013).

Asperger's syndrome (AS): Asperger's syndrome was an official diagnosis from 1994-2013. Asperger's syndrome has also been referred to as high-functioning autism and is evident in those with the diagnosis due to restricted or repetitive patterns of behavior and deficits in social interactions (Ruiz Calzada et al., 2012). The Asperger's syndrome diagnosis was removed from the DSM-5, and those with a previous diagnosis may now have a diagnosis of autism spectrum disorder, Level One, SPCD, or may have lost their diagnosis altogether.

Autism spectrum disorder (ASD): With the release of the DSM-5 came changes to the ASD diagnosis and those with an ASD diagnosis are now on a continuum with the higher functioning individuals on a Level 1 category and those who are lower functioning on a Level 3 status (Volkmar & Reichow, 2013). Mental health clinicians and others who are responsible for diagnosis must decide if criteria are met for the diagnosis and if there is intellectual or language impairment (Volkmar & Reichow, 2013).

Social pragmatic communication disorder (SPCD): SPCD was added to the DSM-5 and is in the communications disorder section of the DSM. Clinicians assigning this diagnosis should assess for difficulty in the use of nonverbal and verbal communication and the impact this deficit has across environments. When assigning this diagnosis, the clinician must ensure that the symptoms are not better explained by an autism diagnosis (Dailey et al., 2014).

Stigmatization: Stigmatization refers to feelings of denouncement or disapproval due to being viewed as different in some manner (Gray, 2002, 1993). The person feels the stigma or difference, and this can result in them feeling less of a person or marginalized (Gray, 2002, 1993).

Assumptions

Assumptions are inherent in the research process and include those things that the researcher believes to be true but cannot prove (Simon & Goes, 2013). I made the assumption that when I advised my participants that their information would be held in strictest confidence, that they would be truthful in their responses to interview questions about their experiences (Simon & Goes, 2013). Truthful responses are an important component of this research; however, I had no way to ensure that they would be honest. I took every precaution including giving them adequate time to ponder my questions and be reflective before responding, reiterated the confidential nature of the study several times throughout the interview, and used a member checking process (Simon & Goes, 2013). It is important to note that I managed my assumptions throughout this research process through the use of the hermeneutic circle. The hermeneutic circle assisted me in managing my personal assumptions, and it allowed for interpretation and opportunities for the findings to appear (Smith et al., 2012). I will elaborate on my personal assumptions related to this research topic in Chapter 4.

Scope and Delimitations

Delimitations in qualitative research originate when the researcher chooses to narrow the scope of the study by including or excluding certain things (Simon & Goes, 2013). A review of previous research pointing to the different experiences between mothers and fathers contributed to my decision to narrow the scope to mothers only (Hoefman et al., 2014; Hoogsteen & Woodgate, 2013; Kite et al., 2011, 2013; Kuusikko-Gauffin et al., 2013; Ruiz Calzada et al., 2012; Schrader, 2013). Asperger's syndrome is a categorically different diagnosis; therefore, I chose to include only children ages 7-17 with a previous diagnosis of Asperger's syndrome rather than also including pervasive development disorder. For consistency and potential transferability, I specifically chose the age range from 7-17 because this aligns with the Autism Diagnostic Observation Schedule (ADOS) module three and higher, which requires that the child be verbally fluent (Hus & Lord, 2014). I used thick description in this study to allow readers to assess the appropriateness of transferability (Miles, Huberman, & Saldana, 2014). Lastly, I ensured that I outlined any necessary future research upon completion of this study.

Limitations

Qualitative research intrinsically presents limitations and delimitations that are typically out of the researcher's control; however, they can also have an impact on the results of the study (Creswell, 2013; Patton, 2015; Simon & Goes, 2013). These limitations usually relate to the research design and methodology (Simon & Goes, 2013). The ability to have access to the mothers with these diagnostic change experiences was critical (Creswell, 2013). I only sought out mothers of children who had previously had an Asperger syndrome diagnosis.

There are also inherent trustworthiness limitations in all qualitative research (Creswell, 2013; Patton, 2015; Simon & Goes, 2013). Qualitative research takes place in the field; therefore, it presents reproduction challenges (Creswell, 2013; Patton, 2015; Simon & Goes, 2013). I used the hermeneutic circle in this phenomenological study to maintain consistency in data analysis, and I maintained a reflexive journal throughout the research process (Edward & Welch, 2011; Stutey & Cureton, 2015). These techniques increased the trustworthiness of this study.

Significance

In hermeneutic phenomenological research, the researcher seeks to interpret a phenomenon with the hope that the new understanding will increase empathy and induce an appreciative understanding of the experiences of the population (Freeman, Gergen, & Josselson, 2015). Ratts, Toporek, and Lewis (2010) contended that counselor educators should be aware of their ability to foster social change through research activities. Research alone cannot change the experiences that these mothers had with services; however, this research assisted me with identifying a need for advocacy efforts to improve their experiences and the experiences of future clients who have a diagnostic change (Ratts et al., 2010).

This research on mothers' experiences with services since this diagnostic change has the potential to effect social change among several groups including the mothers, children, counselor educators, counselors, and insurance companies. By Freeman et al.'s (2015) advice, the object of this research was to generate successful interpretations of the mothers' experiences that can be of use to stakeholders to control future events. Counselor educators can use the interpretations to engage in social justice advocacy at several levels including at the microlevel with the mothers to empower them to advocate for services for their children (Ratts et al., 2010). At the student microlevel, counselor educators can provide instruction on the importance of accurate diagnosis and receipt of services based on diagnosis (Ratts et al., 2010). At the macrolevel, this research can assist counselor educators and clinicians with advocating for changes in medical necessity requirements with insurance companies to align with the diagnostic changes. While some officials at schools and insurance companies recognize the DSM-5 diagnosis codes, there have been no updates to the guidelines for criteria for others (Volkmar et al., 2014a,b). This shortcoming in the process may result in changes to the services mothers' can acquire for their child with an Asperger's syndrome diagnosis (Volkmar et al., 2014a,b).

Summary

The dispute about the removal of Asperger's syndrome and the newly developed ASD continuum continues with questions concerning services and meeting criteria for a new diagnosis (Barahona-Corrêa & Filipe, 2016; Lai et al., 2013; Spillers et al., 2014). Mothers who have a child with a previous diagnosis of Asperger's syndrome have had an experience with a diagnostic change or possibly an elimination of their child's diagnosis depending on whether they met the newly established criteria (Barahona-Corrêa & Filipe, 2016; Kulage et al., 2014; Spillers et al., 2014). Many scholarly articles call for more research on the implications of the DSM-5 changes to the Asperger's syndrome diagnosis, with specific attention given to the future support and care of those with a previous Asperger's syndrome diagnosis (Carmack, 2014; Volkmar et al., 2014a).

In Chapter 2, I provide an exhaustive literature review relevant to the topic of Asperger's syndrome including the diagnosis history and diagnosis characteristics. I share diagnosis and assessment strategies and then outline treatment and service domains. I review the core treatment components and then provide a comparison of the DSM-IV-TR and the DSM-5 criteria. I provide information about the new SPCD diagnosis and discuss the identity and stigmatization concerns and justify why I chose to explore mothers' rather than fathers' experiences with services. I share the concerns about meeting the new criteria and how that may affect meeting medical necessity and insurance criteria. Finally, I provide a review of the literature since the release of the DSM-5.

Chapter 2: Literature Review

In the DSM-5, Asperger's syndrome is no longer a diagnosis (Barahona-Corrêa & Filipe, 2016; Spillers et al., 2014; Taheri & Perry, 2012; Tsai, 2013; Volkmar & Reichow, 2013). In the text revision (DSM-IV-TR), Asperger's syndrome was one of several diagnoses in the PDD category, and now it is included on the three-level ASD continuum (Barahona-Corrêa & Filipe, 2016; Spillers et al., 2014; Taheri & Perry, 2012; Tsai, 2013; Volkmar & Reichow, 2013). Until the release of the DSM-5, the perception of the needs and types of services for children with autism had been different from that of Asperger's syndrome, and insurance companies approve services according to the child's diagnosis (Feather, 2016; Volkmar et al., 2014a). This change will, undoubtedly, create an experience for these mothers as they pursue rediagnosis and continued services for their children (Gill & Liamputtong, 2013; Ruiz Calzada et al., 2012).

The purpose of this hermeneutic phenomenological study was to understand the counseling service experiences of mothers following the change in the DSM-5 diagnostic criteria that alters their child's diagnosis of Asperger's syndrome. Diagnostic accuracy and sensitivity are paramount, especially when there are DSM changes (Blumberg et al., 2015; Volkmar et al., 2014a). The goal of this research was to understand mothers' experiences so that it may provide insight for various stakeholders including mothers, counselors, and counselor educators to better understand the importance and alignment of diagnosis with services (Blumberg et al., 2015; Volkmar et al., 2014b). Additionally, the experiences of these mothers provided enlightenment and allowed for the various levels to determine if advocacy is necessary for those affected by changes to diagnostic criteria.

In this chapter, I explain all the details of my literature search strategy to demonstrate that I searched all relevant literature exhaustively. I describe the foundational theorists behind hermeneutic phenomenology and IPA that includes historical use, the rationale for theory choice, and how it relates to my current study. Finally, I provide an exhaustive review of the current literature that includes the history, characteristics, assessment, treatment and service guidelines for Asperger's syndrome and ASD.

Literature Search Strategy

The literature search for this study was extensive and included multidisciplinary databases as well as specific subjects. The need to search multidisciplinary databases was due to the interest of this diagnostic change across disciplines. The multidisciplinary database searches included Thoreau Multi-Database Search, Academic Search Complete, ProQuest Central, and Science Direct. The individual subjects searched covered counseling, education, health sciences, human services, nursing, psychology, and social work. Within each of the subjects, there were various specific databases including PsychInfo, PsychArticles, SocIndex with Full Text, Education Source, ERIC, MEDLINE with Full Text, SAGE Journals, and Google Scholar. Additionally, several times throughout my searching I selected all databases and used various search terms to determine if any new outcomes would appear.

I used many combinations of search terms to ensure that my search was exhaustive. The searched combinations of terms include *DSM-5*, *DSM-V*, *Asperger syndrome*, *Asperger's syndrome*, *experiences*, *mothers*, *primary caregivers*, *DSM-4*, *DSM-IV*, *diagnostic changes*, *autism spectrum disorder*, *services*, *stigmatization*, and *social pragmatic communication disorder*. This literature search included articles about the subject and went as far back in time as necessary to ensure coverage of the included variables. For example, the discussion of the release of the DSM-5 and the changes to these diagnoses began well before its release in 2013. As early as 2011, Kite et al. (2011) discussed the perceived issues about the proposed changes and concerns about barriers to services. I included literature reflecting the concerns before and after the release of the DSM-5. Additionally, I included the work of Gray who has researched on stigmatization of parents whose child has an autism diagnosis (Gray, 1993, 2002). Perceived and enacted stigmatization is an essential consideration in this research because it may affect whether parents choose to continue to access services after their child's diagnosis changed. Finally, the scope of my literature search included seminal works related to hermeneutic phenomenology and IPA.

Theoretical Foundation

The three key theoretical underpinnings of this research were phenomenology, hermeneutics, and idiography. Phenomenology, with a basis in philosophy, has a concern with the experiences of humans (Shinebourne, 2011; Smith et al., 2012). Hermeneutics, also philosophical, is an interpretation theory most notably tied to the work of the hermeneutic phenomenologist, Martin Heidegger (Shinebourne, 2011; Smith et al., 2012). Idiography, as the third theoretical underpinning, focuses on the researcher's commitment to maintaining an in-depth focus and detailed analysis (Shinebourne, 2011).

Heidegger, and then Gadamer, through their phenomenological beliefs, doubted that there could be any knowledge without interpretation and posited that our relatedness to our research subjects allows us to make sense of and understand each other (Shinebourne, 2011; Smith et al., 2012). Heidegger, though his concept of *Dasein*, expressed the importance of presence and engagement; however, he also stressed that the ability to connect to these things is through interpretation (Shinebourne, 2011; Smith et al., 2012). Likewise, Gadamer emphasized the complexity of interpretation and the importance of recognizing that the interpreter's sense-making is dynamic and will go through a compare and contrast process (Shinebourne, 2011; Smith et al., 2012).

Heidegger

The theoretical basis of this study, at the very foundation, was a Heideggerian approach to phenomenology that asserts that the researcher is a part of the experience and seeks to interpret the meaning of the participant's experiences (Gadamer, 1989; Shinebourne, 2011; Smith et al., 2012). Heidegger focused on appearance and believed there was binary quality to this phenomenon because as something comes forth and presents itself, it is entering a new state (Shinebourne, 2011; Smith et al., 2012). When something appears, there are visible things can be seen immediately, and also things that are not able to be seen that may have hidden meanings (Shinebourne, 2011; Smith et al., 2012). Heideggerian phenomenology examines both the manifest and the latent meaning as it emerges (Shinebourne, 2011; Smith et al., 2012). *Logos*, which is another part of Heidegger's definition of phenomenology, refers to judgment, communication, and reason (Shinebourne, 2011; Smith et al., 2012). While the phenomenon relates to perception, *logos* refers to analysis and making sense or illuminating the phenomenon (Shinebourne, 2011; Smith et al., 2012). While the phenomenon itself may be spontaneous, the phenomenological researcher is the facilitator of making sense of the phenomenon as it appears (Shinebourne, 2011; Smith et al., 2012).

Gadamer

Gadamer, also a writer on hermeneutics, focused on the importance of tradition and history on the process of interpretation (Shinebourne, 2011; Smith et al., 2012). More specifically, the lived experiences of the research participants and what matters to them allows the researcher to examine, comprehend, and interpret the experiences of their participants (Gadamer, 1989; Smith et al., 2012). Gadamer focused on the complicated relationship between the interpreter and the interpreted, and he emphasized that meaning-making is a process in which conceptions evolve throughout the process (Smith et al., 2012). Gadamer (1989) articulated the historical evolution of hermeneutic phenomenology and the divergence from the transcendental thought process. He provided credit to Heidegger for the development of his philosophy, which is an outgrowth of hermeneutics, and acknowledges the importance of the hermeneutic circle and understanding its importance to interpretation (Gadamer, 1989; Smith et al., 2012).

Hermeneutic Circle

Hermeneutic theory includes the idea of the hermeneutic circle, which concerns the relationship between the parts and the whole at various levels (Smith et al., 2012). The hermeneutic circle focuses on a back and forth process in which the researcher looks to the part to understand the whole and looks to the whole to understand the parts (Smith et al., 2012). The circularity of this process has been subject to criticism; however, it is essential for adequate interpretation (Smith et al., 2012). This nonlinear style of thinking assists the researcher with garnering a much deeper understanding of dynamic relationships and is iterative (Smith et al., 2012). Heidegger and Gadamer both provided descriptions of the importance of a new understanding of the phenomenon through a relationship with the fore-understanding (Smith et al., 2012). Researchers using IPA embody the hermeneutic circle and its use in the research process (Smith et al., 2012).

Interpretive Phenomenological Analysis and Idiography

Researchers using IPA focus on examining human lived experience in great detail (Smith et al., 2012). IPA aligns with Heidegger and Gadamer's views that phenomenology is an interpretive process (Smith et al., 2012). Idiography is the third significant theoretical influence on IPA and is significant at two levels (Smith et al., 2012). First, the IPA researcher commits to an in-depth, detailed analysis, and second, they commit to recognizing how the research participant understands the phenomenon or experience in a particular context (Smith et al., 2012). This commitment allows the researcher to focus on the individual particulars, yet still consider *Dasein,* where the researcher examines the personal relationship to the phenomenon (Smith et al., 2012). Researchers use idiography to allow research participants to provide a unique perspective of their involvement or connection to the researched phenomenon (Smith et al., 2012).

Social Constructionism–Data Analysis

Another critical theory to consider specifically for data analysis in this study was social constructionism. Meaning-making does not occur independently of other variables;

therefore, I considered the enmeshment of the language and culture of my participants when analyzing the data (Smith et al., 2012). The shaping of my participants' lived experiences occurred through language and resulted from relationships with others (Smith et al., 2012). Strong (2014) stressed the interconnection of three traditions including the subjective phenomenological experience, the hermeneutic experience, and the ongoing linguistic efforts to negotiate these two traditions.

There is a deep-rooted connection between language and meaning, and the use of language is inherent in experience sharing as well as the mediation of social realities (Strong, 2014). I would be remiss not to theorize how my participants' interactions with others affected their language use and how they developed meaning through the experiential use of language (Strong, 2014). Participants in this study were a part of a larger society in which histories, cultural implications, and personal perceptions formulated how they derived meaning from their experiences (Strong, 2014). Both phenomenology and hermeneutics align with social constructionism (Smith et al., 2012). How the participant constructs their narrative takes on importance when the researcher focuses on interpretation through the use of IPA and adds an idiographic and contextual focus (Smith et al., 2012). Finally, Shinebourne (2011) asserted that interpretations of experience are always shaped and enabled or limited by language.

Theory Relevance

The choice to use hermeneutic phenomenology for this research had a basis in several recent peer-reviewed studies and dissertations that took a similar approach to examining the experiences of parents whose child has an Asperger's syndrome or autism diagnosis. Fusco (2013) conducted a dissertation study on the perceptions of the shift in nosology to the DSM-5. While the Fusco (2013) dissertation took a phenomenological focus, there was no level of interpretation; instead, the author chose to understand how several groups of people including parents, clinicians, and teachers conceptualized multiple factors related to the nosological shift. Schrader (2013), in another dissertation, explicitly explored father's experiences with having a child with an autism diagnosis. Schrader (2013) also used a phenomenological approach; however, chose to specifically use hermeneutics and take an interpretive approach to understanding the lived experiences of the fathers in the study. This method is very similar to the approach taken for this research because Schrader (2013) also desired to understand and gain the participant's perspective of their lived experiences.

Several other peer-reviewed studies used phenomenology as their base theory when exploring parental experiences with having a child with autism or Asperger's syndrome. For example, Gill and Liamputtong (2011) conducted, what they described as, a qualitative study using in-depth interviews and thematic analysis; however, they neglected to identify phenomenology. This study considered the experiences of being a mother with a child with Asperger's syndrome; therefore, implies that this was a phenomenological study. The theoretical framework outlined by Gill and Liamputtong (2011) relates to stigma and how mothers experience stigma when they have a child with autism. My proposed research on mothers' experiences with services has the potential to be impacted by their feelings of stigma because it may affect their decision to continue to pursue services for their child.

Mahmood et al. (2015) conducted a phenomenological study on the coping strategies of mothers with a child with ASD. This study used social constructionism as a theoretical framework to highlight participants' perceptions of autism and life with autism (Mahmood et al., 2015). Mahmood et al. (2015) only briefly made mention of their theoretical framework and did not explicitly tie it into their findings. They did; however, discuss various results that related to context including whether the mothers were employed or not employed, and whether they had education and knowledge of autism or were more superstitious (Mahmood et al., 2015).

Literature Review

My exhaustive review of the literature disclosed the need to explore mothers' experiences with services since the change in their child's Asperger's syndrome diagnosis. While there has been extensive speculation about what may happen with this diagnostic change (Barahona-Corrêa & Filipe, 2016; Spillers et al., 2014; Taheri & Perry, 2012; Tsai, 2013; Volkmar & Reichow, 2013), there have been no studies to date on the experiences of mothers since the modification to the autism diagnoses. I provided a complete review of the literature both before and after the release of the DSM-5 to demonstrate the importance of this study. I included a full history of both Asperger's syndrome and autism, and I highlighted the process that Asperger's syndrome has taken from its inception to its removal as a diagnosis. Finally, many contextual factors can affect mothers' experiences with services, and I thoroughly reviewed each of these germane elements in this literature review.

History

There has been a mystery surrounding the early descriptions of autism and Asperger’s syndrome due to the extraordinary coincidence surrounding the inception of the diagnoses (Barahona-Corrêa & Filipe, 2016; Chown, 2012; Chown & Hughes, 2016; Fellowes, 2015; Robison, 2017; Tsai, 2013; Tsai & Ghaziuddin, 2013; Volkmar et al., 2014a). In 1943, Kanner, an Austrian-born physician living in America, described certain traits as autistic and specifically considered a variance of language abilities as a defining feature (Barahona-Corrêa & Filipe, 2016; Robison, 2017; Tsai, 2013; Tsai & Ghaziuddin, 2013; Volkmar et al., 2014a). In 1944, Asperger, also an Austrian-born physician but residing in Austria, used the term autistic to describe a unique group of children that had impairments in social interactions and restricted behavior and interests (Barahona-Corrêa & Filipe, 2016; Robison, 2017; Tsai, 2013; Tsai & Ghaziuddin, 2013; Volkmar et al., 2014a). Because of the timeliness and similarities of their discussions, there have been speculations of both conspiracy and plagiarism (Chown, 2012; Chown & Hughes, 2016; Fellowes, 2015; Robison, 2017). Robison (2017) attempted to explain this strange coincidence by shedding light on the fact that Georg Frankl influenced both men but in different countries. Georg Frankl was faculty to Asperger when he was a resident in 1932, and when he left Vienna in 1937 and came to America, he brought his ideas with him and shared them with Kanner (Robison, 2017). Kanner, in America, published a paper in the English language and it became an influential topic, while Asperger published a thesis in German that’s later translations caused misconceptions (Robison, 2017). Later, psychiatrist Lorna Wing investigated the work of Asperger which piqued the interest of scholars in the similarities and differences in the work of these two physicians (Robison, 2017). Both men denied having any connection to the work of the other, and the involvement of others began to illuminate the concept of a spectrum (Robison, 2017). While there were similarities in their descriptions, there were also differences including the subjects' functioning in the speech and cognitive domains (Barahona-Corrêa & Filipe, 2016; Robison, 2017; Tsai, 2013). Kanner's syndrome first appeared in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III), while Asperger made no attempt to define diagnostic criteria for his description and, at that time, it remained virtually unknown (Barahona-Corrêa & Filipe, 2016; Tsai, 2013).

Later, Asperger acknowledged Kanner's work and maintained that his subjects were distinctly different from the description provided by Kanner (Barahona-Corrêa & Filipe, 2016; Robison, 2017). The ideas that the two diagnoses were different continued and were distinguishable by the fact that children with Asperger's syndrome were competent cognitively and linguistically and had normal early development (Barahona-Corrêa & Filipe, 2016). The qualitative difference in social interactions between the two was another discernible difference with children because those with Asperger's syndrome would make attempts to relate to others, while there was no interest in relating to others by those subjects with Kanner's autism (Barahona-Corrêa & Filipe, 2016; Tsai, 2013; Tsai & Ghaziuddin, 2013). The number of scholarly publications on Asperger's syndrome grew over the years, and it was finally introduced in the DSM-IV in 1994 as a separate diagnosis (Barahona-Corrêa & Filipe, 2016; Tsai, 2013; Tsai & Ghaziuddin, 2013).

Neuropsychological Characteristics

There are several characteristics to measure the neuropsychological functioning of children with a diagnosis of autism or Asperger's syndrome (Tsatsanis, 2014). The measurement of these characteristics and changes in applicability to the specific nosology of Asperger's syndrome and autism contributes to the understanding of the diagnostic changes. I will describe each to assist with understanding future sections, and the concerns about how the changes to criteria for each diagnosis contribute to the interest about mothers' experiences with services.

Sensory perception. Children may have hyper- or hypo-sensitivities or inconstancies in their sensory systems including visual, tactile, and auditory (Tsatsanis, 2014). Deficits in sensory perception can affect many other developmental domains over time including information processing and social experiences (Tsatsanis, 2014). There is evidence of atypical sensory processing in both Asperger's syndrome and autism from neuropsychological measures as well as behavioral reports (Tsatsanis, 2014).

Motor functioning. Motor functioning includes high-order motor tasks that require agility rather than motor-clumsiness which presents in both autism and Asperger's syndrome (Tsatsanis, 2014). While motor functioning is not a distinguishing factor of Asperger's syndrome, it can frequently be a part of their clinical picture (Tsatsanis, 2014). There is a wide range of deficits in motor functioning across the

Asperger’s syndrome and autism spectrum and can have a significant impact on academics, social, and adaptive functioning (Tsatsanis, 2014).

Attention. Attention, as related to Asperger’s syndrome and autism, refers to having an exclusive focus on unusual or particular details of the environment or the inability to move attention from one activity to another social stimulus (Tsatsanis, 2014). Attention concerns specific to autism and Asperger’s syndrome also relates to the individual’s ability to attend to social stimuli instead of the less conspicuous elements of the environment (Tsatsanis, 2014). There is significant clinical implication with attention concerns in children with Asperger’s syndrome and autism across several domains including differential diagnosis, treatment approach, academic, adaptive functioning and behavioral (Tsatsanis, 2014).

Memory. Memory function in Asperger’s syndrome and autism is multidimensional and includes various constructs including episodic and semantic, and explicit and implicit memory (Tsatsanis, 2014). In children with Asperger’s syndrome, the memory profile can include fixated interests wherein they focus on a narrow topic and accumulate an abundance of facts (Tsatsanis, 2014). On the contrary, children with autism display a deficit in retrieval rather than encoding (Tsatsanis, 2014). Organization of information can also be problematic, and for those with Asperger’s syndrome it can be idiosyncratic, and they may have difficulty connecting past experience to present experience (Tsatsanis, 2014). Memory deficits also impact treatment and services and influence academics, behaviors, and social interactions and treatment and services can vary (Tsatsanis, 2014).

Executive functioning. Executive functioning relates to a group of processing skills that contribute to one's ability to problem solve and guide future behaviors (Tsatsanis, 2014). This characteristic includes several processes, and there is overlap with other domains including memory and attention (Tsatsanis, 2014). The specific operations in executive functioning include inhibition, planning, self-monitoring, flexibility, set shifting, and organization (Tsatsanis, 2014). Deficit-based executive functioning behaviors in children with autism include concrete thinking, a narrow range of interests, response perseveration, disinhibition, inability to flexibly shift perspectives, and difficulty self-monitoring and planning (Tsatsanis, 2014). Children with Asperger's syndrome display deficits in cognitive flexibility and planning, but response inhibition appears to be intact (Tsatsanis, 2014). Children with Asperger's syndrome also struggle with developing problem-solving skills and resolving goal conflicts (Tsatsanis, 2014).

Intellectual ability. Research to date has consistently shown that there is a significant discrepancy between the cognitive profiles of children with autism (Tsatsanis, 2014). Children with Asperger's syndrome consistently demonstrate better verbal skills than perceptual organizational ability (Tsatsanis, 2014). There is also research that points to the neuropsychological profile of children with Asperger's syndrome being similar to that of individuals with a nonverbal learning disability (Tsatsanis, 2014). This variance between and within these two diagnoses in the intellectual ability domain speaks to the discrepant treatment and service needs (Tsatsanis, 2014).

Future directions. The categorical blurring of lines between Asperger's syndrome, ASD, and high-functioning autism continues to occur **(**Tsatsanis, 2014).

Current research acknowledges that the biological pathogenesis is multifaceted and includes various neural pathways and gene combinations (Tsatsanis, 2014). Likewise, the controversy surrounding the behavioral expression of these diagnoses and whether they are distinct or on a spectrum continues (Tsatsanis, 2014). It is imperative for future research to consider heterogeneity in the disorders as well as each of the individuals to inform the etiological and nosological pathways (Tsatsanis, 2014).

Diagnosis and Assessment

The diagnosis and assessment of autism and related disorders must evolve as the criteria for diagnoses changes over time (Mehling & Tasse, 2016; Zuddas, 2013). Diagnosis can occur by clinicians determining if the client meets the most recent DSM criteria or by an evidence-based assessment process or both which is the ideal means for determining diagnosis, service eligibility, and treatment planning (Campbell, James, & Vess, 2014; Mehling & Tasse, 2016). The assessment process can include various measures; however, each of them always has a basis in empirical knowledge and research (Campbell et al., 2014). The clinician must examine elements of reliability, validity, and norming techniques of the assessments (Campbell et al., 2014; Mehling & Tasse, 2016; Zuddas, 2013). The purpose of psychological assessments is multi-faceted and includes not only diagnosis but treatment planning and monitoring, and prognosis (Campbell et al., 2014; Mehling & Tasse, 2016).

Fortunately, the field has come to a consensus that the gold standard in assessment is a combination of the ADOS and the Autism Diagnostic Interview-Revised (Campbell et al., 2014; Hus & Lord, 2014; Zuddas, 2013). The clinical utility of the

ADOS for assisting in diagnosis and treatment planning is that it provides opportunities for presses and observation in each of the autism-associated areas (Campbell et al., 2014; Hus & Lord, 2013). The ADOS also allows for the calculation of comparison scores across age and language levels (Weitlauf, Gotham, Vehorn, & Warren, 2014). The Autism Diagnostic Interview-Revised complements the ADOS because an experienced clinical interviewer asks a parent or guardian 93 question items that focus on language/communication, social reciprocity, and restricted, repetitive, or stereotypical interests and behaviors (Campbell et al., 2014). It is important to note that there have not been revisions to either of these instruments since the release of the new DSM.

Treatment and Service Domains

Since the commencement of Asperger's syndrome as a diagnosis, there has been the development of specific services and treatment strategies; however, service and educational resources are still limited (Volkmar et al., 2014b). Just before the Asperger's syndrome merging into the autism spectrum diagnosis, there was a proliferation of parent support groups for this diagnosis as well as for high functioning autism (Volkmar et al., 2014b). Researchers asserted that this accentuates the fact that children with Asperger's syndrome had insufficient treatment such as services for children with conduct problems, academic learning disabilities, or services for children with autism at a much lower level of functioning (Volkmar et al., 2014b). The gaps in awareness and services were gradually improving, and the identification of core components necessary for treatment is continuing to develop in both the educational and community domains (Volkmar et al., 2014b). Johnson (2015) referred to these services as DSM-entitlements and asserted that there are two different DSM-linked entitlements including state-mandated autism insurance benefit and education benefits.

Education benefits. In Pennsylvania, services provided in the school setting can be from within the school itself in the form of an Individualized Education Plan (IEP) or from an approved outside agency that comes into the school to provide autism-specific services (Pennsylvania Department of Human Services, 2018). There has been an ongoing debate about the educational placement of children with an autism diagnosis (Johnson, 2015; Volkmar et al., 2014b). The self-contained versus mainstream debate is typically dependent on the availability of services in the child's geographic region (Johnson, 2015; Volkmar et al., 2014b). School districts and individual schools may or may not offer autism-specific services, and this may be dependent on a number of variables including the size of the school district (Johnson, 2015).

The Individuals with Disabilities Education Act (IDEA) in Pennsylvania was last signed in 2004 (Pennsylvania Department of Human Services, 2018). Johnson (2015) shared that entitlements in the school setting are associated with a diagnosis, and the impairment must impede both medical and educational functioning before special services will be considered under the autism disability category. Whether a child is eligible for special services depends on a number of factors including diagnosis and levels of educational impairment (Johnson, 2015). Many times parents must advocate for services for their child, and this may entail acquiring an educational advocate that is versed in educational law (Pennsylvania Department of Human Services, 2018).

State-mandated autism insurance benefits. In the western region of Pennsylvania, the counties each have a designated managed care company that approves services to be paid for by medical assistance, or the Children's Health Insurance Program (Pennsylvania Department of Human Services, 2018). Outside service providers get reimbursed to go into the school setting and provide medically necessary services with the goal of transferring skills to school staff and to the child (Pennsylvania Department of Human Services, 2018). Johnson (2015) showed what states have come on board with providing autism insurance mandates for Applied Behavioral Analysis (ABA) treatment, and Pennsylvania implemented this with the Autism Insurance Law (Act 62 of 2008).

In Pennsylvania, there is a requirement that anyone billing insurance for working with a child with an ASD have a Behavior Specialist license through the state medical board (Pennsylvania Department of Human Services, 2018). The Autism Insurance Law (Act 62 of 2008) requires that anyone working with a child with an ASD diagnosis have a minimum of a masters degree in certain specified fields, 90 hours of evidence-based coursework in eight specific content areas, 1,000 hours of clinical experience, and a full year of Functional Behavior Assessment (FBA) experience (Pennsylvania Department of Human Services, 2018). The Licensed Behavioral Specialist (LBS) is typically employed by an outside approved service provider and works in the school or home/community setting or both under the auspices of ABA techniques and interventions (Pennsylvania Department of Human Services, 2018). Additionally, if the child meets medical necessity requirements, there may also be a lesser educated support staff with prescribed hours to assist with implementing the treatment plan and facilitating skill transfer (Pennsylvania Department of Human Services, 2018).

Core Treatment Components

There are several core components essential in any treatment program for children with Asperger's syndrome including social and communication skills training, organizational skills, assistive technology, academic curricula, behavioral management, psychotherapy, and child or parent support groups (Volkmar et al., 2014b). Understanding each of these components contributes to a general understanding of the needs of a child with Asperger's syndrome and provides some insight into a mother's experiences with services.

Social and communications skills. One of the significant aspects of social disability with children with Asperger's syndrome is deficits in social and communication skills (Feather 2015; Talmadge & McAdams, 2015; Volkmar et al., 2014b). Children with Asperger's syndrome often lack insight and the ability to self-reflect which create issues with spontaneity and adjustment in interpersonal and social situations (Volkmar et al., 2014b). Training assists with preparing children with increasing their ability to make friends and become better conversational partners (Talmadge & McAdams, 2015; Volkmar et al., 2014b). Social training for children with Asperger's syndrome should include topic management, interaction flexibility, the perception of nonverbal social cues, understanding social expectations per situation, and operational knowledge of mental state language (Feather, 2015; Talmadge & McAdams, 2015; Volkmar et al., 2014b).

Organizational skills. Executive functioning is another area of shortcoming with children with Asperger’s syndrome (Volkmar et al., 2014b). Organization of activities, task completion, learning from experiences, and avoidance of counterproductive routines are all areas in which children with Asperger’s syndrome require assistance (Volkmar et al., 2014b). There are two distinct ways to approach intervention for these issues including cognitive rehabilitation computer exercises and real-life situational approaches to remediation (Volkmar et al., 2014b). The earlier focuses on the underlying neuropsychological patterns while the latter has an individualized focus on organizational skill deficits (Volkmar et al., 2014b).

Assistive technology. While there is not much documentation on the use of assistive technology with children with Asperger’s syndrome, there are computer-based resources that can adequately address many of their deficits (Feather, 2015; Volkmar et al., 2014b). Given that these children have a natural affinity with technology, this medium can promote adaption and learning in many areas (Feather, 2015; Volkmar et al., 2014). This area is severely lacking in research with autism and related disorders, and many times the parents and other treatment team members are left with the daunting task of determining how to use technology to the child’s benefit (Volkmar et al., 2104b).

Academic curricula. Children with Asperger’s syndrome have unique learning styles, and thus may require accommodations to academic curricula (Talmadge & McAdams, 2015; Volkmar et al., 2014b). Modifications to curricula should take into consideration the child’s social disability and should be flexible enough to consider the long-term goals related to the child’s future life (Volkmar et al., 2014b). Recognizing the intrinsic strengths of the child and including them into the subject matter can assist with assignment completion and increasing the child's motivation and positive self-concept (Talmadge & McAdams, 2015; Volkmar et al., 2014b).

Behavioral management. Children with Asperger's syndrome often exhibit challenging behaviors that are not malicious or willful (Feather, 2015; Volkmar et al., 2014b). Researchers suggest that it is critical to connect the behavior to the child's disability and treat them with therapeutic and educational strategies rather than discipline or punishment (Volkmar et al., 2014b). Data collection and analysis procedures should assist with collecting information on the problematic behaviors and help with determining which treatment protocol will be most useful (Volkmar et al., 2014b). Everyone in the child's life, across settings, will require training so there is consistency, and clear expectations are set for the child (Talmadge & McAdams, 2015; Volkmar et al., 2014b).

Psychotherapy and support groups. Focused and structure therapy can be useful to help children with Asperger's syndrome manage their anxiety, sadness, and negative emotions (Volkmar et al., 2014b). While insight therapy may not be sufficient, the therapist can assist the child with appropriate family functioning, social adjustment, and help with enhancing problem-solving abilities (Feather, 2015; Volkmar et al., 2014b). The therapeutic relationship can address concrete relational issues and increase the child's ability to self-manage (Volkmar et al., 2014b). Support groups can be a means for social contact in the context of activities for the parent or the child, and this may assist with finding support from individuals with similar problems (Volkmar et al., 2014b).

Psychopharmacological treatments. There are currently no pharmacological treatments that specifically address the symptom of Asperger's syndrome or autism (Westphal, Kober, Voos, & Volkmar, 2014). There is early support for some symptomatic-specific pharmacological interventions that may facilitate adjustment in children with Asperger's syndrome or autism, and these can serve as a support to the behavioral interventions (Westphal et al., 2014). Children with co-occurring disorders may already have pharmacological treatment for other diagnoses; therefore, the DSM-5 diagnostic changes may not affect this type of service. However, if they have a pharmacological treatment for symptoms of Asperger's syndrome and they lose their diagnosis or it changes there may be implications (Westphal et al., 2014).

Comparison of DSM-IV-TR and DSM-5 Criteria

The APA Neurodevelopmental Disorders Work Group (NDWG) sought to improve on the limitations of the DSM-IV-TR while preserving the strengths (Volkmar & McPartland, 2014). Over a period, researchers and clinicians reviewed scientific research and literature, reviewed feedback from others, and conducted field trials to arrive at the changes for the DSM-5 (McGuinness & Johnson, 2013). The field trials were expansive and included a scope of individuals across age, cognitive ability, and other factors (Volkmar & McPartland, 2014). After much investigation, the NDWG determined that there was a variance in the use of the diagnostic criteria for Asperger's syndrome and PDD across providers and assessment locations (Lobar, 2016; McGuiness & Johnson, 2013; Volkmar & McPartland, 2014). Overall, clinicians perceived that identification of autism and related disorders was difficult due to the significant variance in behaviors and symptoms across children's developmental levels (Lobar, 2016; McGuiness & Johnson, 2013; Volkmar & McPartland, 2014). The NDWG suggested that changing the criteria was beneficial to accurate diagnosis and treatment; therefore, the DSM-5 came out in May of 2013 with many changes to the diagnosis of autism (Lobar, 2016; McGuiness & Johnson, 2013; Volkmar & McPartland, 2014).

Before the release of the DSM-5 in 2013, clinicians used the DSM-IV-TR to render the diagnoses for the group of PDDs (Kulage et al., 2014; Levy, 2014; Lobar, 2016; McGuinness & Johnson, 2013). PDD was a separate category in the DSM-IV-TR and included autistic disorder, general PDD, and Asperger's syndrome (Kulage et al., 2014; Levy, 2014; Lobar, 2016; McGuinness & Johnson, 2013). The criteria and specific categories changed with the release of the DSM-5, and is no longer a broad category with subcategories; instead, it is a spectrum of disorders (Kulage et al., 2014; Levy, 2014; Lobar, 2016; McGuinness & Johnson, 2013). The concept of a spectrum implies that these diagnoses are not discrete; instead, they are similar and with varying presentations and severity of behaviors (Kulage et al., 2014; Levy, 2014; Lobar, 2016; McGuinness & Johnson, 2013). Based on the spectrum concept, clinicians must view these diagnoses as being on a continuum of various levels with children exhibiting mild to more severe symptoms (Kulage et al., 2014; Levy, 2014; Lobar, 2016; McGuinness & Johnson, 2013).

The DSM-5 workgroup collapsed autistic disorder, PDD, and Asperger's syndrome into a single ASD diagnosis (Kulage et al., 2014; Levy, 2014; Lobar, 2016; McGuinness & Johnson, 2013). The DSM-5 criteria also require that the child's symptoms be present from early childhood and include core symptoms and diagnostic features (Kulage et al., 2014; Levy, 2014; Lobar, 2016; McGuinness & Johnson, 2013). Another change between the DSM-IV-TR and the DSM-5 was the reduction in core domains from three categories to two (Kulage et al., 2014; Levy, 2014; Lobar, 2016; McGuinness & Johnson, 2013). The previous three domains included fixated interests in repetitive behaviors, communication, and social interactions (Kulage et al., 2014; Levy, 2014; Lobar, 2016; McGuinness & Johnson, 2013). The two new areas of focus are a behavioral domain that includes repetitive behaviors and fixated interests and a social-communication domain (Kulage et al., 2014; Levy, 2014; Lobar, 2016; McGuinness & Johnson, 2013).

The DSM-V has four major criteria including continuous impairment in interaction and communication that are reciprocal and social in nature, patterns of interests and behaviors that are restricted and repetitive, symptoms that are persistent from early childhood, and symptoms that interfere with everyday functioning (Lobar, 2016; McGuinness & Johnson, 2013; Volkmar & McPartland, 2014). The DSM-IV-TR required one symptom of fixated interests, while the DSM-5 requires a minimum of two (Dailey et al., 2014; Lobar, 2016; McGuinness & Johnson, 2013). Additionally, the DSM-IV-TR prescribed that the symptoms must occur before the age of three, and the DSM-V does not specify an age rather that they are present in early development with the caveat that there may not be detection until an increase in social demands beyond the child capacity (Dailey et al., 2014; Lobar, 2016; McGuinness & Johnson, 2013; Volkmar & McPartland, 2014). Finally, a new diagnosis, social (pragmatic) communication disorder, was introduced in the DSM-5 that reflects deficits in the social and communication arena without the additional symptom of restricted, repetitive behaviors (Dailey et al., 2014; Lobar, 2016; McGuinness & Johnson, 2013; Volkmar & McPartland, 2014).

Social (Pragmatic) Communication Disorder

Social (pragmatic) communication disorder (SPCD) is a new and differential diagnosis in the DSM-5 (Brukner-Wertman, Laor, & Golan, 2016; Dailey et al., 2014; Gensler, 2012; Lobar, 2016; Lord & Bishop, 2015; Volkmar & McPartland, 2014). The intent of the development of the new SPCD diagnosis is to recognize those children who do not exhibit repetitive and restricted behavioral patterns that are typical of children with autism (Dailey et al., 2014; Lobar, 2016; Lord & Bishop, 2015; Volkmar & McPartland, 2014). The SPCD diagnosis is in the communication disorder category rather than the autism spectrum category (Dailey et al., 2014). The most common feature of the SPCD diagnosis are deficits in the use of language that manifest in an inability to be effective in social communication and develop social relationships (Dailey et al., 2014; Lobar, 2016; Lord & Bishop, 2015; Volkmar & McPartland, 2014). The SPCD diagnosis is not often given to children under the age of four due to them being in the natural process of language development (Dailey et al., 2014).

Assessment of SPCD is difficult because, ideally, it requires capturing the dynamics of interactions in the natural social environment (Brukner-Wertman et al., 2016). The social environment where the pragmatics of social interaction would be evident including behaviors such as turn taking, eye contact, and use of humor also requires cultural sensitivity (Brukner-Wertman et al., 2016). There are limited standardized assessments for pragmatic communication, and these tests are not typically included in official psychological or psychiatric evaluations (Brukner-Wertman et al., 2016). The majority of the instruments available for assessing this diagnosis are screening tools rather than diagnostic instruments (Brukner-Wertman et al., 2016). While the teachers and parents see the child in their social environment and this assists with capturing valuable information, this is not a formal assessment framework (Brukner-Wertman et al., 2016). Therefore, there is a need for more precise specificity for this diagnosis to differentiate it from autism due to inconsistency in language between the two diagnoses (Brukner-Wertman et al., 2016). SPCD focuses on the pragmatics of language, and it is supposed to be the same criteria as the social communication cluster in the autism diagnosis; however, there is no mention of language pragmatics in the autism diagnostic criteria (Brukner-Wertman et al., 2016; Gensler, 2012). This disconnect presents a challenge when the clinician attempts to distinguish if the social communication impairments must be as intense as in the autism diagnostic criteria or if they can be milder to meet criteria (Brukner-Wertman et al., 2016; Lord & Bishop, 2015). Regardless of whether the child's diagnosis changes from Asperger's syndrome to autism or SPCD, mothers of a child with a previous Asperger's syndrome will have their experience to share and may express concerns about identity or stigmatization about service acquisition.

Identity and Stigmatization Concerns

Children with Asperger's syndrome can have a regular physical appearance, yet display pervasive behaviors that have an effect on the entire family (Gill & Liamputtong, 2011; Kite et al., 2013; Kite et al., 2011; Ohan, Ellefson, & Corrigan, 2015; Robinson, York, Rothenberg, & Bissell, 2015; Ruiz Calzada et al., 2012; Shtayermman, 2009). Before the elimination of the Asperger's syndrome diagnosis, Gill and Liamputtong (2011) shared experiences of stigma among mothers of a child with Asperger's syndrome. This experience for these mothers was more invasive than that of other disabilities because of the lack of general public knowledge and the adverse reaction to their child's inappropriate public behaviors (Gill and Liamputtong, 2011; Kite et al., 2013; Kite et al., 2011). The general expectation is that children with higher functioning autism or Asperger's syndrome should engage socially, participate in sports, and be in mainstream academic classes (Gill & Liamputtong, 2011).

Gray (2002, 1993), in his seminal work on stigmatization related to having a child with an autism diagnosis, discussed that parents feel stigmatized by other parents and the school because of their disabled child. Ruiz Calzada et al. (2012) found a theme in their research that parents of children with a diagnosis of high functioning autism or Asperger's syndrome were treated differently by others, and they avoid informing their child about the diagnosis because they did not want to create feelings of abnormality for their child. Additionally, children with Asperger's syndrome do not receive a diagnosis until an average age of 11 years old in comparison to other types of autism that typically obtain a diagnosis at age five to six years of age (Ohan et al., 2015; Robinson et al. 2015). The delay in diagnosis means that these families are more vulnerable to stigmatization and poor prognosis (Gray, 2002; Robinson et al., 2015). Positive outcomes for these diagnoses relate to early identification and intervention; whereas, later diagnosis can lead to the development of co-morbid conditions and poor health (Robinson et al., 2015). Later diagnosis also means that the parents of these children have lost essential time to acquire services, and the skills and knowledge they need to manage their child's condition (Robinson et al., 2015).

Ohan et al. (2015) maintained that stigma could hinder many aspects of services and treatment for children with Asperger's syndrome including deterring parents from seeking help for their child, increasing treatment drop out, and diminishing the importance of adherence to treatment (Ohan et al., 2015). Kite et al. (2011) asserted that feelings of stigma vary between the diagnoses and that society attaches a greater level of stigma to autism than to Asperger's syndrome. This information is critical for this study because historically parents display a sense of relief when they find out their child has an Asperger's syndrome diagnosis rather than an autism diagnosis (Kite et al., 2011). Later, Kite et al. (2013) explored education and health professional's perceptions of the DSM-5 diagnostic changes and confirmed an increased sense of stigma with the label of autism and its more severe conditions compared to Asperger's syndrome being less stigmatic and severe. Diagnostic labels produce stereotypes and stigma and may deter parents of children with a previous Asperger's syndrome diagnosis from seeking a new label of autism (Kite et al., 2013). Contrary to the concern for stigma, Ruiz Calzada et al. (2012) asserted that they had no concern about which label their child had, rather their concern was that their child has access to services. Finally, there is a great deal of concern in the literature that if or when parents do seek out a diagnosis, their child may not qualify for another diagnosis under the revised criteria and this will determine treatment and service qualification (Kite et al., 2013; Ohan et al., 2015; Robinson et al., 2015; Ruiz Calzada et al., 2012).

Mothers' versus fathers' experiences. Parents of children with autism and related disorders report higher levels of stress than parents of children with other disabilities (Reed et al., 2016). Marciano, Drasgow, and Carlson (2015) found that parents of a child with autism typically take on the role of primary caregiver or primary wage earner due to their child's special needs. Research beginning with Gray's (2002, 1993) seminal works indicated that mothers, as the primary caregivers, have different experiences than fathers of children with autism or Asperger's syndrome. Mothers of these children experience a higher level of stigma that may be connected to the mother's tendency to have concern about their family's public presentation (Gray, 1993). Later, Gray (2002) asserted that mothers of children with high functioning autism experience staring, avoidance, and rude comments.

Mothers are typically the principal caregivers of a child with Asperger's syndrome, and they usually manage the child in public settings (Gill & Liamputtong, 2011; Gray 2002, 1993; Talmadge & McAdams, 2015; Robinson et al., 2015). Talmadge and McAdams (2015) found that mothers who have a child with Asperger's syndrome rate their quality of life as lower, are more likely to seek help, have a higher prevalence for depression, and are pessimistic about their child's prognosis. The particular behaviors that contribute to the higher levels of stress for mothers include sensory sensitivities, executive functioning, and social skill deficits (Robinson et al., 2015). Robinson et al. (2015) found a significant relationship between mother's stress and child characteristics and believes this is due to the difference in the way mothers and father experience parenting stress. Mothers, as the parent who typically mediates the problems for the child, will likely be the one with direct involvement in this diagnostic change and the one who seeks to retain or acquire services.

Prevalence Rates

There has been a concern about the prevalence rates of autism since the release of the DSM-5 (Christiansz, Gray, Taffe, & Tonge, 2016; Gibbs, Aldridge, Chandler, Witzlsperger, & Smith 2012; Harstad et al., 2015; Kulage et al., 2014; Smith et al., 2015). Kulage et al. (2014) and Smith et al. (2015) conducted systematic reviews of the literature to determine the effects of the DSM-5 on autism diagnoses. Smith et al. (2015) reviewed 25 articles, and their findings were consistent with previous studies that determined that between 50% and 75% of individual with an earlier autism-related diagnosis would retain their diagnosis under the new criteria. The most significant decreases in diagnosis were among the highest functioning populations including those with a previous PDD or Asperger's syndrome diagnosis (Smith et al., 2015).

The Kulage et al. (2014) systematic review of 14 studies also found decreases in PDD diagnoses; however, the Asperger's syndrome decrease was not significant. Matson, Hattier, and Williams (2012) used two sets of relaxed DSM-5 criteria to examine prevalence rates and determined that many children who had a previous diagnosis of autism would end up in the communication category under the new criteria. Gibbs et al. (2012) found that 26 of the 111 children assessed would not meet DSM-5 criteria, and of this group, 16.6% of those with Asperger's syndrome would not meet the new criteria.

Since diagnosis is directly related to qualifying for particular services, there has been an expression of concern about retaining or qualifying for services.

DSM-5 Service Qualification

The changes to the diagnostic criteria for autism brought a deluge of concerns relative to continued diagnosis, management, and care coordination for children with autism and related disorders (Doehring & Volkmar, 2016; Johnson, 2015; Leventhal-Belfer, 2013; Lobar, 2016). Numerous factors relate to service qualification for children with autism or Asperger's syndrome including meeting diagnostic criteria, insurance approval, and educational guidelines (Johnson, 2015). Johnson (2015) maintained that the DSM-5 has been subject to significant scrutiny due to the wording and the number of criteria necessary for diagnostic satisfaction. The new DSM-5 protocol for the ASD can affect who receives a diagnosis and the social and medical services they receive (Johnson, 2015).

New diagnosis. Based on the new classifications, the child may or may not meet criteria for another diagnosis under DSM-5 standards, and this has a direct effect on the ability to acquire services specific to the needs of the child (Barton, Robins, Jashar, Brennan, & Fein, 2013; Harstad et al., 2015; Johnson, 2015; Kulage et al., 2014; Leventhal-Belfer, 2013; Lobar, 2016; Ozonoff, 2012a,b; Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012; Smith et al., 2015; Worley & Matson, 2012; Young & Rodi, 2014). An example would be a child who does not qualify due to a lack of restricted, repetitive behaviors and is therefore excluded from receiving services (Lord & Bishop, 2015). If a child only has one symptom that qualifies as a restricted, repetitive behavior, they may not receive a diagnosis and ultimately lose or be unable to attain services (Lord & Bishop, 2015). Lord and Bishop (2015) highlighted the fact that it remains unclear how school and insurance companies will address the new SPCD diagnosis, and this uncertainty has the potential of impacting the experiences of mothers, who are likely the primary caregivers. Smith et al. (2015) shared information on their study conducted after the previously discussed systematic reviews and the release of the DSM-5. They maintained that there would be a significant number of individuals who already had a diagnosis of Asperger's syndrome, PDD, or autistic disorder that will not meet DSM-5 criteria (Smith et al., 2015).

Insurance. The majority of the time the authorities that make decisions on service entitlement are unfamiliar with the needs of children with Asperger's syndrome or autism (Volkmar et al., 2014a). Often, advocacy by clinicians and other treatment team members is the only way children are eligible for services (Volkmar et al., 2014a). Insurance and managed care companies vary by state and the entitlements of children with an autism diagnosis differ state-to-state (Johnson, 2015). Doehring and Volkmar (2016) stressed that according to the most recent 2014 census, for every individual in Pennsylvania that had autism services there were two individuals who did not have services. It is probable that this gap is highest among families in poverty (Doehring & Volkmar, 2016).

Johnson (2015) maintained that treatment interventions for autism are costly and this is experienced widespread by not just insurance companies but society as a whole. For example, Applied Behavior Analysis (ABA) therapy, the most effective autism treatment, can cost up to $100,000 in just a year (Johnson, 2015). Because this type of treatment hedges between non-medical and medical, it raises questions about who is responsible for paying (Johnson, 2015). The underlying issue is how diagnosis translates into service access in each state (Johnson, 2015). Leventhal-Belfer (2013) contended that there has already been a narrowing of services for children with autism from services such as behavioral therapy, social skills groups, and family therapy to just ABA, and clinicians and others on a child treatment team need to prepare to advocate for the diverse needs of the child.

Educational services. Barton et al. (2016) provided an analysis of the autism educational assessment practices and requirements by state. Identification of autism and eligibility for educational services varies by state; however, the majority of states follow the federal guidelines in part if not totally (Barton et al., 2016). Grant and Nozyce (2013) shared that the removal of distinctions in clinical presentation has the potential to negatively impact service eligibility through the Individuals with Disabilities Act (IDEA). IDEA specifies that the evaluation for special education consideration must not rely on any single procedure or instrument; therefore, the DSM-5 cannot be the only diagnostic measure (Johnson, 2015). Johnson (2015) maintained that a special education diagnosis of autism is more difficult to get then a medical diagnosis of Autism. Therefore, if the children with a previous Asperger’s syndrome diagnosis are having difficulty meeting medical criteria for a DSM-5 diagnosis of autism then qualifying for a special education will present even more challenges (Johnson, 2015).

Literature since the Release of the DSM-5

Since the release of the DSM-5, findings from the current literature call for more research on a multitude of topics. Bent et al. (2017) asserted that since the release of the DSM-5 rates of autism have leveled and fewer children have received a diagnosis and registered for service funding. Fung and Hardan (2014) discussed the implications for patients and families, general practitioners, and autism-specific practitioners. The DSM-5 provides examples which are helpful for practitioners in understanding what symptoms to look for when diagnosing children (Fung & Hardan, 2014). Diagnostic accuracy is imperative, and when there are changes to diagnoses, the clinicians rendering the diagnoses must understand the most recent diagnostic criteria and recognize there are other means of assessment that are beneficial to diagnosis (Fung & Hardan, 2014; Lobar, 2016). Clinicians should seek out training to establish fluency in the new diagnostic criteria and prepare themselves for ensuring that the client's new diagnosis aligns with the necessary services (Lobar, 2016). Children with a previous Asperger's syndrome diagnosis will require care coordination and educational management to ensure they continue to get their needs met (Lobar, 2016).

Medical Necessity Criteria and Insurance Approval

Given the changes to the Asperger's syndrome and autism diagnoses, there are also implications for meeting medical necessity criteria and insurance approval (Doehring & Volkmar, 2016; Kulage et al., 2014). Kulage et al. (2014) provided information in their systematic review and meta-analysis that in over 50% of articles there were autism diagnosis reduction rates between 25-68% under the new DSM-V criteria. This statistic leads to concern about the number of individuals who will not qualify for various types of funding including school, state, and insurance for various levels of deficiencies in the developmental, social, and communication domains (Kulage et al., 2014). This variance relates to deviations in the methods for diagnosing autism, the diverse range of ages, and the deficiency in having a standardized means of diagnosis (Kulage et al., 2014). Kulage et al. (2014) suggested that policymakers examine ways to continue services especially since some studies found that there is a higher likelihood that toddlers would lose services, and this is a critical age when there is the highest prognosis for positive outcomes (Kulage et al., 2014).

Doehring and Volkmar (2016) stressed when the DSM and the federal government's definition of autism do not align, there can be barriers to services especially in the absence of a co-occurring intellectual disability. This may be the case with children previously diagnosed with Asperger's syndrome, and this lack of alignment will cause confusion and result in inappropriate or nonexistent educational services (Doehring & Volkmar, 2016). Some states have re-written policy to cover Asperger's syndrome clients under certain circumstances (Doehring & Volkmar, 2016). In Pennsylvania, according to the most recently gathered statistics, for every child that receives autism services, there are two that do not receive services (Doehring & Volkmar, 2016). Additionally, there are studies that suggest that this gap in services is highest among those families living in poverty (Doehring & Volkmar, 2016). With as many as 50 different autism approaches in the states at various levels, and a lack of focus on all of the aspects of autism, it is unlikely that there will be improvement soon (Doehring & Volkmar, 2016).

Summary

With the release of the DSM-5, children with Asperger's syndrome and their families have experienced a change or loss of diagnosis (Barahona-Corrêa & Filipe, 2016; Spillers et al., 2014). This change has the potential to impact many areas of the child's life. There has been a lot of expressed concern about access and continuation of services for these children (Farrugia, 2009; Fung & Harden, 2014; Marciano et al., 2015). There have been many studies both before and after the release of the DSM-5 about the prevalence rates of autism and how many children will still qualify for a diagnosis.

Johnson (2015) discussed each of the states policies and how the DSM-5 and co-occurring polices may be a threat to service access. There have been no studies to date about mothers' experiences with this change in the Asperger's syndrome diagnosis and the navigation of their child's services. In the vast majority of scholarly articles thus far, researchers have suggested the need for a more extended inquiry into this issue. Ohan et al. (2015) forwarded that it is imperative to consider other crucial stakeholders such as mental health professionals and teachers to gain a complete understanding of the issue. Likewise, there needs to be additional research with the primary caregivers whose child's diagnosis has changed from Asperger syndrome to autism.

In this chapter, I outlined a vast amount of support for a study on mothers' experiences since their child's Asperger's syndrome diagnostic change. Mahmood et al. (2015) identified both positive and negative coping strategies of mothers with children with autism, and how mothers use these coping strategies in their experience is important. Gray (2002, 1993) discussed the different ways that mothers feel stigma when their child has Asperger’s syndrome or autism. Mothers’ feelings of stigma may have an impact on how they negotiate the service process which will also affect their experiences. I provided compulsory evidence for the need for this study on mothers’ experiences as well as the alignment of my theoretical foundation. In Chapter 3, I illustrated the alignment of my plan to explore the experiences of these mothers through the use of a hermeneutic phenomenological and IPA approach. I also demonstrated how hermeneutic phenomenology and IPA relate to social constructivism.

Chapter 3: Research Method

The purpose of this hermeneutic phenomenological study was to highlight the mental health service experiences of mothers whose child had a previous diagnosis of Asperger's syndrome. When diagnostic changes occur, there is a need for sensitivity, and it is critical that there is collaboration among the treatment team so mothers can obtain the necessary services for their children (Blumberg et al., 2016; Volkmar et al., 2014a). This study helped me to understand the experiences of these mothers through the entire process from first hearing about the diagnostic change, rediagnosis, and retention or acquisition of services. Diagnostic accuracy is paramount and drives medical necessity requirements and ultimately treatment and services for these children (Volkmar et al., 2014a; Volkmar & Reichow, 2013). This study may assist understanding on multiple levels including with counselor educators as they teach and supervise counselors to understand the importance of ASD diagnostic accuracy.

In this chapter, I explain my research design and the rationale for choosing a hermeneutic phenomenological study. I describe my role in the research including personal or professional relationships and other ethical considerations that may arise. I outline my methodology including my participant selection and recruitment. Next, I identify my data collection instruments including the interview, demographic form, and personal reflexive journal. I describe in detail data analysis procedures following the IPA framework and how each connects to my identified research questions. Finally, I describe issues of trustworthiness including credibility, transferability, dependability, and confirmability.

Research Design and Rationale

The research question for this study reflected the exploration of the lived experiences of mothers with therapeutic services and support since the change in their child’s diagnosis from Asperger’s syndrome. I fully recognize that there has been speculation both before and after the release of the DSM-5 about the possibility of reductions or increases in services; however, I solely examined the experiences of mothers in navigating the process. As was evident in Chapter 2, there is a divide in the literature with some authors speculating that this diagnostic change will make the service process easier and others speculating a complete loss of diagnosis and services. This divide speaks to the importance of a study on the experiences of mothers as they maneuver this process with their children.

Research Tradition and Rationale

This study on mothers’ experiences with services since their child’s diagnostic change required a qualitative approach. Qualitative research has a basis in human experience, and it occurs in a natural setting with the researcher as the primary instrument of the study (Patton, 2015). Qualitative studies allow for the researcher to develop and structure a framework for the study, yet they are inductive, which allows the researcher the flexibility to revise throughout the study if necessary (Maxwell, 2013; Miles et al., 2014). The evolution of this study of mothers’ experiences made it clear that I needed to move away from the more rigid experimental studies and be flexible in my investigation; therefore, a qualitative study was the best fit.

More specifically, the phenomenological approach, as a type of qualitative research, is an investigation a particular phenomenon, and the focus is on how this phenomenon comes into being through the participants living in the world (Vagle, 2014). Humans do not construct phenomenological experiences; instead, they find themselves being a part of the experience in their day-to-day lives (Vagle, 2014). Phenomenologists seek to elicit the relationships between the participant's being with others and things (Vagle, 2014). The phenomenological goal is to study the lived world freely and without measures (Vagle, 2014). The mothers of these children had no input into their child's diagnosis changing yet have lived this experience since the diagnostic change. This phenomenological study provided me with a rich source of ideas about how this experience has been for these mothers (Vagle, 2014). There are many phenomenological philosophers; however, this study followed an interpretive approach rather than a transcendental one and therefore aligned with the work of Heidegger and Gadamer (Smith et al., 2012).

Hermeneutic phenomenology was the best fit for this qualitative approach because I sought to understand and interpret the meaning of the lived experience for these mothers (Kafle, 2011; Pietkiewicz & Smith, 2012; Smith et al., 2012). Hermeneutic phenomenology has an orientation towards interpreting the texts of lived experiences, and it progresses from the researcher's interest or concern for the topic to identification and the interpretation of themes (Finlay, 2009; Kafle, 2011). In hermeneutic phenomenology, the facilitation of the meaning-making process occurs in the interrelationship between the underlying dynamics and the conscious (Kafle, 2011). Understanding this dynamic and being mindful of the hermeneutic circle throughout the research process assists in the interpretation of the essence of the experience (Kafle, 2011).

Hermeneutic Circle

The use of the hermeneutic circle is relatively consistent across hermeneutic researchers and speaks to the process of achieving interpretive understanding (Gadamer, 1989; Smith et al., 2012). *Dasein*, or being with, implies that the researcher views the person in context and through an intersubjective lens considering the relational and overlapping ways people engage in the world (Smith et al., 2012). The hermeneutic circle speaks to a nonlinear style of thinking and describes the process of interpretation precisely (Smith et al., 2012). While there have been criticisms of this approach due to the inherent circularity, it is a useful way for researchers using IPA to describe their method (Smith et al., 2012). Like other approaches, the description of IPA is linear and step-by-step; however, the analysis is iterative because the researcher vacillates between ways of thinking about the data (Smith et al., 2012).

Following with the hermeneutic rule, I moved back and forth between understanding the whole in terms of its parts and the parts in terms of the whole (Gadamer, 1989). In other words, the linguistic meaning of the words in the sentence contributed to understanding the interview response and vice versa (Gadamer, 1989). Likewise, each sentence contributed to understanding meaning and interpreting the whole experience (Gadamer, 1989). Researcher consideration of the linguistic meaning assists with interpreting how the participant socially constructs their lived experience (Kordeš, 2016; Strong, 2014). The researcher, simultaneously, should be considering their relationship with the data using the hermeneutic circle (Smith et al., 2012).

Role of the Researcher

I was the primary research instrument of this qualitative investigation because I was the only person conducting the interviews (Maxwell, 2013). Likewise, I was the one compiling and analyzing the data; therefore, it was necessary to keep a reflexive journal throughout the research process (Maxwell, 2013). Maxwell (2013) asserted that the researcher identity and background could bring significant sources of insights and hypotheses to an investigation. Incorporation of the researcher's identity and experiences into their research has increased in support; however, it is critical to have a plan to manage biases (Maxwell, 2013). Including identity memos as a part of the journaling process assisted me with exploring my assumptions and experiential knowledge throughout the research process (Maxwell, 2013).

Relationships with Participants

I ensured that I had no relationships with participants before participation in this study. As a practicing clinician, I used my skills during the interview to assist in alleviating any uncomfortable situations that arose. I had a plan to make referrals if necessary during the interview and information gathering process; however, this was not necessary as my participants did not display any signs of distress. I provided a list of local resources for each participant in the event they found it necessary to find support after the interview (see Appendix B). Finally, there has also been no need for me to provide any referrals outside of our agency due to relationship issues during this process.

Methodology

According to Maxwell (2013), the methodology of a study explains how the researcher will conduct the study from beginning to end. IPA researchers have an interest in what occurs when something arises that has significance to the participant's everyday lived experiences (Smith et al., 2012). Smith et al. (2012) asserted that this happens when something of importance to the participants occurs. The diagnostic change from Asperger's syndrome to another diagnosis has significance to the mothers of children who were affected by this change. This methodology aligns with phenomenology, hermeneutics, and idiography (Smith et al., 2012). The experiences of these mothers are the result of an unexpected change in their child's diagnosis and following an IPA methodological framework allowed me to conduct semistructured interviews to elicit reflections and feelings about this lived experience (Smith et al., 2012). The IPA researcher is devoted to an incredibly detailed examination of each case; therefore, they have a smaller number of participants so they can carefully investigate the experience of each participant (Smith et al., 2012).

Participant Selection

The IPA researcher attempts to find a homogenous sample that will find the research question important and meaningful (Smith et al., 2012). The participants for this study were mothers of children age 7–17 who previously had an Asperger's syndrome diagnosis. Mothers were specifically chosen to keep the group homogenous because they are typically the principal caregiver and because their experiences differ from that of fathers (Gill & Liamputtong, 2013). I chose this age range to align with the ADOS

Module 3 and higher which requires that the child be verbally fluent (Hus & Lord, 2014). Hus and Lord (2014) posited that the ADOS is the gold standard for autism screening and is more useful for older children. Asperger's syndrome is a developmental disorder typically diagnosed in early childhood, and the purposeful choice of an older age range allowed me to interview mothers whose child had already established Asperger's syndrome supports and services (Volkmar et al., 2014a).

To ensure that my sample was in line with the qualitative method and IPA, I selected my participants purposively (Smith et al., 2012). Specifically, I was looking for insights into mothers' experiences, and probability methods would not work for this purpose (Smith et al., 2012). I accessed potential participants through the local human services agency, which is a major gatekeeper (Smith et al., 2012). I asked their personnel to distribute my flyer to service providers and directly to parents. I also used a snowballing method and had my participants refer other potential participants if necessary (Smith et al., 2012). I designed a flyer for distribution by the gatekeeper that detailed the study and supplied contact information.

To ensure that there were no personal or professional relationships with any of my participants, I solicited participants from outside my agency. I sought participants from Crawford County Human Services, which has access to every recommendation for autism services in the county and to the county service providers. Because I do psychological evaluations and make recommendations for testing and services in my county, I made it clear when soliciting participants from Crawford County Human Services that participants can never have had any previous relationship with me. As another option for participants, I sought out referrals from an advocate in our county who assists parents when they are having difficulty with services in any setting.

The saturation principle guides the selection of a sample size for qualitative research (Miles et al., 2014). Saturation refers to repetitiveness in the patterns and themes of the collected data and the idea that no further collection of data is necessary to identify themes (Miles et al., 2012; Rudestam & Newton, 2015). By qualitative guidelines, I had a sample size of six to 10 participants. Smith et al. (2012) suggested that a student project using IPA should have a sample size of three to six participants to ensure that they can develop meaningful points without being overwhelmed by large amounts of data. To ensure I did not miss essential affects, I began with a minimum sample size of six and the intention to continue through to ten to ensure I reached saturation; however, I was able to reach saturation at six participants (Rudestam & Newton, 2015).

Instrumentation

The most suitable method for IPA data collection to obtain a first-person, rich, detailed narrative of these mothers' experiences is in-depth interviews (Smith et al., 2012). In-depth interviews elicit the thoughts and feelings of the participants surrounding the lived experience (Smith et al., 2012). In keeping with the IPA requirement to evoke rich data, and my desire to allow these mothers to be able to reflect on their experience and speak freely; I used semi-structured interviews (Smith et al., 2012). Semi-structured interviews are preferable for providing the necessary space for personal discussion and rapport development (Smith et al., 2012). I audio-recorded each interview and then hand-transcribed them word-for-word. One-on-one interviews allowed for easier interview management as well as for the participants to deeply reflect on their experience and be heard by the interviewer (Smith et al., 2012). All interviews were an hour in length and occurred in a public or private space that was mutually agreeable (Seidman, 2013). Options of locations were determined in advance and included an office, a public library, or another flexible location that accommodated the participant's choices, yet would not undermine the effectiveness of the interview (Seidman, 2013). Interview transcription occurred over the shortest amount of time possible because the transcription itself is a form of interpretative activity and ensures the researcher has a working memory of non-verbal utterances and hesitations (Smith et al., 2012).

Maxwell (2013) asserted that collecting information by using multiple methods assists with expansion and complementarity of information. I requested that the mothers fill out a demographic form (see Appendix C) to assist with triangulation of data. This additional information assisted me with gaining more information about certain aspects of the study and may help to strengthen or enhance conclusions about the mothers' experiences (Maxwell, 2013).

I followed an interview protocol (see Appendix D) that provided a structured format including an opening script, interview questions, and a closing script, and ensured that I included and reviewed all ethical considerations several times (Jacob & Furgerson, 2012). The American Counseling Association (2014) puts forth ethical standards for research that require adherence. Critical ethical considerations for the interview process include entirely and thoroughly reviewing informed consent and confidentiality standards with my participants at the beginning and in the debriefing process after the interviews (ACA, 2014; Creswell, 2013; Patton, 2015).

Informed consent is paramount in the research process and minimizes risks for the research participants (Seidman, 2013). My informed consent was thorough and included an invitation to participate that described the research purpose, how I conducted the research, and for how long (Seidman, 2013). I outlined potential risks including the potential for discomfort or vulnerability they may encounter when speaking about their children's diagnostic changes (Seidman, 2013). It was made clear that their participation was voluntary and they had the right to refuse to participate or stop participating at any point without penalty (Seidman, 2013). I shared the benefits of participation including the potential for the increased understanding of the impact of diagnostic changes on mothers' abilities to keep or acquire services (Seidman, 2013). The informed consent made explicit my intent to disseminate results in written form and request permission to use the participant's words in my dissertation as well as future scholarly articles (Seidman, 2013). Finally, I provided personal contact information as well as contact information for the Walden University Institutional Review Board (IRB) governing the research project if my participants had questions about their rights or anything else about the study (Seidman, 2013).

My interview protocol (see Appendix D) included my interview questions. I used open questions that encourage my participants to talk at length about their experiences with services since this diagnostic change (Smith et al., 2012). The semi-structured nature of my interviews allowed me to begin with an interview protocol but modify if thoughtprovoking areas related to the research questions arose in participant responses (Smith et al., 2012). The interview protocol assisted me with thinking explicitly about the areas I needed to cover and plan for any difficulties that might arise (Smith et al., 2012). I phrased questions openly while ensuring they were not assumptive or leading (Smith et al., 2012). IPA guidelines suggest that an interview protocol includes six to ten questions along with prompts to complete approximately an hour interview conversation (Smith et al., 2102). I followed the following five-step process to develop my interview schedule:

1. I began by broadly defining what I wanted to elicit from my participants, and then I devised interview questions that provided an opportunity for me to answer my research questions (Smith et al., 2012).
2. I established a range of topics that my interview needed to cover (Smith et al., 2012).
3. I arranged the topics in a logical and appropriate sequence that included funneling sensitive topics to the end and determining what topics should be first (Smith et al., 2012).
4. I determined appropriate phrasing for each question and constructed open prompts for the abstract and complex questions (Smith et al., 2102).
5. I piloted my interview questions with someone and revised them as necessary to eliminate closed or leading questions (Smith et al., 2012).

Additional data sources can be beneficial to assist with contextualization and development of the data analysis (Smith et al., 2012). I triangulated data sources in this study with the inclusion of a demographic form (see Appendix C) which collected information about the mother and their child. I had the mothers complete this form before the interview, and it assisted me with supplying demographic information about my participants in the results section of the study. I also kept a reflexive journal that included identity memos and documented my behind-the-scenes thoughts and observations throughout the research process (Janesick, 2011; Miles et al., 2014). This reflexive journal allowed me, as the primary research instrument, to document my relationship with the data and research process throughout (Miles et al., 2014). Finally, the results section of this study included a summary of the journaling process.

Data Analysis

IPA is a qualitative experiential approach to data analysis that draws from phenomenology and hermeneutics (Pietkiewicz & Smith, 2012; Smith et al., 2012; Smith & Osborn, 2007). IPA is an ideal framework to analyze the data from the interview with these mothers because it connects intellectually with hermeneutics and theories of interpretation (Pietkiewicz & Smith, 2012; Smith et al., 2012; Smith & Osborn, 2007). IPA emphasizes that research is dynamic, and the researcher is in an active role in the research process because they are interested in the participant's perception of the event and not merely an objective statement (Pietkiewicz & Smith, 2012; Smith et al., 2012; Smith & Osborn, 2007).

In hermeneutics, there is always concern for interpretation; however, IPA employs a double hermeneutic in which the participant is trying to make sense of their world at the same time the researcher is trying to make sense of the participants trying to make sense of their world (Pietkiewicz & Smith, 2012; Smith et al., 2012; Smith &

Osborn, 2007). IPA is different from other approaches because it seeks to interpret how individuals perceive the phenomenon and how they are making sense of it in their personal and social world (Pietkiewicz & Smith, 2012; Smith et al., 2012; Smith & Osborn, 2007). The IPA method combines hermeneutics and interpretation (Smith et al., 2012; Smith & Osborn, 2007), which made it a good fit for this study on mothers' experiences with services since the Asperger's syndrome diagnostic changes because I attempted to make sense of their meaning through interpretation (Smith et al., 2012).

Meaning is central to analysis in IPA, and the goal is to understand the content and complexity of the meaning, not the frequency (Pietkiewicz & Smith, 2012; Smith et al., 2012; Smith & Osborn, 2011). Meaning is not immediately available in text format; therefore, the researcher must engage with the text from the interviews in an interpretive process (Smith et al., 2012; Smith & Osborn, 2011). IPA guidelines require audio recording of interviews, and the researcher produces verbatim transcripts for analysis (Pietkiewicz & Smith, 2012; Smith et al., 2012). While the IPA process is not prescriptive, the following are the suggested guidelines to assist the researcher through the IPA techniques (Pietkiewicz & Smith, 2012; Smith et al., 2012).

Step 1: Reading and Rereading

The initial step is the original transcript reading, and I read and re-read to become as familiar as possible with the text (Pietkiewicz & Smith, 2012; Smith et al., 2012; Smith & Osborn, 2011). During this initial analysis stage, I began to take notes and moved between the emic and etic perspectives or vacillated between the participant and outsider perspective (Pietkiewicz & Smith, 2012). This movement helped protect from reductionism and allowed for the development of higher-level insights (Pietkiewicz & Smith, 2012; Saldana, 2016). In this initial step, the goal of reading and re-reading is for the researcher to immerse themselves in the data (Pietkiewicz & Smith, 2012; Smith et al., 2012). Each reading added some additional details of the interview and listening to the recordings also added insights (Pietkiewicz & Smith, 2012; Smith et al., 2012). I was cognizant of how the tone of the interview developed from general, to more specific, to a synthesis at the end (Smith et al., 2012).

Step 2: Initial Noting

The second step involved the initial level of data analysis which was the most time-consuming and detailed (Smith et al., 2012). I began some initial noting in the first step and continued noting in this step (Smith et al., 2012). This step was close to being a free textual analysis which means there is no specific way to divide your notes or meaning units; however, this step was as comprehensive and detailed as possible (Smith et al. 2012). Being in the world of the participant helped me understand the why and how of the participant's responses (Smith et al., 2012). These notes and the development of meaning units were likely to describe the things that matter to the participant and what these things are like or mean to the participant (Smith et al., 2012). As these meaning units developed, I began to engage in more interpretive noting which aided in my understanding the context of the participant's lived world (Smith et al., 2012).

I conducted exploratory commenting in multiple ways including descriptive, linguistic, and conceptual comments (Smith et al., 2012). I included descriptive comments about the content or what the participant had said, and wrote or typed these comments in regular text so that it could be differentiated from the linguistic and conceptual comments (Smith et al., 2012). The descriptive content should consist of keywords, explanations, or phrases that the researcher takes at face value (Smith et al., 2012). At this basic level of analysis, I focused on what matters to the participant (Smith et al., 2012).

Linguistic comments focus on the language used by the participant, and they may be related to the content (Smith et al., 2012). I noted verbal nuances like tone, repetition, fluency, metaphors, and anything else related to the way the participant uses language (Smith et al., 2012). I noted linguistic comments in italics for differentiation from the other forms of noting (Smith et al., 2012).

Conceptual comments are more interpretive and represent the first move away from the participant's explicit statements (Smith et al., 2012). As I began to view the comments conceptually, my focus shifted at this point to how the participant understood the topics they were discussing (Smith et al., 2012). Conceptual commenting draws on the researcher's professional knowledge and experiences, and this was useful in understanding the meaning of participant's events and processes (Smith et al., 2012). The perception of exploratory commenting can be that it is stretching the interpretation; however, as long as it is the text that sparks it, it can add depth to the analysis (Smith et al., 2012). I had to remember that the analysis is about the participant and not me, and I was only using my understanding to make sense of the participant (Smith et al., 2012). De-contextualization assisted me with bringing the participant's word and meaning into focus (Smith et al., 2012). This process helped me avoid following typical explanatory scripts and allowed for an emphasis on the importance of context (Smith et al., 2012). De-contextualization entails the researcher reading the text backwards sentence by sentence to ensure they are bringing focus to the participant's meaning of their words (Smith et al., 2012). I underlined contextual noting for differentiation, and these processes can occur in parallel or as separate processes (Smith et al., 2012).

Step 3: Developing Emergent Themes

In the third step, while keeping the transcript central regarding data, I reviewed the larger data set with all of the provisional notes to develop emerging themes (Saldana, 2016; Smith et al., 2012; Smith & Osborn, 2011). Themes are extended units, which can be phrases or full sentences that identify or describe what a unit of data means or what it is about (Saldana, 2016). This shift in focus to emergent themes represented an analytic shift from the main transcript to the initial meaning units developed in the previous step (Smith et al., 2012). This third step reflected the importance of comprehensive noting in the second step because, if the notes were thorough, they would be very closely tied to the main transcript (Smith et al., 2012). Identifying emergent themes required me to focus on discrete pieces of the transcript while also recalling what was learned in the initial meaning unit step (Smith et al., 2012). This process felt awkward to me because I was beginning to break up the natural flow of the transcript and reorganizing the data (Smith et al., 2012).Up until this point, the participant had been leading data analysis, and now the focus shifted to me having a central role in analysis and interpretation (Smith et al., 2012). With each stage of IPA, I moved further away from the participant; however, I remained closely involved with the participant's lived experiences (Smith et al., 2012).

The emergent themes attached to what the participant said and my initial response and interpretation of the transcript (Smith et al., 2012; Smith & Osborn, 2011). It was imperative to remember the hermeneutic circle throughout each step of this process; the parts are interpreted in relation to the whole and vice versa (Smith et al., 2012).

Step 4: Developing Connections Across Emergent Themes

In this fourth step, I searched for connections across emergent themes (Smith et al., 2012). At this point, I moved from a chronological process to a customized system to connect the themes uncovered in the previous steps (Smith et al., 2012). Depending on the themes, my system included charting, mapping, or listing them on a piece of paper and then grouping the meaning units by theoretical ordering (Smith et al., 2012; Smith & Osborn, 2011).

At the clustering stage, it is imperative that the researcher ensures the themes continue to connect to the primary source material (Smith et al., 2012; Smith & Osborn, 2011). Smith et al. (2012) reiterated that IPA is not prescriptive, and the researcher is encouraged to be innovative. In this step, it was not an imperative that I kept all themes; instead, this is the step in which I began to focus on the research question and produced a framework that included the important and interesting aspects of the participant's experience (Smith et al., 2012).

There are two ways to look for connections in themes (Smith et al., 2012) The first was simply to type the themes in chronological order and then review the list and move themes around to form clusters of connected themes (Smith et al., 2012). Smith et al. (2012) contended that I would feel the draw of certain themes to each other in this step. The second way to look for connections was for me to print out the list of themes and cut each of them from the paper so I could use a large space to move the emergent themes around in a spatial representation (Smith et al., 2012). I put emergent themes that appeared to be parallel or similar together, and themes that were opposite of each other were placed at opposite ends of my workspace (Smith et al., 2012).

Specific Ways to Look for Theme Patterns and Connection

Abstraction involves developing super-ordinate themes which are the identification of patterns between the emerging themes (Smith et al., 2012). When using abstraction, I put similar themes together to develop a cluster with a new name (Smith et al., 2012). The super-ordinate theme came out at a higher level as a result of the clustering of similar themes (Smith et al., 2012). Subsumption is similar to abstraction except that one of the emergent themes becomes the super-ordinate theme and pulls together several related themes into one (Smith et al., 2012). In subsumption, there was no need to develop a new name; instead, I retained the identified emergent theme name which subsumed the other themes (Smith et al., 2012).

Another specific way to look for patterns and connections in the emergent themes is polarization (Smith et al., 2012). Polarization provides another higher level of analysis and data organization (Smith et al., 2012). It was worthwhile for me to specifically read the interview transcript and look for oppositional relationships or differences (Smith et al., 2012). An example of polarization was to look for how the interviewee identifies the negative aspects versus the positive aspects of a particular experience (Smith et al., 2012).

Contextualization involves identifying the temporal, cultural, or narrative aspects of the data analysis (Smith et al., 2012). I found these elements throughout the interview, and I proactively highlighted the themes that related to particular life events or moments (Smith et al., 2012). An example in this particular research was when the mother first heard about the diagnostic change. I then organized the emergent themes in relation to the location of temporal moments in the transcript (Smith et al., 2012).

Numeration of themes involves recognition of the frequency that themes occur in the data (Smith et al., 2012). While numeration is not the only indicator of the importance of themes, it assisted me with determining the relative importance of some themes in the data (Smith et al., 2012). Numeration can seem like a quantitative technique; however, it is a patterning of the themes and assisted with determining the relevance and importance to the participant (Smith et al., 2012).

Determining the function of emergent themes allowed me to form a deeper interpretation of the data (Smith et al., 2012). This way of analyzing may seem like it is separating the participant and their way of thinking; however, the use of language is connected to the meaning and thoughts of the participant (Smith et al., 2012). This type of analysis draws from narrative and discourse analysis, but in IPA they are combined with my commitment to the participant's experience (Smith et al., 2012). This type of analysis respects the complexity of theme relationships and how the interviewees present themselves in terms of meaning (Smith et al., 2012).

When I was comfortable that I had exhausted pattern exploration and connection, I documented the exact steps I took to conduct the analysis (Smith et al., 2012). Keeping a reflexive journal was one way I ensured an accurate compilation and explanation of the exact process (Smith et al., 2012). As indicated previously, IPA is not prescriptive, and the strategies are not mutually exclusive (Smith et al., 2012). I determined what worked for this study and the material I had (Smith et al., 2012).

I then developed a table of themes for each respondent and compiled a master table of super-ordinate themes (Smith et al., 2012; Smith & Osborn, 2011). Determining which themes make the master table was challenging and required me to prioritize data based on text richness and how well it highlighted themes (Smith et al., 2012; Smith & Osborn, 2011). I annotated each theme with the transcript page number and line location, so I could refer back to the source of the theme if necessary (Smith et al., 2012). Using Word files or creating a framework of themes on a computer are other options for assisting with data analysis (Smith et al., 2012). I then wrote up a final statement outlining the meanings inherent in the participant's experiences (Smith et al., 2012; Smith & Osborn, 2011).

Step 5: Moving to the Next Case

I moved to the next participant's interview transcript and repeated the process (Smith et al., 2012). I reviewed each transcript individually and bracketed the emerging ideas from all previous transcripts while working on the others (Smith et al., 2012). I allowed new themes to emerge with each case, and while it was inevitable that there would be influence from the previous cases, I recognized hermeneutic parlance and the changing of the fore-structures (Smith et al., 2012). This process continued for each of the transcripts (Smith et al., 2012). At the conclusion of each analysis, I developed a table representation of the themes for each case (Smith et al., 2012).

Step 6: Looking for Patterns Across Cases

The final stage of analysis in IPA required me to look for patterns or themes across cases (Smith et al., 2012). I laid the previously developed tables or graphic representations on a surface so they could all be seen (Smith et al., 2012). This task was creative and assisted with the data analysis by moving to a more theoretical or higher order conceptualization of super-ordinate themes (Smith et al., 2012). At this point, I chose to use concept mapping to assist with data analysis. Shared qualities became evident, and I then developed a table of themes displaying connections among the group as a whole (Smith et al., 2012).

Trustworthiness

Trustworthiness in qualitative research encompasses strategies to ensure that the research project is credible, dependable, transferable, and confirmable (Maxwell, 2013; Rudestam & Newton, 2015). Rather than seeking validity, I attempted to ensure that my results were trustable, believable, and replicable (Maxwell, 2013). There were several ways that this study ensured trustworthiness including reflexive journaling, triangulation, an audit trail, ensuring saturation of data, and member checking (Rudestam & Newton, 2015).

Credibility

Credibility in my research process and findings occurred through triangulation of data from multiple sources including my demographic form, semi-structured interviews, and information in my reflexive journal (Rudestam & Newton, 2015). I also conducted member checks after analysis to ensure that I captured and interpreted my participant's information accurately (Rudestam & Newton, 2015). Member checking assisted with credibility and allowed the opportunity for clarification or expansion of interpreted data (Rudestam & Newton, 2015). My use of the hermeneutic circle and a reflexive journal assisted with taking the necessary precautions to ensure that my personal biases did not taint this study (Kafle, 2011).

Transferability

Transferability, also known as external validity, entails the researcher's use of thick description throughout the research process (Miles et al., 2014). Thick description includes the researcher's efforts to fully explain all research processes and the limitations of attempting to generalize to other contexts or settings (Miles et al., 2014). My research findings included enough information for readers to determine transferability and appropriateness for other settings (Miles et al., 2014). Finally, I ensured that my findings connect to my theories and are replicable in other studies (Miles et al., 2014).

Dependability

To establish dependability, I ensured that the research process was consistent, congruent, and stable across time and methods (Miles et al., 2014). My committee members assisted me to make certain that my paradigms are all clear and in alignment. I kept an audit trail through each step of the research process including process notes in my reflexive journal and evidence of every step of data analysis (Rudestam & Newton, 2015). I provided an explicit explanation of my role and status in the research throughout the study (Miles et al., 2014).

Confirmability

I explained each step of my research process in detail to ensure that others could follow the sequence of my data collection and process of analyzing (Miles et al., 2014). I included sufficient detail so that my study could be successfully audited by an outside source (Miles et al., 2014). I considered alternative explanations and fully expected to hear variance in experiences among my participants (Miles et al., 2014). My reflexive journal included my assumptions, biases, and how they were managed throughout the research process (Miles et al., 2014).

Ethical Procedures

As a member of ACA and a state-licensed practitioner, I adhered to the ACA Code of Ethics (2014) which places vital importance on ethical conduct in all research activities. I strictly adhered to section G on research and publication including responsibilities, rights of research participants, managing and maintaining boundaries, reporting results, and publications and presentations (ACA, 2014). Likewise, as a student at Walden University, I followed all IRB requirements for institutional research and protection of my participants. The IRB requires completion of the National Institute of Health (NIH) Office of Extramural Research web-based training course Protecting Human Research Participants, and I received certificate number 1255494 on 9/21/2013. I recognized that this was only good for a period, and I would need to retake this course if I was still collecting data in September.

The informed consent process occurred at the onset of data collection, and I thoroughly explained the purpose, procedure, benefits, format, and intent to disseminate information (ACA, 2014). I made sure that my participants understood that they can decline to participate or choose to withdraw from the research at any time without penalty (ACA, 2014). Maintaining confidentiality is of utmost importance, and I ensured that my participant's identities were kept private throughout the research process by not connecting individual responses with identifying information (ACA, 2014). I maintained hard copies of demographic forms and transcripts in a locked file cabinet, and I protected electronic files with a password on a computer. I will destroy data after a period, and only I, my committee, and the IRB will have access to the data.

Bias-free writing is extremely critical throughout the research process (Rudestam & Newton, 2015). My interview questions related to experiences with services for their children, and depending on what the experience has been for each of them; they may have viewed it as a sensitive or emotional topic. I took necessary precautions to ensure that my participants did not experience distress; however, if they did, I prepared for necessary referrals to an appropriate resource (Walden University, 2016). Vulnerable populations are another consideration; however, I chose mothers rather than children as participants (Walden University, 2016). The mothers used their child's name in the interview process, and I maintained the confidentiality of the child by using only a letter to identify them in the transcription process. As indicated previously, I will ensure that I had no previous relationship with my participants to make certain that I remained within IRB ethical guidelines.

Summary

This qualitative study followed a hermeneutic phenomenological design to help us understand mothers’ experiences since the changes in their child’s Asperger syndrome diagnosis. As the sole researcher, I was the main instrument in this qualitative study, and I used semi-structured interviews, a reflexive journal, and demographic forms to collect data. I used IPA as the main framework for data analysis, and I ensured that this study is trustworthy and followed all ethical procedures.

Chapter 4: Results

Introduction

The purpose of this hermeneutical phenomenological study was to help understand mothers' experiences with services and supports after their child's diagnosis changed from Asperger's syndrome to ASD. This diagnostic change occurred as a result of changes to criteria in the DSM-5. I initiated this research recognizing that the mothers may share information about increases or decreases in services; however, the intent was to have them share how this contributed to their experience of this diagnostic change. This information will inform all systems involved with diagnostic changes about the importance of being sensitive and aware of the needs of all stakeholders including the mothers and their children. Additionally, by understanding the needs associated with diagnostic changes of this sort, counselors and counselor educators can take a more active role in ensuring knowledge sharing and education of all systems involved with services including the schools, outside service providers, and insurance companies.

In this chapter, I provide details of the setting and demographics of my study. I then share my data collection process and the steps involved in analyzing the data following the IPA framework. Lastly, I provide evidence of trustworthiness and present my study results.

Setting

I presented my study participants with the option of several private interview locations including an office or a public library conference room. I also allowed them to offer suggestions on the time and place of the meeting to accommodate their choices and schedule. Five of the six participants chose to use a private office location, and the sixth participant requested that I come to her home and conduct the interview in a private office area within her home. While I was hesitant to do this at first, in keeping with Seidman's (2013) suggestion of ensuring the interview space is mutually agreeable, I consented to this location. I did ask questions to ensure that this location would not undermine the effectiveness of the interview and data (Seidman, 2013), and she assured me that it was private and that she was comfortable with the area. Additionally, I ensured my safety by calling my office as I arrived at the participant's home and again when I was departing the home after the interview.

Demographics

The demographic classifications of each of the study participants appear in Table 1 below. This study consisted of six mothers ranging in age from late 30s to early 50s who all resided in Pennsylvania. Each of the six participants met the study's criteria by having a child between the ages of 7 and 17 with a previous Asperger's syndrome diagnosis. Four of the six mothers had two children with a previous Asperger's syndrome diagnosis.

Four of the six mothers were married, and the other two identified as single or divorced. In the ethnicity category on the demographic form, five of the six study participants either self-identified as White or Caucasian, while one identified as Hispanic. The actual age range for the six mothers was 39-52. The number of children per participant varied from two to five. Educational attainment varied among the participants with the lowest level being a high school diploma and the highest being a master's degree. Likewise, occupations varied among the participants and included a homemaker, a home health care worker, an adoption caseworker, a licensed professional counselor, a teacher, and a vice president of a home medical supply corporation.

The ages of the mothers' children identified for this study with a previous Asperger's syndrome diagnosis were 11, 14, 14, 14, 15, and 17. As indicated previously, four of these mothers had another child who was either previously diagnosed with Asperger's syndrome or had been diagnosed with autism since the diagnostic change and would have had a previous diagnosis of Asperger's syndrome. Two of the mothers had a child with a younger sibling who had an autism diagnosis, one had an older child with a previous Asperger's syndrome diagnosis, and the fourth had a child diagnosed with autism since the change; however, the mother believed that she would have been diagnosed with Asperger's syndrome previously. This information is essential because it contributes to their experience with this diagnostic change.

Table 1

Study Participant Demographics

Participant	Occupation	Marital status	Age	Ethnicity	# of children	# of children diagnosed with Asperger's / autism	Age of initial diagnosis	Current age
M1	Homemaker	Married	39	Hispanic	5	2	6/4	14/6
M2	Home health care	Married	45	White	3	2	6/7	15/21
M3	Adoption caseworker	Married	40	White	3	1	4	14
M4	Licensed professional counselor	Divorced	47	Caucasian	3	2	5/11	11/12
M5	Teacher	Married	44	White	2	2	7/14	7/14
M6	VP of home medical	Single / Divorced	52	White	2	1	2	17

Data Collection

I began data collection by sending an e-mail to Crawford County Human Services announcing that I had IRB approval (Walden approval no. 06-06-18-0405894). I requested that they forward the recruitment flyer to their e-mail list as well as hang the flyer attached to the e-mail on bulletin boards in the human services complex. My initial recruitment flyer indicated that my age range was mothers of children ages 7–11. I initially received several emails of interest from mothers whose child was over the age of 11. I also received verbal feedback from several autism service providers in the county that if I used my specified age range of mother's children who are 7–11, the mother's child would have had to have received a DSM-IVTR Asperger's syndrome diagnosis between the ages of 3–7. They shared that the younger of that age range would likely have received a DSM-IV-TR pervasive developmental disorder (PDD) diagnosis rather than an Asperger's syndrome diagnosis. Autism service providers suggested that I widen my age range to allow for mothers with children ages 7–17 to share their experiences with support and services since this diagnostic change. I submitted a revised IRB application and received approval for the changes 2 weeks later. I then reached out to the mothers who initially expressed interest to let them know that I was requesting permission to broaden the age range.

As soon as I received IRB approval for the changes, I immediately emailed the mothers who had expressed interest and resent the revised recruitment flyer to the Crawford County Human Services office. The Behavioral Health Rehabilitation Services county coordinator forwarded it to all service providers announcing the expanded age range. Within a few days, I received e-mails of interest, and I responded to each interested participant within a 24-hour period. I sent my informed consent form to each respondent attached to my e-mail response. I requested that they read the informed consent, and I advised that if they were still agreeing to participate to respond in an e-mail indicating their continued interest. I offered my available times for the face-to-face interviews in the return e-mail, and I also solicited phone numbers so that we could discuss and schedule our meeting and choose an agreeable location. In the phone call, I reiterated the information in the informed consent and confirmed the date, time, and place for our interview. I thanked each respondent at the end of the phone call and requested that if the need for a schedule change arose that they let me know via a phone call, e-mail, or a text message.

Each of the six semistructured interviews I conducted included an initial period to complete a demographic form (see Appendix C), review informed consent in detail, obtain signatures, and answer questions. The actual interviews lasted between 40 and 50 minutes. The final time spent with the participants included reviewing informed consent again, thanking them for their participation, and ensuring they agreed to review a summary of the interview to ensure accuracy. I audiotaped the six interviews using an RCA Digital Voice Recorder with a USB that allowed me to immediately transfer the audio files onto my password-protected computer and then into a password protected file. I also kept the audio file on the recorder and put it in a locked file cabinet.

Before the beginning and after each of the interviews, I made entries in my reflexive journal which included my thoughts and experiences surrounding the interview and participant and thoughts about modifications necessary for future interviews (Maxwell, 2013). I also used the journal to explore my assumptions and experiential knowledge to manage my biases surrounding the content of the interview (Maxwell, 2013). Additionally, I made reflexive notes in my journal about any necessary alterations to question order or wording. My reflexive journal was an asset to this process because it allowed me to control my subjectivity and reactivity to the information shared in the interview (Maxwell, 2013). I reflexively discussed in my journal how my role as the researcher conducting the interviews might have influenced the informant responses (Maxwell, 2013). I learned early in the interviews that my topic and questions were significant to the participants. Seidman (2013) pointed out that it may be necessary to redirect participants back to the research questions, and I found myself doing this by requesting that they try to focus on the questions I was asking and provide the specific details of their experience with the diagnostic change. Seidman (2013) suggested that following up on participant responses was an essential aspect of interviewing, but the interviewer should be careful not to interrupt. I found myself interrupting on one occasion in the first interview to pursue an interesting point, and this was one example of an entry made in my reflexive journal.

I relied on the interview protocol (see Appendix D) that I developed to guide me through the open-ended interview questions and elicit the rich data that I was seeking (Maxwell, 2013; Smith et al., 2012). I took very few notes during the semistructured interview so that I could easily monitor the well-being of my participants and check in to determine if they appeared to be distressed. I took brief notes, and I asked them follow-up questions on the areas in which I wanted more information. I was mindful to not interrupt after the first incident. My open-ended questions allowed for gathering rich data about the mothers' experiences with support and services since this diagnostic change (see Smith et al., 2012). Many times throughout the interviews, I asked what particular aspects of the experience were like for the mothers. Seidman (2013) asserted that when the researcher asks this question, it allows the participant to reconstruct what was important to them about their experience without being guided by the interviewer. Likewise, Smith et al. (2012) maintained that as the interview progresses, there should be a shift towards asking for concrete details about the experience as well as the associated feelings and thoughts. I consciously addressed what I thought I understood by asking for the participant to provide more information (Smith et al., 2012).

Many of my questions evoked emotion, and I allowed for silence and gave the participants time to engage in inner reflection before they responded (Seidman, 2013). Given the historical stigma of Asperger's syndrome, I had to keep my participants focused on their experience with support and services since the diagnostic change because they wanted to elaborate on their entire experience with this diagnosis. I was careful not to appear dismissive of the importance of their overall experience with the diagnosis, and I gently guided them back to the purpose of the interview (Seidman, 2013).

I included member checking as the final part of the collection process by allowing each of the participants to review a summary of their themes from the interview (Maxwell, 2013). Maxwell (2013) maintained that member checking is the most critical way of ensuring understanding and identifying interviewer biases and misunderstandings. The brief summaries that I provided to the participants for review included a summary of the specific informative themes that I was using from their interviews. Seidman (2013) suggested that limiting the information to what concerns the participant ensures that information is presented accurately and does not make the participant vulnerable. The six participants agreed with the accuracy of their thematic information I chose to include.

Data Analysis

I followed the entire IPA data analysis procedure with each interview before proceeding to the next interview (Smith et al., 2012). This systematic IPA procedure allowed for individuality and ensured that I allowed new themes to emerge with each participant’s interview (Smith et al., 2012). Bracketing refers to the suspension of the researcher’s pre-determined judgments and experiences to allow for a complete focus on what each participant is relaying (Smith et al., 2012). Bracketing, while controversial in interpretive phenomenology, does have a place in IPA due to the researchers need to begin each interview uncontaminated by what they heard in the previous interview (Smith et al., 2012). In IPA, the interpretation evolves as the researcher proceeds through interviewing and analysis and moves further away from each individual transcript (Smith et al., 2012). I used my reflexive journal to bracket ideas about each interview between every step of transcript analysis as well as before moving to the next interview (Smith et al., 2012).

Step 1: Reading and Rereading

I began the data analysis process by listening to each of the recorded interviews within a 24-hour period to ensure that my interviewing technique was effective (Smith et al., 2012). I made notes in my reflexive journal as I listened to the interview. The timeliness of this process allowed me to make any necessary changes to interview timing, the location of the recorder and participant, and question wording and order (Smith et al., 2012). I completed a verbatim transcription of each of the interviews using the RCA Digital Voice Manager Software. This software allowed me to slow the recordings down to ensure that I was able to capture every utterance of the participant.

The next step in my data analysis included listening to each of the recordings while reading my transcript several times to ensure that I had not missed anything. By reading and re-reading my transcripts, I assured that the participant was the focus of my analysis (Smith et al., 2012). I was mindful to go through this step of the data analysis process slowly and deliberately to ensure that I followed the Smith et al. (2013) IPA protocol and immersed myself in the data. Smith et al. (2012) contended that this part of the analysis process could be overwhelming to the novice researcher due to the number of ideas and possible connections generated. I used my reflexive journal to note my first impressions and feelings which assisted in keeping my focus on the participant and the data (Smith et al., 2012). I actively engaged with the data through repeated reading, and this engagement allowed me to assimilate the entire interview from beginning to end (Smith et al., 2012).

Step 2: Initial Noting

After I completed the reading and re-reading until I felt immersed in the data, I began to make initial notes on the language and content at a variety of levels including descriptive, linguistic, and conceptual (Smith et al., 2012). I used my computer to make initial comments on the transcripts, and I remained open-minded and made notes on anything of interest including the way the participant spoke and thought about an issue (Smith et al., 2012). My goal in this step was to determine what mattered to the participant about their experience and what their experience with services and support was like for them (Smith et al., 2012). I initially underlined important text, and then made descriptive notes to describe the participant's emotional responses and the meaning they made of their experience (Smith et al., 2012). Linguistically, I noted things such as laughter, silence, repetition, tone, analogies, and metaphors (Smith et al., 2012). With conceptual noting, I moved away from the participant's meaning and toward an interpretive reflection of my pre-understandings and my new understandings as a result of what the participant shared (Smith et al., 2012).

Social constructionism. During the initial noting step, I paid particular attention to the use of socially constructed language and how this affected the mothers terms of reference (Smith et al., 2012). The mothers' ongoing involvement with the diagnosis of Asperger's syndrome and then the diagnostic change were not static and many times were paradoxical (Smith et al., 2012). The mothers expressed themselves linguistically, and it was apparent that their experience to date was a crucial factor in how they were experiencing the current diagnostic change (Smith et al., 2012).

Step 3: Developing Emergent Themes

The next step of analysis involved working with the larger data set which included the original transcript as well as the provisional notes I made in step two (Smith et al., 2012). In this step, my focus was to reduce the volume of the data while preserving the quality of patterns and relationships (Smith et al., 2012). I shifted my attention to my notes, which were representative of critical individual pieces of the primary transcript, to identify emergent themes (Smith et al., 2012). In this step, I took a more central role and moved away from the participant (Smith et al., 2012). To turn my notes into themes, I took the participant's original words and my interpretations and developed phrases that represented the essence of the participant's experience (Smith et al., 2012). I also used my computer for thematizing in this step (Smith et al., 2012).

Step 4: Searching for Connection Across Emergent Themes

Until this point, I had followed a chronological order from transcript beginning to end to make my initial notes and then to develop the emergent themes (Smith et al., 2012). In this step, I moved away from the chronological order of the themes and abstractly charted and mapped the themes to determine how they fit together (Smith et al., 2012). My goal in this step was to compile all of the emergent themes into a design that depicted the most meaningful and interesting aspects of the participant's experience with support and services (Smith et al., 2012).

I used my computer, as well as pencil and paper, to assist with finding the connections across themes. I initially made handwritten lists of all of the emergent themes, and then I made a typed list of related themes, as well as a list of those that were divergent (Smith et al., 2012). I noted the frequency each theme surfaced in the interview in the typed list (Smith et al., 2012). I made a note of both positive and negative representations made by the participants (Smith et al., 2012). I then moved back and forth between the transcript and the themes by typing every theme into a list in a new document and then pulling the participant's statement that represented the theme into the document (Smith et al., 2012). Next, I moved all of the similar themes together and determined if any themes were enough alike to be placed together (Smith et al., 2012). Smith et al. (2012) asserted that the researcher should make a graphic representation of the emergent theme structure in the form of a table of themes for each participant as well as a master table of themes. I created an emergent theme table for each participant as well as a master table of themes.

Step 5: Moving to the Next Case

In step five, I moved to each of the interviews in the order they were conducted and repeated each of the preceding steps in the IPA data analysis process (Smith et al., 2012). I wrote in my reflexive journal and made every effort to bracket the emergent ideas from the previous transcripts (Smith et al., 2012). I maintained a commitment to the idiographic process by being thorough and systematic while also committing to view every participant's experience individually (Smith et al., 2012). I allowed new themes to emerge in each transcript and systematically followed each step of the IPA process for each participant (Smith et al., 2012).

Step 6: Looking for Patterns across Cases

My process of looking for patterns across cases included bringing all of the participant's tables of themes together and comparing across them (Smith et al., 2012). I initially printed hard copies of the thematic tables, compared them, and made notes about similarities. I then organized them by color-coding them on the computer, and then I pulled like themes into a master table of themes. My master theme table represents connections and themes for all of the participants as a whole (Smith et al., 2012).

By following the comprehensive IPA data analysis structure, I identified three main themes, twelve emergent subthemes, and seven super-ordinate themes. The three main themes that emerged to support my research question included the support during the process of obtaining a new diagnosis, insurance-funded services, and educationally-funded services.

I identified two emergent subthemes for support during the process of obtaining a new diagnosis including the public's perception and a lack of education and information. The public's perception emergent subtheme had two supporting super-ordinate themes including the concept of mental retardation and the stigma of being a bad parent. It is important to note that the concept of mental retardation was specific words used by the participants and not my interpretation. The lack of education and information main theme had five super-ordinate themes including the inconsistent source of information, initial reaction, concern for all parents/children, desire to educate and advocate, and concern about a loss of services.

The insurance domain had five emergent subthemes including difficulty navigating, lack of community autism-specific services, lack of provider training and knowledge, insurance denial due to not having classic autism symptoms, and assignment of alternative diagnoses. The educational domain had five emergent subthemes including school staff lack of knowledge and understanding, teacher cooperation and understanding, lack of school autism-specific services, alternative schooling, and the need to advocate for special services. I presented the results of my study by identifying each theme and providing direct quotes supporting the themes from the participants. To maintain participant confidentiality, I identified each participant by an "M" to indicate mother with a corresponding number.

Evidence of Trustworthiness

It is imperative that qualitative research is evaluated with criteria that are appropriate and offers a variety of ways of establishing the quality of the research project (Miles et al., 2014; Smith et al., 2012). Smith et al. (2012) offered Yardley's criteria to assess IPA studies. Yardley's criteria include four principles to evaluate the integrity of qualitative research including sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance (Smith et al., 2012). Likewise, credibility, transferability, dependability, and confirmability are common indicators of superiority in qualitative research (Miles et al., 2014). I will describe in detail my adherence to all of these trustworthiness measures.

Yardley's Standards of Quality

My sensitivity to the context of this research began in the initial stages and included a comprehensive literature review, my choice of the IPA method, my self-awareness throughout the interview process, and my disciplined focus on how I could make sense of how my participants are making sense of their experiences (Smith et al., 2012). I displayed a commitment to the sensitivity of the interview context and ensured the comfort of my participants (Smith et al., 2012). I conducted in-depth interviews and maintained rigor by digging deeper into the participant's statements to ensure quality and depth in research findings (Smith et al., 2012). I ensured that I maintained a complete audit trail to establish transparency, and I have described my entire research process in detail (Smith et al., 2012). I coherently explained the themes and relationships among them as well as the underlying theoretical assumptions (Smith et al., 2012). The impact and importance of this research were initially justified in the proposal and were reiterated in the provision of recommendations and implications (Smith et al., 2012).

Credibility

Maxwell (2013) maintained that triangulation involves collecting data using a variety of methods. Triangulation reduces the risk of bias and increases the researcher's ability to assess the generality of participant explanations (Maxwell, 2013). In my research, triangulation of data sources occurred through the use of interview transcripts, a participant demographic form, and my reflexive journal (Maxwell, 2013). I employed member checking by requesting that respondents validate a summary of their themes used in the data analysis (Maxwell, 2013). All of the six participants endorsed the summary of their themes. I used the hermeneutic circle and a reflexive journal to assist with taking the necessary precautions to ensure that my personal biases did not taint this study (Kafle, 2011). The use of the hermeneutic circle occurred with me moving back and forth between the entire interview transcript, notes, themes, and super-ordinate themes to understand and interpret the mothers' experiences with this diagnostic change (Smith et al., 2014).

Transferability

While qualitative research is not generalizeable, there are processes that the researcher can follow to ensure transparency so that the reader can transfer their processes to other contexts (Miles et al., 2014). I used several research methods to ensure transparency. I followed an interview protocol to ensure consistency in questions, while still allowing the flexibility to add or change questions as needed to ensure my research question was answered, which is essential to IPA analysis (Smith et al., 2012). I maintained an audit trail in my reflexive journal, and I provided detail of every step of my research process to ensure my study was replicable (Miles et al., 2012). I explained the limitations with generalizing to other settings, yet provided enough information so that my readers could determine the appropriateness of transferring to different settings (Miles et al., 2014).

Dependability

I ensured that my research process is consistent, and I collected rich data by conducting intensive interviews and transcribing them verbatim (Maxwell, 2013). The interviews were very detailed and provided a complete depiction of the participant's experience (Maxwell, 2013). I have relied on my committee members to provide feedback on the alignment of my paradigms, and I have explained my role in the research process (Miles et al., 2014).

Confirmability

I included enough detail about the exact steps of my research process to ensure others can follow it, and if necessary, an outside source could conduct an audit of my research method (Miles et al., 2014). I remained open to opposing interpretations, and I shared variances in participant experiences (Miles et al., 2014). I maintained a reflexive journal throughout every step of the research process to reduce bias and allow me to begin each participant's data analysis with a fresh perspective (Maxwell, 2013).

Results

The research question for this study was what the lived experiences are relating to services and supports of mothers with a child whose previous Asperger's syndrome diagnosis merged with ASD? It is critical to understand the entire process that these mothers encountered with this diagnostic change. In my data analysis, I found three apparent main themes related to mothers' experiences including the support in the process of obtaining a new diagnosis, insurance-funded services, and educationally-funded services. In the process of directing the interview from general to specific, I found twelve emergent subthemes (Smith et al., 2012). Following the unstructured interview approach allowed me to ensure that I got more than the key topics that I identified in my interview protocol (Smith et al., 2012). In addition to the emergent subthemes, I also gathered seven super-ordinate themes that were neither anticipated or expected (Smith et al., 2012). See Table 2 for a master list of all of the emergent themes.

Table 2

Master List of Emergent Themes

Asperger's syndrome diagnostic change support and service main themes			
Process of obtaining a new diagnosis		Insurance-funded services	Educationally-funded services
Emergent Subthemes			
Lack of education / information	Public's perception	Difficulty navigating	Lack of school staff knowledge/understanding
Superordinate themes	Superordinate themes	Lack of community autism-specific services	Teacher cooperation / understanding
Inconsistent source of information	Mental retardation	Lack of provider training/knowledge	Lack of school autism-specific services
Initial reaction	Stigma of bad parenting	Denial due to not having classic autism symptoms	Alternative schooling
Concern for all parents/children		Assignment of other /alternative diagnoses	Need to advocate for special services
Desire to educate/ advocate			
Concern about loss of services			

Main Theme: Obtaining a New Diagnosis

In my participant interviews, I asked them to answer the following questions about the initial support they received when this diagnostic change occurred, and they sought out a new diagnosis:

- When and how did you first hear about the Asperger's syndrome diagnostic change?
- What has your initial reaction to the change in your child's diagnosis?
- What has been your experience with your child receiving a new diagnosis?

Given the diversity in the group and the resources available to them, the source of information about this diagnostic change varied; however, the mothers' experiences with obtaining a new diagnosis had many common features. Mothers with a child with a previous Asperger's syndrome went through a process to obtain their child's initial diagnosis, and now the Asperger's syndrome diagnosis that was a turning point to understanding and services for their child, no longer exists (Robinson et al., 2015).

Emergent Subtheme 1: Lack of education/information. There have been consistent calls for more education and information about the Asperger's syndrome diagnosis (Gill & Liamputtong, 2011; Robinson et al., 2015), and this void in information-sharing is also evident in the participant's responses with the changes to this diagnosis. In this research, I found that (1) there was no consistent source of information about the diagnostic change, (2) the mother's initial reaction was unsettling, (3) there was an expression of concern for all families, (4) the mothers had a desire to educate and advocate for others, and (5) there was a concern about loss of services.

Superordinate Theme 1: Inconsistent source of information. There was no consistency with the source of information about this diagnostic change. Each of the mothers heard about the change from a different source ranging from the internet and professionals working with their child to a just general conversation. For example, M2 shared, "I had my son reevaluated, and they were telling me that there's really not anything such as Asperger's syndrome anymore, it's underneath the autism spectrum now." Some of the mothers could not remember exactly how or where they had heard it, and M5 stated,

> Oh, I’m not really sure. Uumm, probably at some point when my seven-year-old was starting to show signs of potentially being on the spectrum or having some ADHD, some diagnosis. I think that it must have been then. I can't pinpoint it. It may have been during something online too. I may have found it online.

Alternatively, M6 recalled, “I heard it in a conversation with someone.”

Superordinate Theme 2: Initial reaction. There was a clear pattern to the mothers’ explanations of their feelings surrounding first hearing about the diagnostic changes. The mothers’ initial reactions to these changes were unsettling and included confusion, lack of understanding, and blame. I asked the mothers to share their initial response and feelings related to hearing about the changes to the Asperger’s syndrome diagnosis, and M1 was initially confused and stated:

> I remember that, and it didn't make sense to me. I feel Asperger's is unique in its own, its own way, and it doesn't fit the umbrella, it's kind of like trying to put tea and coffee together. Might be slightly similar in ways, they have caffeine, whatever but they're not saying autism. Autism is its own thing. Asperger's is absolutely its own thing. When you, when you take it and throw it in there with autism you hear more of that kid doesn't have autism, that's not autism, that's just a spoiled brat.

Similarly, M2 stated,

> I was kind of like, well, how can they change it. You know being that it was that so many years and now instead of him having Asperger's, it seems like there's three more diagnosis put on top of it.

M6 expressed that she blamed herself for not knowing until she heard it in conversation and stated:

> I was like what do you mean it's not a diagnosis anymore blah blah blah, and they are like, oh it's not going to be in the DSM 4 or DSM 5 or whatever it is today. So I did a little research on my own and realized that they had done away with the Asperger diagnosis. Honestly, initially, I blamed myself, I felt at fault that I should have known.

Giles (2014) highlighted the importance of considering the impact of diagnostic changes on all stakeholders and reminded that the reactions to these changes do not take place in a vacuum. The participant's initial reactions and statements made it evident that there was little to no education and initial support provided in their communities.

Superordinate Theme 3: Concern for all parents/children. The participants in this research expressed concern for all of the parents and children that this diagnosis affected, not just their own. Some expressed concern for all of those who were considered high-functioning autism while other participants expressed concern for those who were lower functioning and the affect this change would have on them also. For example, M1 emphatically shared, "I was very, very, very disappointed because I felt like it was going to leave a lot of kids high and dry, including my own." Equivalently, M3 went to a greater length to explain her concern about all of the families and children this change would affect and stated:

> I remember having like this feeling in the pit of my stomach, and then my next thought was; how disrespectful to parents who have kids that are that classic

> autism. Because, how can you compare our children, my son does not look like, does not act like, and I just thought, if that's the picture we're going to put out there is my kiddo then what are those parents going to experience what kind of backlash are they going to be experiencing because then they say, hey my kid has autism. So I thought it was really disrespectful to both sides, both the both of those types of parents.

Hoogsteen and Woodgate (2013) shared that an advantage of living in a rural area is that, with time and increased awareness, a family of support develops. The mothers in this study expressed concern for everyone that this diagnostic change affected based on their knowledge of the differences across the spectrum. Hoogsteen and Woodgate (2013) stated that society's lack of knowledge and understanding of autism is a significant barrier in rural communities. M3's concern about "backlash" is reflective of her concern that this previous lack of understanding may become more of a burden moving forward.

Superordinate Theme 4: Desire to educate/advocate. The majority of these mothers expressed a desire to educate others about the new diagnosis and how the previous diagnosis compared. M3 emphasized the diagnostic differences and her need to provide information and stated:

> People look at autism and they think, oh well this is how they act and this is what it looks like, and I'm almost having to re-educate people that there's, and I don't like saying higher and lower functioning, but there's this level of functioning at this end of the spectrum, and then over here there is this level of functioning, and

> there are very, very different. And even though they're under the same diagnosis you can't, you can't compare them.

M4 shared that she went through a process and eventually got to a point where she also began information sharing and asserted:

> I was annoyed. I felt that it just clumped a whole group or a whole population of children together without really differentiating the level of autism spectrum that they're functioning on. So after I got over my annoyance, I'm one that likes to educate people and try to tell them what I understand and what I know and then our own personal experiences, so I thought well, you know, somebody can say that he's on the spectrum. I'm still going to say; well he's more Aspergery than anything.

Ruiz Calzada et al. (2012) maintained that when parents have increased access to a support network of parents with children with a similar diagnosis; this can lead to a feeling of empowerment. Empowered parents are more likely to advocate for not only their child but for a broader group of children also (Boshoff, Gibbs, Phillips, Wiles, & Porter, 2016).

This diagnostic change is a personal experience that inevitably becomes a social experience that these mothers must share through language (Strong, 2014). This use of this socially constructed language allows M4 to navigate between her subjective and her social experience with this change (Strong, 2014). M4’s use of the term “Aspergery” to describe her son to others is constructed socially, and this language allows her to make her personal encounter with this diagnostic change an experience that she is comfortable sharing socially (Strong, 2014).

Superordinate Theme 5: Concern about loss of services. The concern about the loss of services has been ongoing since the discussion of this diagnostic change began. The mothers whose children had services when the diagnostic change occurred expressed initial concern about a loss of services for their child due to their level of functioning. M1 contended:

> Well, well kids with Asperger's because they function highly, and can to some extent, can almost be your typical kid, but not. I felt like because the criteria changed that these kids with Asperger's that function too high wouldn't get the supports that they need pretty much across the board, school, community, extracurricular services that are therapy based, and shortly after I found out, that was very true.

Likewise, M3 expressed similar concerns and stated:

> Because my kiddo is of above average intelligence, I was really concerned of what he would be eligible for, because his Asperger's manifests very differently than what classic autism manifests. And so I was concerned if he was going to be eligible for any services, if he'd be grandfathered in, because there was talk at that time of what criteria kids with Asperger's would actually be grandfathered in under that umbrella.

Lobar (2016) maintained that the changes to the diagnostic criteria might cause children with high functioning autism diagnoses to not meet criteria for services across settings. The mothers in this study consistently expressed this concern, and many lost services around the time of the diagnostic change even though they received an autism diagnosis. This inability to acquire or keep services impacts the children as well as their parent's ability to manage their symptoms (Lobar, 2016).

Emergent Subtheme 2: Public's perception. Blame and stigma are feelings associated with parenting a child with Asperger's syndrome, and the public's perceptions of these children contribute to these feelings (Gill & Liamputtong, 2011). The mothers in this study expressed concerns about the public's perception surrounding this diagnostic change from Asperger's syndrome to ASD, and the resounding super-ordinate themes that surfaced included the public's comparison of an ASD diagnosis to mental retardation and the stigma of being a bad parent. The findings of this study regarding the initial experience with the public's support indicate a general feeling of a lack of support and understanding for mothers.

Superordinate Theme 1: Mental retardation. Before the release of the DSM-5, Gensler (2012) maintained that parents might prefer one label within the autism spectrum over the others due to the assumption of an intelligence level. The mothers in this study clearly stated that they both felt and heard that the public associates the ASD diagnosis with mental retardation. For example, M2 claimed:

> Before with him having Asperger's, it was like, OK, I got Asperger's let's deal with it. Now it just seems to be, I guess in the worldview before it was like those are retarded kids or you know that, and now that that's kind of what it feels like, that they've put him into a retardation category.

When explaining the diagnosis to the general public, these mothers have been asked directly if their child is mentally retarded, and this causes the mother to have to explain the diagnosis further. Gensler (2012) asserted that the definition of Asperger’s syndrome excludes mental retardation, which the DSM redefined as intellectual disability. M6 also explained her experience and stated:

> And usually when I say Asperger's people will say, what is that? I got the same thing when it was PDD. What is PDD pervasive development disorder what does that mean? Oh is he retarded? No, I didn't say he was mentally retarded.

M3 added to this and stated, “Because then they say, hey my kid has autism, and they're like oh but he doesn't speak, is he retarded, you know things like that. And they don’t know that those diagnoses don't necessarily always go together.”

Superordinate Theme 2: Stigma of bad parenting. A reoccurring theme in the interviews included the mothers’ concern about receiving the label of being a bad parent and the potential inability to receive services because of the perception that the mother was the problem. M1 stressed:

> For years upon years upon years, I have had people come to my home, and they walk in expecting me to be a bad parent because of my children. It's kind of like, I feel like they see an Asperger's diagnosis and automatically rate that in there as oh well that parents too easy on their kids or they're not disciplining them enough or you name it. And these people walk in, and that's what they're expecting, they're expecting a parent that isn't doing anything, doesn't care, just allows the kid to walk all over them. You name it and that's not what they get. In no way

> shape or form am I a bad parent. I do my best to teach my kids, all of my kids, the same values the same morals and respect and so on and so forth. A kid with Asperger's is different and requires different communication, different techniques, just a little more understanding, a little more patience. And you have to think outside the box sometimes, because that's where they're at, outside of the box. And when I'm not scolding them and disciplining them for their behavior the way other people think I should, I'm labeled a bad parent.

Likewise, M3 shared a specific example of an incident in the community in which she overheard someone talking about her parenting. She was proactive and took the opportunity to educate someone on the diagnosis and offered the following:

> I'm getting everybody rounded up and I heard a couple behind us make a comment. I would just spank that kid’s butt he needs to learn how to sit in his seat and eat his dinner and I took the kids out to the front room where my husband was paying the bill. I said Oh I forgot something in the dining room. So I went back into the room and I actually sat at their booth. Hi, I'm the mom that was at that table right in front of you and I just want to introduce myself and tell you about my child because you made it abundantly aware to me of what a terrible mom I was and how bad my kid was. I want to tell you about him. So he has Asperger's and he doesn't really deal well with new places and I educated them. They were, they looked mortified, and I hope they were, I really hoped they were. I was so angry that I didn't want them to see anger because I thought then the message

> they're just going to be like oh it’s just an emotional mom making excuses. And so I tried to hold myself together.

M5 relayed information on how she felt about the stigma associated with parenting a child with autism and said, “Sometimes it makes you feel pretty inadequate like maybe you've done something wrong.” When I asked her how she felt about it, she went on to say:

> I'm actually comfortable with telling people. I feel like it's helpful in some ways if they've known him long enough because they're going to notice some anomalies. And I want them to understand where they're coming from. That maybe it’s just part of my pride because I don't want someone to think that we haven't been able to parent some of this out of him. Some of it is not going to parent out. It just isn't.

Gill and Liamputtong (2011) maintained that mothers with a child with Asperger’s syndrome might receive a negative public reaction to their child’s inappropriate behavior. Children with Asperger’s syndrome have a normal physical appearance and a general lack of knowledge about Asperger’s syndrome contributes to the mother’s feelings of stigmatization (Gill & Liamputtong, 2011). Additionally, Hoogsteen and Woodgate (2013) discussed the struggles that parents living in rural areas have with acquiring parental support due to the lack of knowledge and understanding in society.

All of the mothers were familiar with the associated language and feelings surrounding the socially constructed term, stigma. These mothers experience with the feelings of stigma began long before this diagnostic change, and as Kordeš (2016) asserted, this current diagnostic experience is merely a point in the experiential history which is continually constructing itself. The mothers are in the process of expanding awareness of their experience with stigma within the broader experience of this diagnostic change (Kordeš, 2016).

Main Theme: Insurance-Funded Services

In the interviews, I requested information about the mothers' experiences with obtaining or keeping insurance funded services. The following questions served as the initial probe to gather this information:

- What has been your experience navigating the managed care/insurance system to get services approved since this diagnostic change?
- What has been your experience with the outside agencies providing services in the home/community setting and the school setting since this diagnostic change?
- What are some specific examples or stories associated with these experiences?

Emergent Subtheme 1: Difficulty navigating. These mothers were required to navigate through a process with the managed care company or insurance company to acquire or continue services for their child (Johnson, 2015). The mothers expressed frustration with difficulty in navigating the insurance process as a result of this diagnostic change. The consensus among these mothers was that the insurance companies were not helpful and they found the process to be frustrating. M1 expressed her frustration by stating:

> I don't think they care to even acknowledge it truly, if they didn't have to. I don't feel in any way shape or form the insurance companies are helpful. There are a lot of things that would be good for kids with Asperger's slash autism spectrum umbrella term whatever it is. It’s frustrating. They, they don't go the extra mile for these kids.

Likewise, M2 shared her dissatisfaction and shared:

> It kind of frustrates me, I guess is what I want to say because, you know you just can't go away and understanding one diagnosis and they change it and then you feel like you're starting at square one again. And then, of course, it seems like because it changes all of the services and what medically you can get or whatever, everything changes, and it is so hard to get your child involved.

Insurance companies base service entitlements on how closely the child’s diagnosis connects to specific diagnostic criteria (Johnson, 2015). This change impacts policy and can occur in two different ways including being directly tied to a diagnosis or indirectly influencing the insurance company’s policy (Johnson, 2015). Reduced ambiguity about which types of autism insurance covers should make the process easier; however, that is dependent on each state’s private insurance mandates (Johnson, 2015). While Pennsylvania does include Asperger’s syndrome in their private insurance mandate definition (Johnson, 2015); it does not appear to have benefitted the mothers in this study.

Emergent Subtheme 2: Lack of community autism-specific services. There was a resonating concern expressed by the mothers about a lack of Asperger’s or autism-specific services in their areas. The mothers expressed concern that their child had to have another diagnosis to qualify for services or they had to go to another county to access the necessary services for their child. For example, M1 stated, “There always had to be a diagnosis of ADHD accompanying Asperger's to even participate in these programs, and the therapies aren’t in any way shape or form made for children with Asperger's.” Additionally, M3 asserted:

> Again, fortunately, and because they are out of a different county, because of his diagnosis, this has been the only time this has worked for me, his diagnosis allowed us to get an out of county agency because they specialized in children with autism.

Hoogsteen and Woodgate (2013) maintained that parents encounter restricted access to services as well as fewer autism services and programs when living in rural areas. Hoogsteen and Woodgate (2013) asserted that the appropriate services across settings are often inaccessible in rural areas. The mothers in this study validated this and expressed concern about a general lack of autism-specific services.

Emergent Subtheme 3: Lack of training/knowledge. The mothers who were able to access services for their child expressed concern that the service providers lacked training and specific knowledge of autism and Asperger’s syndrome. M1 expressed that the service providers who worked with her child took the initiative to educate themselves and stated, “We were fortunate over the years to have people that did their own research and figured out ways to adjust things for kids on the spectrum with an Asperger’s diagnosis.” M4 added that her worker also did independent research and geared interventions specifically to her child’s need. She stated:

> I think when she, when the worker was addressing him tried to use a lot of visuals because my son is very visually oriented, so they did a lot of drawing and artistic expression. And she also learned, I think she did a little bit more research. She was a fairly new counselor, but she was very dedicated and very eager to dive in. So, I recall her telling me that she'd done a lot of extra reading. And we even talked about that whole Asperger diagnosis versus the autism spectrum diagnosis, and she could empathize with my frustration.

This void in training and knowledge is evidenced by the current active pursuit in Pennsylvania by the Bureau of Autism Services to ensure that all children diagnosed with autism have access to the appropriate techniques delivered by trained professionals (Pennsylvania Department of Human Services, 2018). This endeavor is called the ABA in PA Initiative and is a nonprofit organization comprising lawmakers, professionals, and parents who are advocating for professionals to have more training in autism-specific interventions (Pennsylvania Department of Human Services, 2018).

Emergent Subtheme 4: Denial due to not having classic autism symptoms. The mothers expressed concern related to hearing that their child was losing services due to not having classic autism symptoms. Some mothers discovered that their child did not meet criteria due to not having classic autism symptoms thorough a direct statement while others presumed that was the reason for the loss of services. For example, M3 contended:

> Ya, services actually for him ended really quickly. So he was in 6th grade and within the next waiver period he was denied services and he lost his BSC and his

> TSS. Because under that diagnosis, he didn't really qualify for it as much. He didn't have those classic signs of autism. He had other behavioral issues you know other social problems. So he lost his services, and I can't pinpoint that is exactly why the loss of certain services but it was all in that same timeframe that he became ineligible.

M6, conversely, did not assume that was the reason; instead, the insurance company directly stated that her child did not qualify for services, and she shared, “I did inquire about, what they call them, TSS workers. I inquired about that when we first moved up here and they told me that he wasn’t quote unquote bad enough.” M4 also shared that she was told directly that her son was losing services because of his higher level of functioning and stated:

> They said that he was too high functioning. That even though we have had a couple of episodes where my son had gotten out of control and had physically attacked me; they said well you know it's probably more of a sensory overstimulation, and they didn't think that he needed TSS on a long-term basis or even a short-term basis.

Levanthal Belfer (2013) expressed concern about access to services with the DSM changes from a clinician’s perspective. Before the most recent diagnostic changes, there were reductions in the range of services offered to children with Asperger’s syndrome, and the main focus was on behavioral therapy including applied behavioral analysis which is recommended for classic autism and not Asperger’s syndrome (Levanthal

Belfer, 2013). Likewise, Johnson (2015) maintained that insurance and services link tightly with specific diagnoses for treatment approval.

Emergent Subtheme 5: Assignment of other diagnoses. These mothers expressed concern about other diagnoses being added to their child’s diagnostic conceptualization to explain symptoms that were previously described by Asperger’s syndrome. For instance, M2 shared:

> It seems like there's three more diagnosis put on top of it. It went from PDD to Asperger’s syndrome to autism to autism with speech impairment and intellectual impairment. And throughout the earlier one ADHD was a part of that too. And manic depressive symptoms were added.

M3 expressed that she has heard that many of his symptoms that were previously explained by Asperger’s syndrome are not any longer, and she feels like he has more diagnoses to explain his various symptoms. She shared:

> Let me back up, so he has always shown signs of depression. We've always struggled with anxiety with him. And when he was Asperger's, what I used to hear a lot was well a lot of times Asperger's does have a lot of symptoms I guess you could say that also are anxiety like, symptoms or depression-like symptoms, and we don't normally give those diagnoses they kind of go hand in hand a lot of times. When he lost the Asperger’s and got a diagnosis of autism, and he got a whole host of other diagnoses. So then came the depression, and the generalized anxiety diagnosis and the OCD diagnosis on top of that, because no longer did his diagnostic criteria include and explain some of those behaviors.

Volkmar et al. (2014a) asserted that in adolescents and young adults, anxiety and depression comorbidity rates are as high as 50%. Given the fact that the majority of the children in this study are adolescents, the addition of these diagnoses may apply to an awareness of their tendency to socially isolate or repeated failed experiences (Volkmar et al., 2014a). Likewise, Asperger's syndrome shares traits with an obsessive-compulsive disorder (OCD), but it remains unclear if OCD is an actual comorbidity of autism or if autism alone explains the obsessions (Volkmar et al., 2014a).

Main Theme: Educationally-Funded Services

I requested that the mothers share their experience with services in the school setting with acquiring or keeping services for their child when this diagnostic change occurred. The following questions served as the foundational probe for information about their experiences:

- What has been your experience navigating the school system since this diagnostic change?
- What are some specific examples or stories associated with these experiences?

Emergent Subtheme 1: School staff lack of knowledge/understanding. The participants in this study expressed concern about the lack of knowledge and understanding exhibited at all levels of school administration. It was evident that the mothers' concern about the lack of knowledge and understanding exhibited in the school system was not referencing any particular group within the system; instead, it was at all levels of staff. M1 generalized her concern to all adults in the system and stated:

> The adults that he needed to notice and be there for him didn’t. My getting involved didn't help either. I kind of attempted a few times to discuss with the school you know he needs help; he's got an Asperger's diagnosis. He's getting bullied. A lot of teachers aren't understanding what's going on; they just think he's being rude.

M4 shared that even the principal at her child’s school did not seem to care about her child’s diagnosis and shared:

> Well, his school was not supportive. In fact, the principal just didn't even seem to understand what Asperger's was. And the principal admitted that he didn't have children of his own. So I don't know if that made a difference. But the Asperger's diagnosis just seemed to not be a big concern for them, and then we left. And of course later on he ended up with the autism spectrum diagnosis.

Likewise, M6 asserted:

> They don't know what Asperger's is. They don't know how to treat Asperger's. They keep, from day one, since I’ve had him up here, oh he has ADD, no he doesn't have ADD, oh he has ADHD. No, he doesn't have ADHD, this is what he has. Do you even understand what that is? You know, I'm all for mainstreaming him. You know I don't want him to be isolated. But it's unfortunate that the teachers, and I'm not damning the local school system, I think compared to others in our area which are even smaller and even, I think, less forgiving, I guess is a good way of putting it. It's kind of scary to me to think that the teachers and the educators up here don't specialize in something like that.

Alenizi (2015) maintained that the ideal placement for a child with Asperger’s syndrome is in the mainstream classroom; however, this requires the teacher to have expertise in special education. Furthermore, the students with Asperger’s syndrome are often blamed for their lack of understanding because they appear intelligent, yet lack social understanding and regularly cause stressful situations (Alenizi, 2015). Teachers, without adequate training, lack understanding of the condition and the ability to control hostile situations (Alenizi, 2015).

Emergent Subtheme 2: Teacher cooperation/understanding. While there were resounding statements about a general lack of knowledge in all levels of school staff, the mothers also identified teachers that went above and beyond for their child to ensure inclusivity. Some of the experiences began negative, and the mother was able to turn the situation around by sharing information about her child and the diagnosis. Others were positive from the beginning, and the teachers were initially supportive. M1 offered an example of a situation that began negative, and she was able to have an impact by educating the teacher about Asperger’s syndrome. She stated

> Example, I had one teacher who emailed me about him and it began with the usual he’s argumentative, he's rude, he's this, he’s that. I had one phone discussion with her and did a mini-education session on Asperger's and that everything she was seeing was typical behaviors especially when he's in a heightened sense. This teacher was able to take what I gave her and apply stuff she found on her own and they were extremely successful. But again she did this on her own. This was not

> from the school or from any therapy or from this or that. This was just a decent person doing what was right.

M4 discussed how welcomed she felt when her child was moved to another school after a negative experience and stated:

> Oh my goodness, they welcomed us, they there was no stigma. There was an understanding; there was a lot of support expressed through phone calls and e-mails. I was invited to come into the classroom anytime I wanted to. I worked closely with his ES teacher, and he's a wonderful, wonderful man. And he saw potential in my son. The other principal and the other teacher at the other schools did not see potential; they just saw a kid that they couldn't control and nobody suggested that I call the special ed department. Nobody offered me any kind of support other than well you know maybe you need to homeschool him and that's what I got. This other school, this new school that he was attending, they understood him, they understood his level of functioning and they expected more out of him.

M5, on the other hand, offered an example of a teacher who has had a positive impact on her child and diagnosis does not seem to matter. She pointed out:

> His teacher knows him. He's been there for three years. She knew him before he had any diagnosis, and so she knows him for who he is, and not what he is. And I don't feel I have to explain him in that manner to her. Diagnosis isn't really important.

M6 compared experiences between Pennsylvania and Ohio and shared:

> He loves the vo-tech teacher and he loves him. They get along very well and probably the only other including Ohio, the only other teacher, he used to play football and a middle school teacher was the coach, and if you got in seventh grade you automatically got him in eighth grade. The guy was fabulous. I mean he was such a self -esteem builder for these for the kids.

Alenizi (2015) asserted that it is not easy for these teachers to handle a child with Asperger's syndrome in their class, and they need adequate training to allow them to be successful. It was evident that some of the staff that these mothers have encountered have either had this proper training or have a natural ability to foster acceptance.

Emergent Subtheme 3: Lack of school autism level-specific services. This study took place in a rural area of Pennsylvania, and the mothers expressed concern about an overall lack of autism services as well as a lack of autism level-specific services. M3 offered an example of the school trying to place her child in a classic autism classroom as a remedy when she was trying to get services to meet her child's needs. She stated:

> Because you know in a school setting, I remember in that meeting with the provider them saying to me well there's an autism classroom in his school, he can be placed in that. And I just thought that autism classroom is for children who are not potty trained and who are nonverbal. My kiddo has an IQ of over 120. You know ya we still have hygiene issues and things like that. But he is he's not going to assimilate into that classroom and not only that with his Asperger's he actually mimics a lot and behavior matches. So if I were to put him in a classroom like that I thought for sure he would be getting worse. So that was their solution, that he

> didn't meet the criteria any more for services. And here's this option now in school because the school has an autism classroom we don't need to provide services for you. But it was a highly inappropriate setting for him to be and he would have then been in a most restrictive classroom which would have violated the special education law. I felt like we were like between a rock and a hard place.

M4 shared her experience with wanting her child in the autism classroom and there not being enough space to accommodate his placement there. She shared:

> I can't even tell you what a nightmare it was. They didn't have room for him in the autism classroom at one of the elementary schools here in town. So they wanted to send him to another elementary school 12 miles away. There was a grief reaction, I think really to go from Asperger's to full autism spectrum to me, that was a label like intellectually to me it was a label, but emotionally I just felt like they were shoving my son into a program that really wasn't individually tailored for him.

M6 has started to avoid IEP meetings because she does not feel they are worthwhile and her child is getting anything out of it anyhow. She asserted:

> Like I actually didn't go to the IEP meeting last year because I wasn’t going to sit there and listen to them tell me the same thing that they tell me every year you're not doing anything different for me. This is what I see. I see you doing a bunch of paperwork. You get extra money from the state as long as you can provide the paperwork but you're not providing him the services, nothing.

Boswell, Zablotsky, and Smith (2014) maintained that a child's geographical location should not determine the educational services they receive; however, there are apparent discrepancies in access to care in more rural areas. Boswell et al. (2014) asserted that schools should examine their systems to address placements and services of children with autism better. Finally, Boswell et al. (2014) also suggested that schools should determine who they can partner with to better identify and serve children with autism.

Emergent Subtheme 4: Alternative schooling. The mothers in this study expressed thoughts of homeschooling or have chosen to home school their child at various points in their child's education. M2 offered, "The school system and I don't have a good relationship. I am currently homeschooling my 15-year-old." M3 chose to home school at a specific point in her child's education and stated:

> We homeschooled for a little bit in seventh grade when the diagnosis changed, because he wasn't fully prepared to walk right into the middle school. So we homeschooled for about half the year to kind of get him acclimated to the workload before we transitioned him in, and it was a disaster.

M5 is not homeschooling but has her child in an alternative school placement, and stated, "I recognize that he would not be able to function in a regular school without an IEP." She then added:

> He is in a private church-run school, so they don't even do IEPs. So, we really haven't had to deal with the IEP end of it. His teacher knows him. He's been there for three years. She knew him before he had any diagnosis, and so she knows him

> for who he is and not what he is. And I don't feel I have to explain him in that manner to her. Diagnosis isn't really important.

Hurlbutt (2011) maintained that many parents choose to home school their children due to a lack of autism-specific educational programming. The parent’s experiences in the Hurlbutt (2011) study expressed that the schools were either unwilling or unable to provide the necessary services, and that is the reason they decided to home school.

Emergent Subtheme 5: Need to advocate for special services. The mothers in this study expressed a need to advocate on behalf of their child and many referred to this process as a “battle.” Several of the mothers involved educational advocates in their “battle,” while some chose to advocate themselves. M1 shared her frustration with advocating for special services for her child and stated:

> I feel in general angry. Myself, I do feel angry because no parent of any child diagnosis or not should have to battle a school to have to do what’s best for their children. The school is supposed to be there to teach, to educate, support, nurture, and care about all kids. Not just kids they feel like. Not just kids that are normal, not just kids that are athletes not just, not... It needs to be all kids. Instead of a battle, I feel it should be a partnership. And I feel the schools should be doing all they can to be a partner with the parents. Unfortunately, it’s more of a battle for any parent to get the school to cooperate acknowledge or do anything or change anything. It is a constant uphill battle.

M3 also expressed frustration with the process of acquiring individualized services for her child and shared:

> And I've had to advocate every single time you're looking at his diagnosis under a classic autism diagnosis. You are not looking at his diagnosis as if he had Asperger's because that changes the whole scenario of whether this incident was a manifestation because of his diagnosis. So even with school psychologists, I run into that numerous times and it's us educating them. Listen, his diagnosis used to be Asperger's, and this is what Asperger's this and he criteria for Asperger's was and now do you think that his diagnosis played a part in this school issue. Then it changes the story completely. Like oh yeah. Yeah I can see how that would work. So I just feel like it's caused more confusion.

Boshoff et al. (2016) shared meta-synthesis findings that concurred with the frustration and stress expressed by the mothers in this study. The mothers described the battle they had to fight, and similarly, Boshoff (2016) referred to this as a challenge that is life-long and encompasses being proactive and focused on all aspects of the child's world.

Summary

In my study, I used the IPA method to collect and analyze the data to ensure rigor and consistency in the process. My findings point to a need for more support for mothers whose child had a previous Asperger's syndrome diagnosis. Additional supports need to focus on increasing education and understanding of children with a previous Asperger's syndrome diagnosis. The mothers in this study described their experience with support and services since the change in the diagnosis; however, it was evident that their frustration with the lack of support and understanding was established well before the diagnostic change.

In the following chapter, I interpret and synthesize the mothers' experiences in complete detail. I then describe the limitations of this study, and I will share my recommendations based on these mothers' experiences in this study. Finally, I provide the implications for this study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this hermeneutic phenomenological study was to help understand mothers' experiences with support and services since the Asperger's syndrome diagnosis merged into the autism spectrum continuum. Understanding mothers' experiences when there is a diagnostic change of this nature can assist various stakeholders with being sensitive to the mothers' needs as well as their children's needs. The data in this study revealed that these mothers need additional support to obtain or keep services for their children at multiple levels including the services provided by the educational system as well as those funded by insurance. These mothers have experienced the need to seek out advocates or advocate for themselves to get their children the appropriate supports across settings. While there were consistent accounts of individuals who were supportive, there were also emphatic reports of the mothers finding it necessary to campaign for their child to get the necessary support and services. In this chapter, I discuss the findings of my study, provide recommendations, and acknowledge the implications of the study.

Interpretation of the Findings

IPA follows the principles of hermeneutics and idiography (Smith et al., 2012); therefore, I share interpretations drawn from my thorough and systematic analytic process. The use of the hermeneutic circle allowed me to vacillate back and forth in the analytic process from the various parts and wholes to interpret the meaning of my participant's texts (see Smith et al., 2012). Focusing on in-depth analysis allowed me to extract the meanings of the mothers' experiences, and I share these interpretations in detail in the following sections.

Process of Obtaining a New Diagnosis

The process of learning about the diagnostic change and then obtaining a new diagnosis was the initial encounter point for support and services. The first step in illuminating the mothers' experiences with support and services was to explore how they initially found out about the diagnostic change. By using the unstructured interview approach, I asked probing questions to gain an in-depth understanding of how these mothers experienced this initial process (see Smith et al., 2012). There were two consistent subthemes that emerged including a lack of education/information and the public's perception. Within each of these subthemes, superordinate themes also consistently came to the surface. I interpret each in the following sections.

Lack of education/information. The mothers in this study consistently expressed concern about the lack of information-sharing and education about this diagnostic change. Robinson et al. (2015) maintained that when a child receives a diagnosis of Asperger's syndrome, the parents are better able to understand their child. Receipt of the diagnosis becomes a pathway to understanding and a means for the parent to rebuild their confidence (Robinson et al., 2015). For many families, arriving at the point of receiving an Asperger's syndrome diagnosis was not easy, and they viewed it as light at the end of the tunnel (Robinson et al., 2015). For the mothers in this study, finding out that this diagnosis no longer existed was distressing.

Inconsistent source of information. The mothers in this study shared the source of information about the diagnostic change, and there was no consistency. The sources ranged from professionals to the internet to personal conversations. Some heard about it before the change occurred, while others were not aware of the change until well after the diagnostic changes had occurred. Additionally, many could not even recall exactly where they were informed about the changes, and they speculated on the origin of the information. It was apparent that the mothers felt there should have been more information sharing throughout the process given the fact that the decision had an impact on their child.

Initial reaction. The emotions felt by the mothers upon learning about this diagnostic change included confusion, lack of understanding, and blame. Giles (2013) asserted that decisions such as this diagnostic change do not take place in a vacuum, and there will be stakeholder reactions. Stakeholder reactions were evident in this study as these mothers tried to express their frustration with not knowing about the change and not having a voice in the decisions surrounding the change.

Concern for all parents/children. There was concern expressed for all of the children and families impacted by the diagnostic change. Hoogsteen and Woodgate (2013) maintained that support networks build in rural areas over time, and this was evident in the visible worry for others expressed by these mothers. Given the extreme variances in autism symptoms across the spectrum, one mother indicated that she thought that it was disrespectful to those with a previous Asperger's syndrome diagnosis, as well as those who had an autism diagnosis. Her remarks indicated a general feeling that the decision was insulting to both sides, and there should be more recognition of the individuality of all children on the spectrum.

Desire to educate/advocate. Given the variance in symptoms displayed across the spectrum by children with an autism diagnosis, the mothers expressed a desire to educate others about the changes to the diagnosis. This ambition appeared to originate from an ongoing concern about society's lack of understanding about the differences in autism as well as a personal need for others to understand their child. Boshoff et al. (2016) maintained that education and advocacy are forms of a parental coping strategy that can allow for a feeling of hope to return. The benefits can be both personal and can also bring broader benefits to society (Boshoff et al., 2016). In this study, mothers sought to improve the understanding of autism for both personal and societal reasons

Concern about loss of services. The mothers expressed concerns about the potential loss of services due to the higher functioning level of their child with Asperger's syndrome. Shared concerns covered all service settings, and the basis of the mothers' fears was the fact that their child appears to be typical and higher functioning than children with classic autism symptoms. Lobar (2016) expressed concern about a loss of services due to a general lack of autism diagnostic knowledge and understanding across health professions both before and after the new diagnostic criteria. Johnson (2015) articulated that the new DSM guidelines affect who qualifies for the new diagnosis, and the new diagnosis determines what services they will receive in the school and community settings.

Public's perception. The mothers in this study were clear about their concern about public perception of the DSM-5 diagnostic change. Gill and Liamputtong (2011) asserted that the perception of blame and stigma are prevalent with mothers of a child with Asperger's syndrome. Historically, these mothers have been exposed to the public's negative reaction to their child; therefore, they have an ongoing sense of defensiveness. The manifestation of Asperger's syndrome is very different than autism, and these mothers have continually experienced the general public's negative reaction to their child. Likewise, they have witnessed how the public reacts to children with autism, and know that there is a higher rate of acceptance for these lower-functioning children (Gensler, 2012).

Mental retardation. The mothers in this study expressed ongoing concern about the general public's assumption that their child is "mentally retarded" when they must share that their child has autism rather than Asperger's syndrome. Gensler (2012) asserted that parents had a preference about the label of their child due to the assumption of an intelligence level even before the release of the DSM-5. These mothers expressed concern about the concept of mental retardation both before and after the diagnostic change. Some mothers expressed that there has always been an association with lower intelligence, and others conveyed that this is a new association since the diagnostic change.

Stigma of bad parenting. There has been an ongoing stigma associated with being the parent of a child with Asperger's syndrome (Gill & Liamputtong, 2011). Children with Asperger's syndrome do not have the same profound behaviors as those with lower functioning forms of autism (Farrugia, 2009; Gill & Liamputtong, 2011; Gray 1993, 2002). The mothers in this study all relayed concern about the perception others have of their parenting when their child exhibits inappropriate behaviors. The mothers in this study have clearly gone through both feeling and experiencing stigma directly. The stigma concern has occurred over a period, and it is not a new concern with the new diagnosis; however, the mothers are concerned about relaying their child's new diagnosis that the public already associates with lower functioning. They shared examples of the way they believe others perceived them as well as explicit examples of overhearing others discussing the inadequacy of their parenting. The mothers' shared feelings of inadequacy and anger and feeling like they needed to defend their actions and educate the public.

Insurance-Funded Services

Diagnosis is the gateway to obtaining or keeping services for children with Asperger's syndrome or autism (Johnson, 2015). The mothers in this study must have services for their child approved through an insurance company for the service provider to receive payment (Johnson, 2015). The insurance-funded service process is complex and includes obtaining the recommendation for services, the insurance approval process, choosing a service provider, and finally participation in the services. Once again, I used the unstructured interview approach to gain an understanding of the mothers' experiences with this particular process. There were five homogenous subthemes that surfaced including difficulty navigating services, lack of community autism-specific services, lack of provider training/knowledge, denial due to not having classic autism symptoms, and assignment of other diagnoses. I interpret the five subthemes in the following sections.

Difficulty navigating. Johnson (2015) asserted that the passage of state-level insurance mandates was dependent on a preexisting autism infrastructure. Autism infrastructure refers to the prevalence of identified autism and the availability of professionals to diagnoses autism (Johnson, 2015). States with autism insurance mandates are assumed to have advantages including entitlement to services and improved access to services for children (Johnson, 2015). Pennsylvania is a state with insurance mandates that includes a previous diagnosis of Asperger’s syndrome as a part of the autism definition (Johnson, 2015); however, this did not make the process any easier for the mothers in this study.

The mothers in this study expressed an overarching feeling of frustration with the process of maneuvering through the steps to obtain insurance approval for services for their child. The mothers’ responses were indicative of feeling like they were on an opposing team and that the insurance companies were not allies in the process. The mothers expressed that they do not believe the insurance companies made any extra effort to accommodate children with Asperger’s syndrome through this diagnostic change process.

Lack of community autism-specific services. Spillers et al. (2014) expressed concern that the changes to the DSM-5 would impact services and that regardless of the level of functioning; services should still be provided. A major concern was that there would not be tailoring of services to the individual’s needs, and the diagnostic change would lead to generalized services (Spillers et al., 2014). The general consensus among the mothers in this study was that there was a lack of services both before and after the diagnostic change. Hoogsteen and Woodgate (2013) described the lack of professional support and services as isolation. The mothers in this study expressed resentment that there were no services specific to the individual needs of their child within their county. One of the mothers expressed that she considered herself fortunate to have received approval for out-of-county services; however, she was fearful, given previous experiences, that they would not receive insurance approval of a transitional service when the current service ended.

Lack of provider training/knowledge. The mothers in this study expressed concern about a void in official autism-specific training among service agencies. Many of the mothers expressed that they felt fortunate to have individual workers that took the initiative to learn independently from their agency and to adjust interventions to meet the needs of their child. The mothers seemed to feel an alignment with the workers who went above and beyond and had a clear appreciation for their ability to increase their skills and tailor their interventions specifically to their child.

The ABA in PA Initiative is a nonprofit advocacy organization that is committed to guaranteeing that all children in Pennsylvania with an autism diagnosis have access to applied behavior analysis which is an evidence-based treatment for autism (The ABA in PA Initiative, 2018). The Pennsylvania legislation in Act 62 required that there was access to ABA therapy previously; however, medical assistance had not been covering it as a distinct service (The ABA in PA Initiative, 2018). The goal of this advocacy group is to ensure that all service providers have staff that meets the minimal training requirements by the behavior analysis certification board (The ABA in PA Initiative, 2018). There is continued concern about where this leaves those children with a previous Asperger's syndrome diagnosis because ABA is not typically a recommended treatment when Asperger's syndrome is the primary diagnosis (Levanthal Belfer, 2013).

Denial due to not having classic autism symptoms. Levanthal Belfer (2013) asserted that before the release of the DSM-5 there had already been reductions in services for children with Asperger's syndrome. Because the Asperger's syndrome diagnosis has changed to autism and ABA is the preferred treatment modality for autism, there are limitations and barriers to service approval based on the child's level of functioning (Levanthal Belfer, 2013). When discussing their child's loss of services, these mothers consistently referred to them not functioning highly enough, not having classing signs of autism, or not being bad enough.

Representatives from insurance companies informed some of the mothers that their child did not meet insurance coverage criteria for these reasons while others presumed this was the reason. Volkmar and Reichow (2013) shared that the important thing with the changes in diagnostic criteria in the DSM-5 is that individual who benefit and needs services are still able to access them. Levanthal Belfer (2013) suggested that we be prepared to stand firm and insist that there is an inclusion of services that meet the diverse range of challenges that manifest with these children.

Assignment of other diagnoses. The mothers voiced concern that their child's symptoms that were previously explained by their Asperger's syndrome diagnosis are no longer, and there has been an addition of other diagnoses. While there is certainly comorbidity that goes along with Asperger’s syndrome, it is critical that there is consideration of the entire behavioral profile before rendering other diagnoses (Levanthal Belfer 2013; Powers & Loomis, 2014). Many clinicians encounter children with inappropriate diagnoses rendered by professionals who are not familiar with Asperger’s syndrome (Levanthal Belfer, 2013). Inappropriate diagnoses can lead to inappropriate treatment including the administration of medications for other disorders such as depression, anxiety, and obsessive-compulsive disorder (Powers & Loomis, 2014).

The mothers in this study conveyed concern about whether their child was receiving the appropriate medications as well as interventions based on their current diagnostic profile. It is critical to remember that the majority of the mothers’ children were adolescents. The typical Asperger’s syndrome traits of ongoing social skill deficits including isolation, awkwardness, and obsessions can lead to other diagnoses; therefore, we should not minimize the possibility of comorbidity during adolescence (Powers & Loomis, 2014). However, many of these symptoms may still be explained by Asperger’s syndrome, and it is imperative that those diagnosing are considering the neuro-cognitive features of Asperger’s syndrome that may influence the child’s behavior and our understanding of that behavior (Powers & Loomis, 2014).

Educationally-Funded Services

Autism became an official disability category in the 1990 Individuals with Disabilities Education Act (IDEA), and the act requires that schools evaluate the child, with parental permission, to determine special education eligibility and necessary special services (Brown & Wolf, 2013). Johnson (2015) maintained that because autism is a neurodevelopmental classification with onset in early childhood, special education benefits are an important part of services that these mothers must pursue. Before and as a result of this diagnostic change, the mothers had to go through a process to obtain and maintain services in the school setting for their child with Asperger's syndrome. Unstructured interviews served as the basis for gathering in-depth details about the mothers' experiences with educationally-funded services. Five subthemes consistently emerged including lack of school staff knowledge/ understanding, teacher cooperation/understanding, lack of school autism-specific services, alternative schooling, and need to advocate for special services. I will interpret the subthemes in the following sections.

Lack of school staff knowledge/ understanding. Alenizi (2015) maintained that children with Asperger's syndrome could appear average or above average; therefore; their educational needs may go unnoticed for some time. Additionally, because children with Asperger's syndrome demonstrate average or above average intellectual ability, the mainstream classroom is the preferred setting (Alenizi, 2015). The teachers in the mainstream classrooms with these children are typically not trained in special education or inclusive practices (Alenizi, 2015).

The mothers expressed frustration with their perceived lack of understanding and knowledge demonstrated by staff at all levels of the educational system. This frustration included teachers who did not understand what was going on as well as the principals and other levels of school administration that awareness of the behavior associated with

Asperger's syndrome. The mothers portrayed an overall sense that they felt dismissed when they tried to increase the school staff's understanding of their child. Alenizi (2015) stressed that, for the sake of all stakeholders, there needs to be proper training to understand and meet the needs of children with Asperger's syndrome.

Teacher cooperation/understanding. Alenizi (2015) stressed that all teachers with students with Asperger's syndrome in their classroom need specialized training to ensure that they are meeting the child's needs. Likewise, it is important to consider that just because there have been diagnostic changes does not mean the child's needs are different (Volkmar et al., 2014a). The teachers and schools that can meet the individual needs of the child on both the academic and the psycho-social levels will be the most successful (Bolic Baric, Hellberg, Kjellberg, & Hemmingsson, 2016).

Mothers in this study were able to identify particular school staff that provided them and their child with adequate support and interventions based on their individuality rather than their diagnosis of Asperger's syndrome or autism. The mothers shared their role in turning negative experiences into positive experiences by educating school staff on their child and Asperger's syndrome. The additional mothers shared positive experiences that included teachers that were initially accepting and inclusive of their child. This interview line of questioning stimulated the most positive responses. The mothers displayed a sense of relief when discussing the affirmative teachers that were accepting and understanding of their child. In addition, the mothers seemed to exhibit an overall sense that they felt like these teachers were on their team, and this alignment provided them with some much-needed comfort.

Lack of school autism-specific services. Boswell et al. (2014) stressed that the geographic area where a child resides should not be the determining factor in the types of services they can access. There is a clear discrepancy in rural and lower socioeconomic areas which causes a lack of specificity in services (Boswell et al., 2014). This disparity is particularly noticeable for those with a previous Asperger's syndrome diagnosis due to the invisibility of the diagnosis (Hoogsteen & Woodgate, 2013). The mothers in this study were from a rural area of Pennsylvania, and it was evident that there is a general lack of autism-specific services, and an even larger concern is the deficiency in school programming for those with Asperger's syndrome. The mothers expressed a range of concerns with the underlying theme being that the school did not have the individual services to meet the child's needs so they were offering the mother an alternative placement that was either more or less restrictive. The placement offered by the schools appeared to be what the school had available at the time rather than taking the child's individual needs into consideration. The general agreement among these mothers was that, although the school may have agreed to provide an individualized education plan, they were not necessarily meeting the needs of their child.

Alternative schooling. Hurlbutt (2011) shared that due to unavailable programming in public school systems for children with autism, many parents are opting to homeschool their children. Hurlbutt (2011) found that the reasons for choosing to homeschool were that the public school system was either unwilling or unable to meet the educational needs of their child. Another concern with the public school educational programs that may be available is that they are not meeting the individual needs of the child, and the only option is to place the child in a more restrictive environment in which the other children have severe deficiencies (Hurlbutt, 2011).

Mothers' reports in this study coincide with Hurlbutt's (2011) findings, and they all noted having a concern about the ability of the public school system to meet their child's needs regardless of whether they had homeschooled their child or not. Some of the mothers expressed success in homeschooling their child while others were not successful, and the transition back into regular public school did not go well. The overall impression was that the public school system was not able to meet their child's needs so the mothers felt the need to take it into their own hands whether this was homeschooling or placing their child in a private school.

Need to advocate for special services. Boshoff et al. (2016) identified the reasons why parents advocate for special services and how they advocate to access and receive services. There are both personal and societal advantages of advocating, and while it is challenging, there are also benefits. Advocacy can be empowering and can increase the parent's sense of control over their child's situation (Boshoff et al., 2016). The personal investment that is required when advocating can be another demanding role that the parent of a child with autism must balance (Boshoff et al., 2016).

There was a lot of emotion expressed when discussing the topic of advocating for educational services with these mothers. The general agreement was that it was a battle with the school system, and they either had to advocate by themselves, or they felt it necessary to seek out an educational advocate. The mothers shared that they felt like the school should be partnering with them to meet their child’s needs and that was not their experience. Instead, they were met with uncooperative school administration.

Limitations of the Study

There are inherent limitations in all qualitative research, and this study is no exception (Creswell, 2013; Patton, 2015; Simon & Goes, 2013). The limitations with this study are related to sample size, sample demographics, and the location of the study. Additionally, my role as the researcher conducting the interviews will be discussed.

A limitation of this study may be the sample size; however, I was purposive in choosing my sample, and I ensured that I reached saturation (Miles et al., 2012; Rudestam & Newton, 2015). The saturation standard refers to the researcher hearing repetition of information across the interviews (Rudestam & Newton, 2015). It became evident as I progressed through my interviews that I had reached saturation by my sixth participant because I heard repetitiveness in response patterns with each and every interview.

Another limitation of this study relates to the fact that I chose to interview mothers as opposed to fathers or a combination of the two parental roles. To keep my sample homogenous, I chose to interview mothers only. My choice to interview mothers was based on the variance in experiences between mothers and fathers and the mother’s tendency to take on the role of primary caregiver (Marciano et al., 2015). The mothers’ identified children for this study were all male. While one of the mothers had a daughter with a diagnosis of autism, it occurred after the release of the DSM-5; therefore, she did not qualify to be the identified child in this study due to not having a previous Asperger's syndrome diagnosis.

All of the mothers in this study identified as white or Caucasian except one mother who identified as Hispanic. This mother shared that in her culture there is a tendency to be loud, and she believes that she had to manage this throughout this experience "so as not to become overbearing." She referred to the concepts of la Familia and advised that she is defensive of her family. She shared that "with maturity came knowledge and wisdom", and she believes that although she has become angry many times in this process, she has been able to control herself so that she "does not fly off the handle and appear disrespectful."

The location of my study may also be a limitation due to all of the mothers being from the same rural county in Northwestern Pennsylvania. However, my study was focused on gathering rich details about the experiences of my participants rather than generalizations to a larger population (Miles et al., 2012). This study took place in a rural area of northwestern Pennsylvania. The experiences of mothers with a child with a previous Asperger's syndrome diagnosis may vary in larger populated areas where there is access to more community and educational resources.

The location of the final interview was in one of the mother's homes, and this may be seen as a limitation. The final mother that I interviewed was the first to respond to my call for participants; however, was the last to be interviewed. While she was extremely eager to share her story, she was in the process of moving, and this situation caused several delays in the interview scheduling process. This mother seemed passionate and was very eager to share her experience with me; however, her current life situation was limiting her availability. After several reschedules, I finally consented to conduct the interview in her home office after taking the necessary precautions to ensure her confidentiality and my safety.

Finally, my role as the researcher conducting the interviews may be seen as a limitation also (Maxwell, 2013). I am a professional counselor who has experience working with children with Asperger's syndrome and autism; therefore, it was imperative that I kept a reflexive journal in which I entered my personal experiences surrounding the participants, interviews, and the overall process. The reflexive journal allowed me to begin each interview with a fresh perspective and not allow personal biases to any part of the research process (Maxwell, 2013).

Recommendations

This research emanated from the requests of previous authors to date requesting that others conduct more research on all aspects of this diagnostic change. The specific purpose of this particular study was to help us understand the experiences with the support and services of mothers whose child had a previous Asperger's syndrome diagnosis. The findings of this study show that mothers experiences with this diagnostic change have been complex, and more research is necessary. Likewise, quantitative researchers may be able to use this information as a basis for measuring how many mothers have had similar experiences by using the themes in this research to create variables (Rahman, 2017).

Schrader (2013) gathered information on fathers' experiences of having a child diagnosed with autism and pointed out the differences in experiences between the two parental roles. Because this study was limited to mothers' experiences with this diagnostic change, it would be beneficial to gather either just father's experiences or gather information from both parents. Hoogsteen and Woodgate (2013) maintained that there are differences in available resources between lower and more densely populated areas. Expanding this study to include other geographic areas would be beneficial for determining if there are variances in experiences between urban and rural areas. Given that all of the mothers in this study identified as white or Caucasian, it would be beneficial to focus a study on other cultures.

There are multiple stakeholders involved in this diagnostic change, and this study only focused on the mothers. Additional research on the experiences of others such as school staff, insurance representatives, and counselors would be valuable. For example, the school staff may not have the appropriate training to work with children in their mainstream classrooms who present with Asperger's syndrome. Likewise, the insurance representatives have a protocol to follow that others may not be aware of or understand that hinders their ability to appear supportive. Counselors who do not attend conferences may not be aware of the impending changes until the release of the newest DSM. Understanding this experience from their perspective would be valuable to overall improvements for future diagnostic changes.

Implications

The results of this study allow the various stakeholders involved with these mothers to begin to acknowledge the needs of these mothers and support them through the required processes when there is a diagnostic change. There are multiple processes that the mothers have to navigate including hearing about and obtaining the new diagnosis for their child, and then continuing or beginning services in the community and educational settings. While this research cannot change the mothers' experiences, it can assist with advocacy efforts to ensure improvements when there are future diagnostic changes. Counselors and counselor educators are in a position to be key players when there are diagnostic changes such as this change to the Asperger's syndrome diagnosis. Counselors and counselor educators can assist with advocacy efforts to get the appropriate education and information-sharing systems in place. By establishing an information-sharing framework, there may be improvements in all stakeholder experiences when there are future diagnostic changes.

It was clear that there was a void in information sharing from the beginning of this diagnostic change. Mothers would benefit from proactive information sharing in advance of diagnostic changes or earlier in the process so they are better prepared. This information sharing could occur jointly in meetings with all stakeholders or counselors could supply the information to their clients in individual sessions. All school staff can use the findings of this study to make changes to increase all staff's knowledge about this diagnostic change and more specifically about the behaviors associated with the previous Asperger's syndrome diagnosis. Insurance companies can use the findings to make the approval processes easier to navigate and ensure that there are clear guidelines about required diagnosis and accompanying service alignment.

Conclusion

When there are diagnostic changes that impact a mother’s child, they need to feel supported through the entire process. This support is essential and needs to occur from the very beginning when there is a need to communicate the information to the mother. From that point, the mother needs support to either obtain or keep educationally-funded or insurance-funded services in both the school and community settings. The findings of this study highlight the need for support for these mothers at multiple levels and by multiple stakeholders when there are diagnostic changes.

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Appendix A: Interpretive Phenomenological Analysis Data Analysis Flow Chart

Step One: Reading and Re-Reading the Transcripts

- Total immersion the original data
- Participant is the focus of analysis
- Bracketing occurs here
- Repeated re-reading to locate richer sections, contradictions, and paradoxes

Step Two: Initial Noting

- Exploratory examination of semantic content and language
- No rules – free textual analysis with multiple ways to conduct exploratory commenting
- Thinking about the participant's lived world and identifying abstract concepts
- Three types of noting - Descriptive, linguistic, and conceptual comments
- De-contextualization of participant's words and meanings

Step Three: Developing Emergent Themes

- Comprehensive and exploratory larger data set used to develop emergent themes
- Simultaneous reduction of volume of detail while maintaining complexity
- Shift to working with the notes rather than the transcript
- Manifestation of the hermeneutic circle – the whole becomes a set of parts and then comes back together as a new whole at the end
- Emergent themes capture and reflect an understanding of the phenomenon

Step Four: Developing Connections across Emergent Themes

- Charting, mapping, or listing the themes and then connecting them by theoretical ordering and clustering
- Specific ways to look for theme patterns and connections – abstraction, subsumption, polarization, contextualization, numeration and function
- Document exact steps/process
- Develop table of themes into a graphic representation

Step Five: Moving to the Next Case

- The fifth step is moving to the next interview transcript and repeating the previous process
- Each transcript must be individual and emerging ideas must be bracketed
- Recognition of hermeneutic parlance
- Develop a table or graphic representing themes for each case

Step Six: Looking for Patterns across Cases

- The researcher pulls all graphic representations together to look for patterns or themes across cases
- Triangulation – Review demographic form and add/enhance information
- Triangulation – Review reflexive journal and compile summary

Appendix B: Free Crisis and Human Service/Autism Resources

[redacted]

[redacted]

[redacted]

Someone is available 24 hours a day, 7 days a week to assist you and your friends or family.

[redacted]

[redacted]

Appendix C: Demographic Form

Participant ID:

Mother's Occupation:	**Marital Status:**

Age:	**Ethnicity:**	**Number of Children:**

Number of Children Diagnosed with Asperger's Syndrome/Autism:

Age of Initial Asperger's Syndrome Diagnosis:	**Current Age:** 7 8 9 10 11 12 13 14 15 16 17

History of Services/Interventions

(Please check the box and indicate the number of years of each services)

☐Case Management: _____ ☐School Based Individual: ___ ☐Education Plan (IEP): _____ ☐Summer Therapeutic: _____	☐In-Home/Community Services: __ ☐Inpatient Hospitalization: ____ ☐Residential Treatment Facility: __ ☐Activities Program/Camp: ____	☐Outpatient Therapy: ____ ☐In-School Intervention (External Agency): ____ ☐Other:

What is your comfort level with your understanding/knowledge about your child's diagnosis?				
☐5- Extremely Comfortable	☐4 - Very Comfortable	☐3 - Moderately Comfortable	☐2 – Slightly Comfortable	☐1 - Not Comfortable
What is your comfort level with understanding services available in the school setting?				
☐5- Extremely Comfortable	☐4 - Very Comfortable	☐3 - Moderately Comfortable	☐2 – Slightly Comfortable	☐1 - Not Comfortable
What is your comfort level with understanding services available in the home/community setting?				
☐5- Extremely Comfortable	☐4 - Very Comfortable	☐3 - Moderately Comfortable	☐2 – Slightly Comfortable	☐1 - Not Comfortable

Appendix D: Interview Protocol and Questions

Opening Script

Good afternoon, my name is Pam Riley and I will be conducting the interview we discussed in an email last week. I appreciate your willingness to allow me to interview you on such short notice. Your participation in this research project on the changes to the Asperger's syndrome diagnosis will contribute to the study and help us understand more about what your experiences with services have been like since this change. I will be interviewing you and several other mothers whose information will contribute to this research. I did send you information about this study, but I would also like to review a few more items with you. I want to make you aware that your participation is voluntary, and you can choose to stop the interview at any time. Additionally, you can decline to answer any questions by just letting me know. I will be audio taping as well as taking handwritten notes throughout this interview. Upon completion, I will provide you with a copy of the audiotaped transcript and my notes. The purpose of this is to allow you an opportunity to review them and make any changes you would like. The goal is for me to capture and interpret exactly what it is you want to say. Finally, this study may be published in a scholarly journal or presented at a conference or meeting. Your name will not be used, and if direct quotes are used, pseudonyms will replace names. This interview will take 60 minutes, and I will do my best to stick to that time. We will only go beyond that time if you choose to do so. Do you have any questions? Are you ready to begin?

Interview Questions

1. When did you first hear about The Asperger's syndrome diagnostic change?
2. What has your initial reaction to the change in your child's diagnosis?
3. What has been your experience with your child receiving a new diagnosis?
4. What has been your experience navigating the school system since this diagnostic change?
5. What has been your experience navigating the managed care/insurance system to get services approved since this diagnostic change?
6. What has been your experience with the outside agencies providing services in the home/community setting and in the school setting since this diagnostic change?
7. Can you relay any specific examples or stories associated with these experiences?
8. Describe your feelings or the meaning you make of this diagnostic changes as it relates to stigmatization. (I recognize that I may need to share the definition of this term).

Closing Script

Is there anything else that you would like to discuss related to this diagnostic change and the impact it has had on you and your child's services that I have not already asked? Thank you for your time, and as I indicated earlier, I will be sending you a copy of my transcript and notes for review. Please let me know of any changes that you would like to see made or items I may have missed. Finally, please remember that your participation is voluntary, and you can choose to stop participating at any time. Thanks again!