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Parent Perspectives on how the COVID-19 Pandemic Affected Symptoms of Autism Spectrum Disorder in Their Children

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MA, Adler University, 2017

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Developmental Psychology

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Abstract

Autism is a disorder that is characterized by struggles with socialization and developmental delays that often involve much guidance and support. The purpose of this study was to explain the experience of parents as they attempted to manage behaviors related to symptoms of autism during the worldwide quarantine prompted by COVID-19. This study aimed to close the gap in literature and explore to see if there were any concerns that could be addressed by future studies. The study was framed around Bowen's theory, which addresses emotions within a family unit, and the interdependence theory, which addresses how humans thrive to be together and they are dependent on one another. These theories work together in this study to explain the overall emotional experience of the family unit through the eyes of the caregiver. The study was a qualitative study with a descriptive approach that utilized seven semistructured interviews to explain the individual experience. The data were then analyzed utilizing narrative analysis, using bracketing and clustering. Participants reported much intense emotion over watching their children struggle and experience meltdowns over things that were beyond the caregiver's control. The parents also experienced this additional stress, and it was difficult for them to manage and maintain their own mental health. Findings also suggested that parents continue to want the best for their children, even if access to the appropriate resources is difficult. The study addressed positive social change by calling attention to the inability for parents of children with autism to secure adequate resources, which can result in additional research to increase supports for these families.

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Dedication

I dedicate this research to all children and families who have struggled to find the appropriate resources and guidance they need. I dedicate this research to the individuals who struggled to be understood and those who went out of their way to help them be understood.

This research is also dedicated to my family and their never-ending support. Despite all of the ups and downs I have been through, they continued to push me and make sure I made my dreams come true. If not for them, I would not be here writing this. I would not be the person I am today.

Finally, I dedicate my research to future researchers and those who may be reading this at this time. Know that you are not alone in your struggles, and your hard work will pay off. Just keep pushing yourself to be the best you that you can be.

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To Dr. Melanie Shores, thank you for being there for me since the prospectus. It was a very stressful time for me, but you were always prompt in returning my attempts at communication, and you always provided the best advice. Thank you for helping me tweak my words to make them more apparent to those that may not follow the inner workings of my brain. You made me believe in myself.

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Chapter 1: Introduction to the Study

Background

This study aims to explain parents' perceptions of the presentation of symptoms of autism spectrum disorder (ASD) in their children during a quarantine that was prompted by a worldwide pandemic. Individuals with ASD may experience various levels of symptoms (Burton et al., 2020). Social insufficiencies primarily characterize these symptoms and include struggles with identifying social cues and with language. The difficulties that these children and their families are having were difficult to manage prior to quarantine. When coronavirus-19 (COVID-19) caused a worldwide quarantine, it interrupted the lives of many individuals. However, children with ASD experienced additional struggles because they require routine and predictability, which can result in additional stress for caregivers. Fully understanding the experience of the ASD population and their families can provide additional resources and guidance to recover from the pandemic and reduce the impact if there is a future quarantine.

Although there is research involving effective treatment, symptoms of autism, and effects of the quarantine on mental health, there is little to no description of parents' experience during the quarantine. There is a current gap in research regarding symptoms experienced during quarantine. The available research suggested that there is much research on how parents' mental health is affected as well as what methods of treatment are currently being utilized to treat symptoms of autism. However, current research has not fully addressed if the quarantine and lack of access to interventions has had an effect on the presentation of symptoms. The study of this phenomenon is important to social change because it may provide a wider understanding of the parent's experience of symptoms of ASD in their children as well as how social isolation can affect the presentation of these symptoms. Due to children with autism being a vulnerable population, this study addressed the caregivers' perception of the presentation of symptoms of autism during the worldwide pandemic.

Problem Statement

The situation or issue that prompted me to search the literature is the need to develop a more appropriate understanding of the autism population and the stress their caregivers endure. In addition to that, research suggested that this stigmatization is experienced by mothers who are caring for children with ASD and it negatively impacts their mental health (Oti-Boati et al., 2020). Since research found that educating society on mental health is effective in reducing stigma, this suggests that there needs to be more education and support for this group. Another area of interest for me is the COVID-19 quarantine. Many mental health facilities shut down face-to-face appointments, making the lack of access to interventions difficult. There are many effective interventions to treat the behaviors associated with ASD including but not limited to cognitive behavior therapy (Maskey et al., 2019), art therapy (Schweizer et al., 2020), and Lego therapy (Levy & Dunsmuir, 2020). Due to the worldwide quarantine, access to these resources were limited, which may have had a negative impact on individuals with autism and thus may have led to additional stress for their caregivers (Alhuzimi, 2021). Therefore, the impact of the quarantine on families who address needs of individuals with ASD must be identified and described.

Since COVID-19 is a new disease, new studies have been recently published regarding the quarantine prompted by COVID-19 (Alhuzimi, 2021). An exhaustive search and review of the literature suggests that there has been insufficient research on caregivers' experiences while attempting to manage their children's behaviors during a worldwide pandemic. Though studies suggest that parents have been negatively impacted by the quarantine (Althiabi, 2021), it is unclear what the parents experienced during this time. There may have been effective technological interventions available to assist parents with managing their children's behaviors, but they are not meant to replace typical face-to-face interventions (Nuske & Mandell, 2021). This suggests a possible reduction in the effectiveness and accessibility of resources for those with autism, which may lead to additional stress for parents attempting to manage the behaviors. Being able to identify the effects of the quarantine can help determine the need for supports in the autism community. To date, parents' experiences while attempting to manage their children's ASD symptoms during quarantine specifically from the DSM-V in the northeastern region of Pennsylvania have not been adequately described. This information can provide additional education to the region to increase the available supports for the autism community. It can also support any need for additional resources.

Purpose of the Study

The purpose of this qualitative study was to examine how parents describe their experiences with managing their children's behaviors related to ASD during the quarantine prompted by COVID-19. It also addressed any personal struggles that were endured while attempting to manage those behaviors during the pandemic.

Research Question

The specific research problem that was addressed through this study is as follows: How do parents describe their experience during the COVID-19 quarantine while managing their children’s behaviors related the ASD?

Conceptual Framework

The theories and/or concepts that will ground this study include Thibaut and Kelly’s (1959) interdependence theory and Bowen’s Theory (Galloway, 2019). These theories work together to help explain the interactions and emotions experienced by the parents of children with ASD. Thibaut and Kelly’s (1959) theory addresses the interactions between humans and how those interactions affect human behavior and development. Bowen’s theory addresses how family dynamics and emotions of others play a role in the presentation of emotions in other members of the family (Galloway, 2019).

In order to develop lasting relationships, regular social interactions are required (Kelley & Thibaut, 1959). It is likely for two individuals to develop a lasting and compatible relationship through these interactions, which can lead to codependence and additional support for one another. Individuals with autism already struggle with these interactions. Isolation and inability to socialize beyond their immediate family members results in loss of support and positive bonding.

Bowen’s theory addresses how an individual in the family unit affects the entire family (Galloway, 2019). This is important to look at because it can identify how parents struggle in managing significant behaviors in their children as well as stigma experiences by individuals who do not understand the circumstance.

The logical connections between the framework presented and the nature of my study include additional stress being placed on families of children with autism due to the quarantine, which may have led to additional struggles for families. The parents and the children are impacted by each other’s emotions, which may lead to more significant behaviors and lack of appropriate support. Due to parents playing an important role in the application of interventions (Hernendez-Ruiz, 2020), this additional stress and lack of outside support can lead to a negative experience in managing their children’s behaviors. These theories were further addressed in Chapter 2.

Nature of Study

To address the research questions in this qualitative study, the specific research design included phenomenology. According to Faurot (2020), phenomenology attempts to explain a phenomenon in nature. In this scenario, the parental experience with managing behaviors during a worldwide quarantine was researched. In order to address this phenomenon, interview responses were gathered from the families of individuals with autism. Parents were interviewed about their perception of the presentation of symptoms of autism during the COVID-19 quarantine. From this analysis, information was presented on the experience of symptoms presented by individuals with autism as reported by parents during the worldwide pandemic and quarantine caused by COVID-19.

For my research design, I recruited seven participants for the interviews via convenience sampling. Only families of individuals with autism were included. The requirements for participation were that the individual must have been diagnosed with ASD before the COVID-19 quarantine. Parents presented their recollection of symptoms due to the individual with ASD being a more vulnerable population. From these responses, I utilized narrative analysis to gather insight regarding the lived experiences of the participants.

I utilized the responses to describe the parental experience of observing and managing symptoms of autism in their children. Family responses were recorded. Responses were analyzed and sorted depending on the negative or positive articulation of events. Data analysis was completed utilizing bracketing, which is a method of removing bias by setting aside one's own ideas and biases to present the most accurate description of collected data and clustering meaning of responses. Clustering of data points was also utilized to identify common themes in response to the interview question.

There were also exclusion standards for the study. The individuals with autism were not interviewed due to the population being a sensitive population. The individuals already struggle to socialize. Adding additional expectations can unneeded distress; therefore, parents were interviewed. Also, there were exclusions for parents. The parents were excluded if they did not play an active role in the lives of their children with autism. In other words, parents were included only if they were involved in care and interventions of their children with ASD.

Definitions

In order to present accurate information, clarification of terms utilized in the study was necessary. The definitions are as follows:

Autism spectrum disorder (ASD) or autism: This disorder is a developmental disorder that is classified in the DSM-V (APA, 2017). This neurological disorder is usually presented in early childhood and includes impairments in: (a) communication and socialization, (b) forming relationships, (c) social cues, (d) repetitious behaviors, and (e) emotional dysregulation. Severity of the disorder is classified as mild, moderate, or severe depending upon the functionality of the individual. The severity of the disorder can also affect motor movements.

Coronavirus-19 (COVID-19): COVID-19 is a disease that became declared a worldwide pandemic in March 2020 (Oomen et al., 2021). It prompted countries to develop various changes to routines to stop the spread of the deadly disease (Turan et al., 2020). This disease led to the cancellation of many available services such as flights, doctors, and mental health services to ensure the safety of the citizens of the world (Oomen et al., 2021).

Pandemic: Pandemics are described as health concerns that affect an entire country or world. For the sake of this study, pandemic was utilized to describe a disease that quickly spread across the entire world, effecting billions of people.

Quarantine: A quarantine is restricted access to outside facilities such as stores, restaurants, schools, etc. This study describes a quarantine as being with only immediate family members for the majority of the time since the start of the pandemic. This may include minimal interactions for grocery trips or doctor visits; however, face-to-face socialization with individuals outside of immediate family members or those that did not abide by the safety recommendations were not included.

Parents: Parents are the individuals that primarily provide the care for the child with autism. For this study, they must have been actively participating in the care of the child before and throughout the pandemic. Biological parents who were not involved in the care were not considered for this study; however, active foster and adoptive parents who were responsible for the care of the child for more than 75% of their life were included.

Assumptions

The following study was developed around the perception and description of witnessed symptoms of autism during the COVID-19 quarantine, presented by parents of the individuals. Phenomenological studies address a phenomenon that must be further explored and focusses on the participants' perceptions of the phenomenon; therefore, it may not be the generalized accurately (Creswell & Poth, 2017). The suggested participant number can be as limited as three or up to 15 individuals. This provides information from the group about a shared experience of a phenomenon. The assumption for this idea is that the participants share their own experience during the phenomenon as fully and effectively as they can.

Scope of Delimitations

This study aimed to explore the parents' perceptions of symptoms of autism during the worldwide quarantine. Due to the specific category of participants required for the study, a criterion-based selection was used to determine if there was a similar shared perception of the experience. Participants were parents of children with autism. The study was limited to caregivers who were actively involved in the child's life as a primary caregiver for at least 75% of their lives. Each participant participated in an interview that was semistructured. Additional information was requested as needed.

Limitations

One of the main concerns was that the family's recollections of events may have differed than those of the individual or outsiders who did not know the individual. The parent may not be able to effectively represent how their child is feeling and why the behaviors are being presented as they are. Parents can also misrepresent the severity of the behaviors due to the behaviors occurring on a regular basis in the home. In order to address this, I encouraged the parents to provide as much detail as possible. These concerns were addressed by encouraging parents to identify any changes they had noticed in triggers, frequency, intensity and duration of tantrum behaviors, and any behavioral changes.

Another challenge that could have limited the study is that additional stress induced by social isolation, inability to gather resources, losing work, and other pandemic/quarantine related stressors may have impacted the parent's overall wellbeing. These additional stressors could have affected the overall recollection and presentation of their experience, including their children's behaviors. This was addressed by encouraging parents to be as open as possible about any additional stress that they endured during the quarantine. This can provide a broad understanding of the entire experience. It may also lead to a need for additional studies regarding the relationship between these stressors and managing behaviors.

Another limitation was my possible bias. In order to reduce this bias, I utilized bracketing. This allowed my own views to be set aside to most accurately record and represent the data presented by the participants.

Significance

This study is significant in that it can explain the experience of symptoms of autism during a worldwide pandemic and quarantine. With this explanation of the experiences of symptoms during a quarantine, a better understanding of the phenomenon emerges. This study suggests that individuals with autism and their families have experienced great difficulties during the quarantine, which should prompt the development and easier access to resources in case there is a similar situation in the future. The study can also adds to the knowledge of symptoms of ASD and how they are experienced during a quarantine. An increased understanding should prompt identification of an effective intervention in the case of a future pandemic. It also suggests that there is a need for easier access to resources for these families in need.

Summary

Chapter 1 addressed the importance of filling the gap in literature regarding the presentation of symptoms of autism during the COVID-19 quarantine. It described the purpose of the study, which is to address the parent’s experience of symptoms of ASD in their children during a worldwide quarantine prompted by COVID-19. Symptoms of

ASD already include concerns with socialization and interaction. Adding a worldwide quarantine provides additional struggles. Per the interdependence theory, these interactions are critical for human development. Absence of these interactions may affect the presentation of symptoms. Understanding the presentation of symptoms is important to maximize supports for the ASD population. Chapter 1 also presented information regarding the conceptual framework, which was interdependence theory, and the research design, which is a phenomenological approach.

In Chapter 2, previous literature relevant to the study is presented. The main ideas and limitations of previous studies are discussed to define the gap in literature. In it, I also describe the symptoms of autism as well as what is known about the experiences of those with ASD during COVID-19. The research methodology is presented in Chapter 3. This chapter discusses the sample size, research design, role of the researcher, and data collection methods. Chapter 4 presents the analysis and findings of that methodology. Finally, Chapter 5 summarizes and interprets the results of the study. It also presents any need for additional research.

Chapter 2: Literature Review

The purpose of this qualitative study was to improve the understanding of how parents describe their experience while managing behaviors of autism in their children during the quarantine sparked by COVID-19. When COVID-19 first appeared in the United States of America in March 2020, society did not know how to prepare or adapt, especially individuals with ASD and their families (Alhuzimi, 2021). These families were already struggling to find the appropriate care for their loved ones, and then they had to promptly change their routines due to numerous safety precautions that were initiated to protect the world from the deadly virus (Althiabi, 2021). When many first learned of the virus in the United States, they were in disbelief that the world was going to shut down. However, very quickly and without warning, U.S. school systems were shut down for 2 weeks initially, and eventually indefinitely. Many other systems were also shut down. The virus put the world into a state of chaos and uncertainty. The state of the world added to the additional stress caused by the behaviors and needs of individuals with ASD, suggesting that professionals must research to understand the impact better.

There has not been a significant amount of research on ASD and COVID-19 since worldwide onset of the virus. However, much of the current research identified areas in which COVID-19 and the quarantine have affected the mental health of families of individuals with ASD. They expressed the viewpoints of the family members and how other disorders can cause struggles for individuals with ASD. This information is crucial in understanding the autism population, but it does not address the entire problem. There is not sufficient information regarding how COVID-19 and its quarantine have affected the presentation of symptoms of autism and the experience of parents in managing these symptoms.

This literature review aims to provide information regarding parents' experiences of managing their children with ASD. The goal of this literature review is to identify what autism is and how to diagnose the disorder. It provides an understanding of the struggles that this population has to endure. It addresses treatments that have been effective in the past for treating ASD symptoms. I also describe COVID-19 and how others have reported effects on the autism population.

Literature strategy

I conducted the literature review via the Walden University Library using their internal search tool called Thoreau. The included terms were *autism* AND *ASD* AND *autism spectrum disorder* AND *autistic*, *COVID-19* AND *coronavirus-19* AND *symptoms* AND *signs*. The dates of most of the articles were within the last 5 years. I included older resources in the research to widen the knowledge and information presented about autism. I also used dated resources to help explain the theoretical framework of the study.

Theoretical Framework

There are two theories that frame this study. These theories work together to describe the problem. This study incorporated the interdependence theory, which has been used to study the interaction between individuals in various relationships (Balliet et al., 2016) and Bowen's theory, which has been used to identify how a child with autism's behaviors affect the family unit (Cridland et al., 2014).

Interdependence Theory

One theory that framed this study was the synthesis of Thibaut and Kelley's (1959) interdependence theory. This theory addressed the interactions between humans and how those interactions affect human behavior and development. It is essential to understand these interactions due to socialization and interaction with others being one of the main struggles for individuals with autism.

History

The interdependence theory was first developed in the late 1950s (Thibaut & Kelley, 1959). Still, since its initial development, the approach has continued to grow and expand while keeping the original framework (Van Lange & Balliet, 2015). The continued growth of the theory suggests that it is a significant theory and continues to play a large in social psychology. Adding ideas supporting the view means that the approach is crucial for understanding human development and interaction.

During the same time as the development of the interdependence theory, many other social theories were also being developed (Van Lange & Balliet, 2015). These theories all influenced one another and developed based on the same ideas. Some of the most critical ideas addressed at this time were social dilemmas and goal expectations. The ideas also expand beyond social psychology as studies identified aggression and group interactions as essential components of human development.

Structure

In order to understand how interdependence theory describes human behavior, it is essential to understand the main components and ideas behind the development of the theory. Thibaut and Kelley (1959) developed the basis of interdependence theory around key features and a defined structure (Van Lange & Balliet, 2015). Human interaction can be predicted and explained by these features and structures. Humans learn and grow by developing relationships dependent upon the interactions.

Features. The features of the interdependence theory suggest what needs to happen for the theory to be relevant (Van Lange & Balliet, 2015). Having this structure helps understand the interaction between the individuals. The first feature is that a situation occurred. Thibaut and Kelley (1959) described this situation as an interaction between two individuals that can form a relationship after numerous interactions. After the interaction, the people involved are affected or transformed (Van Lange & Balliet, 2015). From there, the individuals interact with one another and adapt to the situation in practical ways. The interaction is important in understanding the impact of quarantine on individuals because interactions are crucial for human survival.

Factors. There are also many factors to consider when attempting to predict the interaction between individuals (Van Lange & Balliet, 2015). These factors can sway the results and predictability of the behaviors. Understanding these factors and how they affect interactions is critical to understanding the interdependence theory. However, it is important to note that in Thibaut and Kelley's (1959) original theory, they found that predicting interactions is uncertain when utilizing their matrix. Professionals must consider many additional components during the interaction. The multiple components suggest that human interaction is complex, and any variation of events may be critical in changing or challenging that interaction. With an unprecedented worldwide quarantine prompted by a deadly virus, interactions are limited and may have long-lasting effects. Adding those potential effects to the difficulties individuals with autism already endure may pose additional concerns.

One of these factors is how dependent the individuals are on one another (Van Lange & Balliet, 2015). Suppose individuals are more independent and make decisions based on their desires, thoughts, and needs. In that case, they are less likely to be swayed by the other individual's desires, ideas, and needs. The opposite is true for more dependent individuals. The more independent individuals have deeper thought processing, while the dependent individuals have more shallow thought processing. This thought processing is essential in understanding interdependence theory and interactions between two individuals because it aids in predicting and understanding the interaction.

Another critical factor is how individuals influence the situation's outcome (Van Lange & Balliet, 2015). Whether or not the people affected are influenced more by morals or the majority behavior determines an outcome. Suppose an individual is more likely to follow the majority or be influenced by others rather than their moral judgment and understanding of right or wrong. In that case, their behaviors will reflect that idea.

The individuals' interests and whether or not they align also play a significant role in human interactions (Van Lange & Balliet, 2015). If the individuals have similar interests and desires, their interaction is more likely to be positive. However, the inability to modify one's actions and interests to address the concerns of the other individual may lead to conflict or negative interaction. The lack of cooperation between both parties may lead to distrust.

Finally, the individuals need to understand how their actions will affect the other individual (Van Lange & Balliet, 2015). The inability to understand how one’s actions and behaviors affect that of another interrupts the interaction. Predicting how an action can affect someone else is more easily predictable when interacting with someone familiar such as family, friends, or teachers. When interacting with someone new, most individuals fill in this unknown information with assumptions based on interactions with other people. These assumptions can be an effective way to structure interactions, but this information is not always accurate.

Relevance

The interdependence theory is relevant because individuals with autism already struggle to recognize and follow social norms (Lever & Geurts, 2018). Due to the pandemic and quarantine, there were restrictions regarding mobility, which led to the unavailability of resources that have been previously helpful to manage behaviors for the autism population (Althiabi, 2021). It is essential to understand the experience of symptoms during isolation and quarantine to identify whether it is necessary to address other struggles. Without extensive interactions with individuals outside of their immediate family, individuals with autism may not appropriately develop the skills needed to socialize and communicate effectively. If there are struggles, additional research can be framed to explore the best care for individuals. Any needed further analysis can be prepared to aid in managing the symptoms of autism during any future isolation or quarantine.

Bowen Theory

Another theory that was synthesized for this literature review is Bowen Theory. This theory addressed how the family dynamics and emotions of others play a role in the presentation of emotions in other members of the family (Galloway, 2019). This theory is important because it suggests that the emotions and well-being of other individuals in the family are dependent upon the emotions of the family unit rather than just the individual. This suggests that parents may be able to accurately report the emotions of their children with autism.

History

As early as the 1950s, family researchers have been exploring how the family is a unit rather than just an individual (Gilbert, 2006). Dr. Murray Bowen witnessed this in the interactions and well-being of patients with schizophrenia with their families. He then wondered if the same phenomenon could be experienced and generalized to all individuals.

Concepts

Nuclear Family Emotional System. Something that Bowen focused on is that families operate as a unit and not just on an individual basis (Galloway, 2006). An interesting concept mentioned is that the individual cause and effect thought process must be abandoned. Instead, thinking must be changed to examine the entire family unit.

Another interesting concept is that conflict or turmoil are handled in a more appropriate manner (Galloway, 2006). When there is conflict or a disagreement, the individual is to think of how they can change their own behaviors to contribute positivity towards the family unit. This avoids blame of others or attempting to change other's behaviors. In turn, emotions of the unit are affected in a similar manner.

The main idea of this concept is that when one individual in the unit is affected, it affects other individuals in the unit (Gilbert, 2006). One way that this occurs is due to the teachings of family traditions and learning to be a part of the unit from lived experiences. This develops a sense of belonging and despite attempting to be an individual, the family unit is what develops personality. This also plays a part when natural instincts tend to kick in. When one person in the unit is feeling stressed emotions quickly spread to other individuals in the unit. The same can be true for individuals with autism and their families. This concept makes it easier to track and predict anxiety and various other emotions.

If someone is able to predict the emotions and how they affect others in the family, those emotions can also be changed (Gilbert, 2006). One individual can change the patterns of the relationships by changing how they act or respond to that situation. This can then lead to a more positive experience during the relationship.

The Differentiation of Self Scale. This concept encourages the individual to be themselves and not to be too involved in the dynamics of the family (Gilbert, 2006). It suggests that it is important to be an individual and not define an individual by their emotions, and it is framed upon the idea that human emotion and the ability to adapt relies upon a scale. This scale determines emotional functioning.

Cutoff. This concept suggests that if emotions are overwhelming it will likely lead to cutoff, which is when generations of families are separated from others (Gilbert, 2006). It was found that individuals in group homes did significantly better when families were encouraged to participate in treatment.

Family Projection Process. This concept suggests that even though siblings can be raised by the same two individuals with the same number of supports, they can be very different individuals (Gilbert, 2006). This leads back to the differentiation and how each individual has their own level, which is usually a result of how the parents interact with the children. When family members pay more attention to one child that child is likely to become more anxious and require extra guidance in life. The children that are not as hovered over as less likely to have anxiety and they are more likely to become independent.

It is important to note that this concept does not suggest that parents are to completely blame for the conflicts that their children are having (Gilbert, 2006). They may struggle to admit their role in the problem, and they often require special training or coaching to change their own behaviors. This is critical in building a strong foundation for relationships.

In regard to children with autism, everyone within the family is affected. Individuals with autism require extra support and guidance, which tends to lead to that additional dependency. It is important to determine where the appropriate levels of support and guidance are.

Societal Emotional Process. This concept suggests that as society changes, family dynamics change (Gilber, 2006). Society changes fairly quickly, and sometimes humans cannot adapt fast enough. As society changes, families begin to break apart or struggle. These struggles can be detrimental to the family unit. There are many factors that determine the breaking of the family including parenting styles and outlying factors such as gang activity.

Relevance

All of these concepts are important in understanding how families interact and grow together. Bowen had suggested that families should be viewed as a unit, and often they share similar emotions throughout that unit.

In turn, relationships form by individuals being willing to give and take a little from each other (Gilbert, 2006). This also results in different emotions being passed from one individual to another. Families that rely a lot on one another are often the ones that feel worn out and struggle to appropriately manage the conflicts outside of their family. For example, parents of children with autism may become very worn out due to having to give a lot of their time and patience to their children to help them learn and grow. This can leave them feeling exhausted and unable to work or take care of themselves appropriately.

Cutoff is also an important concept that can affect the emotional wellbeing of families of children with ASD during the COVID-19 quarantine. These families were unwillingly cutoff from individuals in their families. It added a lot more stress as many had to adapt to the new way of life and attempt to keep relationships with loved ones. They also struggled to maintain their own family inside their households.

Another great impact on the family unit for individuals with autism can be the lack of understanding and support for the community. Society tends to reject things that they do not understand, and unfortunately, individuals with autism and their families can be severely impacted. With COVID-19 and the worldwide quarantine, these families were forced to adapt to numerous changes indefinitely. They may not have been able to adapt appropriately.

Working Together

Additional stress being placed on families of children with autism due to the quarantine, which may lead to additional struggles for the family. The parents and the children may feed off of each other's emotions, which may lead to more significant behaviors and lack of appropriate support. Due to parents playing an important role in the application of interventions (Hernendez-Ruiz, 2020), this additional stress and lack of outside support may lead to a negative experience in managing their children's behaviors.

Literature

Factors to Consider

Autism is a disorder that can affect the daily lives of individuals diagnosed and the families attempting to manage the behaviors. These behaviors are expressed in different ways and impact other parts of life. To have a significant understanding of the disorder, considering specific factors is critical.

Age

It is important to address age when discussing ASD. Age appears to play a significant role in the experience of symptoms (Lever & Geurts, 2018). However, some studies have suggested that adolescent age does not correlate with the experience of symptoms (Greenlee et al., 2020). Symptoms of autism appear to be much more severe and frequent in younger children, but the symptoms appear to become less significant as the individual ages. The significance of symptoms decreasing with age can be due to their abilities flourishing, maturity levels raising, learning new skills, or many other factors. This idea is important to consider because it identifies a population at risk, leading to an additional need for resources.

Age plays a factor in the representation of symptoms in other ways as well. For example, older individuals with autism tend to rate their irritation to sensory stimulation as more frequent than individuals witnessing the behaviors (Lever & Geurts, 2018). This idea suggests that the adult with autism feels much more irritated than what they are presenting. This perception is most likely due to learning skills throughout their youth and practicing them to manage behaviors better. This idea is important to keep in mind because the individual with autism may be having a mental struggle that they are managing only to the point that limited external symptoms are presented.

Gender

Another factor that plays a significant role in the presentation of symptoms of autism is gender. About 80% of the autism population are male (Cai et al., 2018), suggesting that males are more affected by autism. However, that is not necessarily true.

Humans are naturally social creatures, but individuals with autism struggle to communicate and socialize effectively (Greenlee et al., 2020). Studies suggested that females are more prone to socialize than males. This socialization can add additional stress and discomfort to the individuals experiencing symptoms, making the presentation of symptoms in females much more significant than in males.

Though males and females both experienced similar difficulties in socialization, females experienced more significant side effects to those symptoms (Greenlee et al., 2020). For example, researchers found that anxiety levels in girls were able to be predicted depending on their ability to communicate. This finding suggests that being female plays a significant role in how symptoms are presented and affect other disorders.

Bullying

Bullying should also be taken into consideration when attempting to aid the autism population. Studies have suggested that adolescents with autism are victims of bullying more than any other population (Greenlee et al., 2020). On average, 10-15% of typically developing children and 14-24% of adolescents with disorders other than autism report being the victim of bullying. About half of the reported 46-94% of adolescents with autism have reported being victimized by a peer at least once. This data suggests that individuals with autism become victims of bullying twice as much as other populations. The data are a concern because it appears that an ASD diagnosis can be a target for bullying.

Another concern is how individuals with ASD respond to bullying. Although there have not been significant findings that an autism diagnosis correlates with other struggles to cope with bullying, there are studies that suggest individuals experience more mental health difficulties such as anxiety and depression that can make it more difficult to cope (Greenlee et al., 2020). Another study found that some individuals also stand up to bullying, whether the victim or someone else (Fisher & Taylor, 2016). These responses to bullying become very concerning due to the individual’s difficulty with social cues and understanding. They may put themselves in additional harm due to their inability to understand.

Symptoms

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) was developed to identify symptoms of various mental health disorders (American Psychological Association [APA], 2017). The DSM-5 classifies ASD under the category of neurological disorders, meaning that symptoms of ASD are usually presented and recognized in early childhood development. Some studies suggested that behaviors may be prevalent in children as young as nine months old (Sacrey et al., 2021); however, symptoms may also become more prevalent during adulthood. These developmental abnormalities can lead to impairments in socialization, academics, or even personal functioning. Children with ASD may experience these impairments at varying different levels of the spectrum.

These impairments result in the need to identify further and classify the disorder. The DSM-5 accomplished this by including subcategories of disorders in the neurological disorder category (APA, 2017). The DSM-5 presented ASD under the communication disorders subcategory. Deficits with language and communication characterize these disorders. The DSM-5 defined language as any combination of a system of symbols or words used to communicate according to a set of rules. Communication is defined as the attempt to use verbal or non-verbal behaviors to express something to another individual. Individuals with ASD struggle with these skills.

Diagnosing

To consider an ASD diagnosis, researchers identified guidelines that the clinician must follow (APA, 2017). Due to the guidelines, a trained professional must administer appropriate testing for an individual to be diagnosed with ASD (Sacrey et al., 2021). One of the first considerations should be that other neurological disorders may explain behaviors and symptoms experienced (APA, 2017). Ruling out other disorders first can be an effective way of identifying ASD. Autism is a very complex disorder, and it is affected in different ways. It is important to correctly identify whether the behaviors are due to ASD.

It is imperative to pay close attention to the details of symptoms when diagnosing ASD (Sapmaz, 2018). Mental health professions often misdiagnose ASD as a manic disorder or other disorders due to the explosiveness of emotions and the inability to communicate effectively. These misdiagnoses can be detrimental to the individual's wellbeing due to the specific requirements for treating the disorder.

Communication and Socialization. According to the DSM-5, the presentation of various difficulties with communicating and socializing with other individuals characterizes ASD (APA, 2017). Some of the basic communication skills learned at a young age may not be understood by an individual diagnosed with ASD. Eye contact, waiting to speak until someone else is finished talking, and even considering other people's opinions can be difficult for individuals with ASD. This deficiency in communication skills can lead to much difficulty for both the child for being unable to communicate their needs and the parent for being unable to identify what their child needs or wants (Greenlee et al., 2020). These struggles are not ideal for either the parent or the child.

Another area that individuals with autism struggle are with forming relationships with peers (APA, 2017), which is critical for development during adolescents (Greenlee et al., 2020). Individuals with ASD struggle to hold age-appropriate conversations with others. They may not understand social boundaries and may approach others in a way that may not be appropriate. They also struggle to reciprocate conversation due to a lack of understanding. Individuals with ASD may appear to be focused only on themselves and may not show any interest in other individuals, their thoughts, or their feelings. They can also be misunderstood by others and even bullied or shunned. This inability to communicate effectively and bond with others will lead to additional developmental delays.

Individuals with autism also struggle with socioemotional understanding (APA, 2017). Not only do they struggle to understand the socioemotional responses from other people, but they also struggle to express their own emotions in an effective manner (Sapmaz, et al., 2018). Individuals with autism struggle to show appropriate facial expressions that caregivers can analyze, and they often resort to aggression or self-harm behaviors. The inability to physically express their emotions can make it difficult for those with ASD to form and maintain relationships with others (APA, 2017). The failure to develop appropriate relationships with others can result in more deficiencies in communication skills.

Individuals diagnosed with ASD also struggle to adjust their behaviors to meet the needs of those around them (APA, 2017). For example, sharing may be difficult for individuals with ASD because they first had the toy or wanted it. They may not understand that it may be considerate to share with others, and you should not just take something from someone else if you want it. Again, this can result in aggressive or selfharm behaviors (Sapmaz et al., 2018). The inability of the child with ASD to understand
these social boundaries can result in confrontations with others.

In addition to that, some individuals experience the inability to reciprocate conversations (APA, 2017). The difficulty with conversation can make it difficult for individuals to form and understand relationships, interrupting the overall well-being of the individual's life. They may end up feeling very alone and struggle to form a bond with the individuals around them. Not being able to bond or trust others can affect the individual's willingness to participate in treatment or interventions.

This difficulty with communication can lead to social and emotional deficiencies, but it can also affect physical abilities. Struggling to communicate and understand various social cues may interfere with an individual with autism's physical health. For example, the research found that high-functioning girls with autism struggle significantly in communication compared to typically developing individuals (Burton et al., 2020).

The inability for these young girls to communicate and understand social cues poses a threat to their health due to the inability to give appropriate gynecological exams (Gallagher et al., 2019). Being unable to withstand a physical examination may lead to physical health concerns in the future.

Repetition. Another characteristic of ASD is repetitious behaviors that can be restrictive to the individual's daily life (APA, 2017). Studies have also found a link between repetitious behaviors and negative mental states such as anxiety and stress (Martinez et al., 2021). Many children with ASD have very restrictive interests, and they find it difficult to transition from one thing to the next. These patterns of behaviors have become comfortable to the individual with ASD, and any sort of change can lead to them feeling uncomfortable.

Bystanders can see some of the repetitious behaviors (APA, 2017). For example, some individuals may self-stimulate by flapping their hands or making noises that can calm them. They may find comfort in things being lined up appropriately or organized to their liking. These behaviors may not appear restrictive, but at times, the behaviors can interfere with the individual's daily life. It can also lead to others misunderstanding or misjudging the individual.

In addition to the physical behaviors, individuals with ASD also find it challenging to change routine or transition from one activity to the next (APA, 2017). They repeat their routines, and any slight change may affect their overall mood and wellbeing. These patterns of behaviors can become very restrictive due to the individual not wanting to change their routine. The restrictive patterns can stunt emotional and social growth, which can affect the functioning of the individual. Not understanding social cues and communication can make it even more difficult for individuals with ASD and their families.

Individuals with ASD also have a very restrictive set of interests (APA, 2017). Many individuals with ASD become fixated on a topic or an object, and they do not want to discuss or participate in any other activities. They will only attempt conversation with others if it is about their favorite topic of interest. They may become distressed if the subject is changed or talk over the other individual. They may also develop habits or routines in their play that can be very restrictive. These struggles again can lead to misunderstandings and misjudgments that the individual with ASD struggles to understand.

Finally, individuals with ASD can experience low sensitivity to various sensory inputs (APA, 2017). Individuals with ASD may not feel pain or experience temperature in the same way that a typically developing child may experience it. The lack of sensitivity makes it very difficult to keep the child safe. They may continue to participate in dangerous behaviors even though they broke an arm last time. The behaviors pose a risk to their physical well-being.

The opposite may also be true: Individuals with ASD may also experience oversensitivity to stimuli from the environment (APA, 2017). They struggle to process excessive or unexpected noises, leading to agitation, frustration, and tantrum behaviors. Often, someone needs to remove the stimulus for the individual to be able to calm down. The oversensitivity can become very restrictive and possibly dangerous. For example, an individual with ASD may become overly stimulated by a fire alarm, leading to the inability to respond appropriately to the alarm. The sensitivity can lead to other emotional and physical struggles.

Summary. According to the APA (2017), there are two main symptoms that individuals with ASD can experience. First, they struggle with age-appropriate socialization and communication skills. Second, they experience repetitive and restrictive patterns of behaviors. Caregivers often witness these behaviors during early childhood, but they may not be as apparent with higher functioning individuals. It is essential to understand these basics to receive a complete understanding of ASD and how parents experience these symptoms during the COVID-19 quarantine.

Cooccurring Disorders

Although autism is a disorder on its own, it is essential to address other cooccurring disorders when discussing autism. Celia et al. (2018) suggested that it is ideal to conduct a nursing assessment to identify psychological and physical disorders in individuals with autism, and treatments vary depending on the disorder. It is vital to have a broad understanding of the various symptoms and disorders that an individual with ASD is experiencing because they can be a susceptible population. It is crucial to identify the most appropriate approach for interventions and support.

However, identifying cooccurring disorders with ASD can be very difficult due to the deficiencies in communication (Sapmaz et al., 2018). An individual with ASD may be unable to communicate that they are feeling empty or having suicidal thoughts. Due to the lack of communication, mental health professionals may miss a depression diagnosis.

The family or caregivers play an essential role in identifying these symptoms.

Intellectual Disorders

It is important to note that individuals with ASD often have a low intellectual quotient (IQ) of less than 70 (Sapmaz, 2018). These low IQ scores can result in a lack of verbal ability and understanding, leading to even more deficiencies in communication skills. The low IQ is concerning because individuals that have a low IQ struggle in various areas socially, educationally, and emotionally. They may also struggle to learn new skills to help them live a more effective life. Parents take on the additional stress and struggle as they attempt to teach their children new things that may be essential to living, but their children may not understand.

Bipolar Disorder

Bipolar disorder is a disorder that includes manic episodes (Sapmaz et al., 2018). Some of the symptoms include irritability, aggression, inability to sleep appropriately, and mood dysregulation. These can all be symptoms of autism, but the behaviors and symptoms intensify with bipolar disorder. Mood instability can be unpredictable and challenging to manage. The mood instability can lead to additional irritability in family members and caregivers and mistreatment of the individual.

Sapmaz et al. (2018) found that individuals with autism often have a co-occurring diagnosis of pediatric bipolar disorder. These individuals experience much more significant symptoms of pediatric bipolar disorder than those without ASD. The cooccurrence is interesting because individuals with ASD can experience significantly less understanding of their surroundings and emotions than a typically developing individual. With finding it challenging to communicate, individuals with ASD may also feel withdrawn from the general population. Not being able to understand or communicate how they are feeling may increase the overall frustration. Parents attempting to manage these behaviors can feel overwhelmed and not sure what to do to help their children.

Depression

Depression also is common in individuals with autism, and treatment methods vary depending on the child's abilities (Menezes et al., 2020). The variance is presumably due to the deficiency in emotional regulation skills (Santomauro et al., 2016). Research suggested that between 17 and 44 percent of individuals with ASD are diagnosed with depression. The range of percentages depends upon the age of the individual. As many as 50% of adults with an autism diagnosis have experienced reoccurring major depressive episodes, while around 70% have experienced one major depressive episode in their lifetime. The prevalence and risk present with these disorders identify a strong need for treating depression in this population.

These individuals experience a wide range of depressive symptoms (Santomauro et al., 2016). Symptoms can include feelings of worthlessness or suicidal tendencies. A cause for concern arises because depression can be deadly if left untreated, especially since individuals with autism express symptoms in more intensive ways. Their inability to effectively communicate or understand their own emotions can lead to aggressive or self-harm behaviors that can be life-threatening. It is important to identify, diagnose and treat symptoms of depression. It is important to have a team of individuals specialized in recognizing and treating these disorders. Parents are critical in being able to notice and address these concerns as they are the individuals that are with their children the most.

Anxiety

Anxiety is yet another disorder experienced in conjunction with autism (Ireri et al., 2019). Individuals with autism experience thoughts that cause fear, and they are often unable to manage those fears appropriately. These phobias are consistent and interrupt the daily functioning of the individual with ASD. They can include fear of more common things such as a specific animal. It is easy to avoid that specific animal. However, they can also include everyday items such as a vacuum, which is less simple to avoid. These fears can affect their daily lives. Individuals with co-occurring diagnoses of ASD and anxiety can result in avoidant behaviors, emotional distress, and tantrum-like behaviors.

Anxiety and ASD can interact and make the symptoms more significant (Maskey et al., 2019). Autism symptoms may make these phobias and fears more significant due to the individual's lack of emotional understanding and regulation. These disorders can also affect the symptoms of autism as well as the treatment options available. Parents also can play a role in the presentation of anxiety in their children. Adding a worldwide pandemic can add additional anxiety for both parties.

Interventions

The most important step to treating ASD is to be educated and have support. Having a positive support network for the child and family and understanding ASD is also beneficial to treatment for ASD. Fung et al. (2018) found that parents involved in a support group and received education on ASD treatments were significantly more likely to apply effective interventions. Constain et al. (2018) also found that educational interventions for parents and teachers effectively allow individuals with autism to receive the most appropriate care. Without appropriate education and support, parents and educators can become burnout rather quickly.

Restrictive

There are many specific treatment methods for symptoms of ASD with varying degrees of restriction, depending on the individual's needs. Due to the large range of the autism spectrum, there are various degrees of symptoms, resulting in various degrees of restrictive interventions. Identifying the individual's abilities is critical in determining what the most appropriate intervention includes.

Hospitalization. One of the most restrictive interventions for ASD is inpatient hospitalization (Taylor et al., 2019). Hospitalization is an intervention utilized in extreme cases when the child is a threat to themself or others. Like all other disorders, hospitalization or long-term care is a last resort treatment method. Mental health professionals consider hospitalization if behaviors and symptoms are detrimental to the safety and well-being of the individual or others around them.

Though hospitalization is a last resort scenario, children with ASD are hospitalized more frequently than the general population (Taylor et al., 2019). These individuals are six times more likely to receive pediatric inpatient treatment, and the treatment can last up to 12 times longer than the typically developing child. The research estimated that 11% of individuals are diagnosed with ASD receive inpatient hospitalization by the time they turn 21-years-old. These numbers are significant due to the wide range of individuals affected, which results in the need to analyze these treatment facilities.

It is important to note that there are varying models of inpatient treatments, including specialized and unspecialized facilities (Taylor et al., 2019). Due to the varying expressions of symptoms in individuals with ASD, it is clear that individuals with ASD require specialized treatment in these hospitals. Identifying this potential need is critical to the understanding of ASD.

An important idea to consider the effectiveness of inpatient treatment for individuals with ASD is whether or not the facility specialized in ASD (Tayor et al., 2019). Specialized treatment teams are more effective in treating individuals with ASD through applied behavior analysis (ABA), social work, and speech and occupational therapy specific to ASD treatment. These treatments can be longer in duration due to the observational aspect of the treatment, which can be the cause of individuals with ASD receiving a longer stay in these facilities than the general population. Having these resources available to individuals struggling with ASD and possibly other co-occurring disorders is critical to the effective treatment of ASD.

The effectiveness of the ASD specialized facility and the general population facility were compared (Taylor et al., 2019). Interestingly, research found that individuals with ASD treated in generalized and specialized treatment facilities experienced a significant decrease in behaviors of concern from the time admitted to the time discharged. However, it is important to note that the individual needs to be in a stable state of mind to be discharged, and significant behaviors need to be minimal. A more significant finding was that the average change in behaviors was more significant in individuals treated in a specialized facility.

Researchers conducted a two-month follow-up study that identified the long-term effects of the individuals who received inpatient treatment (Taylor et al., 2019). All individuals that had received inpatient treatment experienced varying degrees of regression, presumably due to their return to a less controlled environment. The home and community environment may have additional stressors not experienced in the facilities; therefore, it is common for regression to occur. However, an important finding is that the individuals in a specialized treatment facility experienced less significant regression in treatment. The reduced regression suggests that specialized treatment facilities have a more effective impact on behaviors and symptoms than generalized facilities.

What becomes concerning is that only ten inpatient facilities specialize in treating ASD and other developmental disorders within the United States, resulting in a lack of available resources (Taylor et al., 2019). More frequent hospitalizations occur, leading to various concerns. As mentioned previously, inpatient is the most restrictive intervention method, resulting in the individual missing out on various occasions in the general population. They were away from family and caregivers, which results in a lack of familiar support. The individuals can also develop more significant behaviors that other individuals are experiencing. Also, individuals with ASD may become accustomed to the facility’s structure, making transitioning to the general population very difficult and stressful. Therefore, it is critical for inpatient hospitals to be specialized in ASD.

Medication. Another restrictive intervention is the use of medication (Esler et al., 2019). Although this is an effective treatment method, studies found that doctors prescribe individuals with autism more psychotropic medications than those with similar developmental disabilities. Studies also found that there is limited research on the effectiveness of medications in treating the symptoms of autism (Vasa et al., 2014). These methods of intervention should be a last resort.

Less Restrictive

Other intervention methods are less restrictive. The individual's rights are not as controlled, and they have more freedom. The freedom allows them to have life experiences that resemble the experiences of the general population.

Family. Family plays a significant role in the treatment and well-being of individuals with autism. These are the first individuals they interact with and learn from; therefore, they need to learn how to help individuals with ASD, which means they can have the greatest impact on them. It is important to help the family or caregiver to be able to help the child with ASD. Caregivers utilize various techniques for the treatment of these symptoms.

Teaching interventions to parents can lead children with ASD to learn more effective communication skills (Wainer et al., 2017). Through coaching, parents could learn skills that they could use to help their children. Parents that participated in the coaching reported that they were satisfied with the interventions they learned. A followup study found that the parents were able to utilize the techniques effectively. These techniques can allow the parents to feel more effective as a parent, and it can help the child with ASD be more exposed to the skills due to their time with parents.

Another effective intervention method for family members was group therapy and support groups for parents (Fung et al., 2018). Researchers conducted a study to address the psychological well-being of mothers of children with ASD. In this study, researchers tested flexibility, cognitive function, and values in pre-, post-, and follow-up tests. In the study, a group of parents lead other parents and provided support. The study found that the support and guidance provided lead to positive psychological well-being. Parents need to have healthy psychological well-being to provide the most appropriate care for their children. Parents become burnt-out, and they may not have the energy to be as helpful to the child as they can be.

Music Therapy. Another specific method identified by researchers as effective in treating ASD and cooccurring disorders is music therapy (Cibrian et al., 2020), based on psychological and physiological research (Khyzhna & Shafranska, 2020). The basis of this therapy suggests that music affects both physical and mental health, both areas that are affected greatly by the symptoms of autism.

Research also suggested that it is proven to be effective in improving behaviors in individuals with autism (Cibrian et al., 2020). Utilizing music therapy is an effective way to increase communication, which is one of the main symptoms of autism (Khyzhna & Shafranska, 2020). Vocals in music therapy increase the use of words due to repetition and imitation, but music is effective in relaxing. Music therapy plays an important part in this study because this intervention method may not have been affected by COVID-19; therefore, it would still be available as an intervention option.

Creative Therapies. There are many uses for treating symptoms of autism with creative therapy. For example, art therapy can help improve the self-esteem and selfimage of individuals with autism, which can affect the overall well-being of the individual (Schweizer et al., 2020). Creating an art product reduces the frequency and intensity of behaviors of individuals with autism. Lego therapy has also been proven to be a significant treatment intervention for ASD that increases the socialization and variety of play in individuals with ASD (Levy & Dunsmuir, 2020). These are effective intervention methods because they discourage repetitive play and encourage creativity. This creativity is important for individuals with autism because some of the symptoms can be very repetitive and restrictive.

Modified Cognitive Behavior Therapy (CBT). One of the most effective intervention methods for treating ASD is modified cognitive behavioral therapy methods. CBT not only helps treat the symptoms of autism, but it can also help individuals that are suffering from depression be able to modify their line of thinking to improve the symptoms of autism (Sapmaz et al., 2018). CBT can be effective in treating minor meltdowns and more intensive behaviors (Melvin et al., 2020). effective in the prison setting in teaching individuals with autism who committed sexual offenses to think through the point of view of their victim; however, the effects were often unable to be applied by the individual in the general setting (Melvin et al, 2020). Another interesting concept that CBT can be utilized to treat is fears and phobias in children with autism by changing their thought processes (Maskey et al., 2019). In order to do this, it requires much training and repetition for the individuals and their families to effectively use skills. Due to the need, CBT may not have been an available intervention method when many mental health facilities went virtual. It is my hypothesis that inconsistent treatment may have affected the experience of symptoms during the quarantine.

Cornoavirus-19 (COVID-19)

The final component of this study involved COVID-19, a deadly virus that wreaked havoc worldwide by spreading quickly (Oomen et al., 2020). It demanded changes in routine and limited social interaction. This quickly led to a decrease in the mental health of individuals, resulting in a large increase in mental health needs, including treatment for anxiety and depression (Martinez et al., 2021). Unfortunately, there was not much access to the required resources due to the worldwide quarantine. Individuals with autism were affected substantially, and little was known on what the best approach would be (Martinnez et al., 2021). Many children with autism strive off special education centers or other structured settings, and they were limited during the quarantine. This led to a significant increase in negative behaviors such as aggression and impulsivity. Despite some parents and caregivers trying, the structure of a school or day care setting is not easy to mimic. It left many individuals without appropriate care, having negative effects on those individuals.

Conclusion

The purpose of this review was to describe the symptoms of autism and how a worldwide pandemic and quarantine can play a role in the presentation of these symptoms. Though there has been research conducted on the matter, there is still a lot to learn about the COVID-19 quarantine and how it affected the presentation of symptoms and experience of parents while attempting to manage these behavioral symptoms. Most of the research only focused on the mental health experience of the parents or a comparison of behaviors with neurotypical children. More research on the caregiver's recollection of the symptoms is required to establish a better understanding of the experience through the point of view of those who lived through it. It is important to conduct additional research to fully understand the experience and assess whether there is a need for additional assistance.

Chapter 3: Research Method

The importance of understanding parents' experience while managing symptoms of autism in their children during a quarantine led to the need of this qualitative study. Chapter 3 reviews the research design and rationalizes the study. The study focused on parents or caregivers describing their experience while managing symptoms of autism in their children during the COVID-19 quarantine. The goal of the study was to describe the symptoms in order to build knowledge and understanding of ASD.

This study addresses social change in many ways. First, this study can broaden the understanding of a disorder that has not been fully studied. An appropriate understanding can lead to additional support as well as acceptance. It also addresses the experience of symptoms during a worldwide pandemic, which can aid in addressing concerns in future situations. Finally, it may also determine if current intervention methods can be generalized across other settings.

Research and Design Rationale

The following research question was developed to address the gap regarding COVID-19 and symptoms of autism: How do parents describe their experience during the COVID-19 quarantine while managing their children's behaviors related to ASD? To address this research question, I utilized a phenomenological approach. This approach was best to address the parents' perception of the symptoms of autism while caring for their child with ASD during the quarantine. The lack of sufficient research on this matter leads to insufficient understanding of effective intervention methods, additional stress on parents, and lack of sufficient support for the families. Due to addressing a specific culture in a specific situation, phenomenology was the most appropriate approach for this study.

Much of the previous research regarding this topic followed a quantitative approach. Quantitative data collection occurs through surveys and rating scales and can be used to measure the intensity of the symptoms. The data are then scored and analyzed to determine any affects dependent upon the participants' responses. Quantitative studies involve a large number of participants to increase the ability of generalization. There is a smaller number of participants with qualitative designs, which makes it easier to identify the experience of the individual.

Surveys limit the perception of symptoms, making it not the best approach, because every individual's experience is different. Many caregivers become accustomed to their environment and the behaviors of their children and others may not be. They may describe tantrums, hitting, and biting as being minor on a scale because there was no broken skin when others may describe it as extreme. A survey might not be able to capture these sorts of distinctions. Also, a survey may not include open ended questions, and it limits responses to the initial ideas of the researcher. With qualitative designs, interviews are more open-ended and encourage further explanation of ideas. Quantitative designs are effective to analyze change and comparing two phenomena, but qualitative designs are more effective in describing an experience.

The phenomenological approach was selected because it addresses the lived experience of individuals who had experienced similar situations. This is the most appropriate design because it addressed the lived experience and how it is relevant, unlike a narrative design that only tells the story.

The purpose of this study was to describe the experience of the individual as well as how the information can be utilized to better the lives of the individuals. This purpose rules out narrative study because the purpose sought more than just a story. Ethnography also was not appropriate for this study because ethnography attempts to address the experience of a specific culture. This study aimed to involve any cultures that may have responded to the outreach, and it did not focus on a single culture. Instead, it focused on a specific experience: describing the experience of symptoms of ASD during the COVID19 quarantine. Grounded theory was also ruled out because the goal of the study was not to develop a theory. Due to the other methods being ruled out, the phenological method is the most appropriate.

Utilizing a qualitative design allows the participants to effectively describe their lived experience through the phenomenon. In other words, the participants explain their experience throughout the phenomenon and how it affected them. Participants are also able to ask for any clarification in case of misunderstanding of the question asked. The purpose of this study was to gather as much information and detail that the participant was willing to share to broaden the understanding. For this study, I collected broad details on the parents’ ideas, experiences, and perceptions of the experience of symptoms in their children with ASD.

Role of the Researcher

I currently work as a therapist in an office setting with a history with working with children with autism, which is my preferred population to work with. In the past, I worked with children with ASD in various settings including the school, home and community settings. I worked with these children 1:1, with teachers and with parents. I learned just as much from these children as I taught to them. Exploring and understanding this population has consistently been a passion of mine. For this study, I was the researcher attempting to investigate this phenomenon. I developed the research questions and analyzed the data while also keeping my biases in check.

Methodology

The following study had a qualitative research design. Participants were gathered via convenience sampling on a small-scale depending on specific criteria. Participants were identified through intensive recruiting through the social media platform. Focus was on parents that were seeking support in ASD support groups.

I gathered seven participants. Gathering this number of participants was effective because it kept the participant level low. This allowed the study to focus on the individual experiences while still allowing for different ideas to be presented, and similar themes were identified throughout the interviewing process, which suggested seven as an effective number of participants.

There were numerous requirements for participation in the study. One criterion was that the participant must be the legal caregiver of a minor diagnosed with ASD through the DSM-V. A legal caregiver should have physical custody of the child for the majority of the time and be actively involved in parenting the individual. They must also have been present with the child for the majority of the COVID-19 quarantine. Also, the child must have been participating in services from a mental health facility in either the home, school, and/or community setting before the quarantine sparked by COVID-19. Finally, participants could not be from the family of individuals that I have worked with in the past.

Participants were provided with an informed consent form addressing the expectations and their agreement to participate in the study. A summary of the purpose of the study was discussed, and the roles and responsibilities of the participants was made clear. The limit to confidentiality was addressed. In depth interviews was conducted via telephone or video chat depending on the participants' comfortability. The interviews were 60 minutes each; however, interview times varied depending on the amount of information the participants wanted to share. With the participants' permission, the interviews were recorded to be coded and analyzed appropriately. Audio recordings was securely coded to protect the identification of the participant, but the data could still be accessed.

The interview questions in this study explored the participants' experiences. The parents were asked to describe what services and assistance they had in place before quarantine, and their perception of their child's experience of ASD symptoms, using as much detail as possible. Then, they were asked what services they had in place during quarantine, and their perception of their child's experience of ASD symptoms. Next, parents were asked what they would have liked to see more or less of during the quarantine. Last, parents were also asked how they attempted to manage behaviors during quarantine as well as their effectiveness.

All participants were given a transcript of their responses to the interview to ensure accuracy. The transcriptions were sent via email in order for the individual to review for accuracy. The participants were encouraged to make any needed corrections and voice any concerns with the transcripts or their understanding of them. Once accuracy was determined, safeguards such as passwords and environmental limitations for playback were utilized to protect the responses and the identities of the participants.

Data analysis was completed utilizing bracketing and clustering meaning of responses. Bracketing is a method of removing bias by setting aside one’s own ideas and biases to present the most accurate description of the collected data. I achieved this by setting aside my own beliefs and experiences to report the data collected by participants. I reminded myself that it is not about presenting my experience and ideas because I do not qualify as a participant in my own study. Instead, to gather a more accurate understanding, it is important to only present the ideas of those that qualify. Clustering meaning in the responses provides themes for the gathered data.

Trustworthiness

Trustworthiness is a critical part of any psychological research (Morse, 2015). This term refers to the study’s credibility, transferability, dependability, and confirmability. If these criteria are not met, the study’s trustworthiness diminishes.

Credibility

Credibility is important because it represents the accuracy of the data collection.

to maximize credibility during the research, confirmation of the responses was gathered. Also, the responses were reflected for accuracy in representation. The participants were asked to clarify any responses, and they were also given the opportunity to review responses as well as interpretation of those responses.

Dependability

Dependability of the study was achieved by keeping record of the entire methodology. In this situation, the study could be repeated as necessary to determine if similar results would be presented. A detailed record of procedures was kept to maximize the ability of other researchers to recreate the research. Sampling, data collection, and data analysis methods were all described in great detail. Coding and recording procedures were repeated to ensure correct recording of data.

Confirmability

Confirmability was achieved by including the participants in the process for accuracy checking. Allowing participants to confirm or explain misinterpreted ideas allows for the accuracy of the study to increase. Also, allowing the participant to participate in the editing of the transcripts allows for greater understanding of the ideas that the participant was trying to express. Also, I had to check my own biases and ensure that my own ideas did not affect the interpretation of the data. This was achieved by allowing participants to review transcripts and interpretations.

Ethical Procedures

Ethical procedures were practiced throughout the entirety of the research. The best interests of the participants were kept in mind, and all participants were provided information regarding the expectations of the study. Participants were given the opportunity to withdraw from the study at any time for any reason. They were provided an informed consent describing the amount of harm the study contains, which is minimal.

All identifying information was restricted and only released on an as needed basis. Data were protected on a secured drive only accessible to authorized individuals.

Summary

Chapter 3 described the research methods utilized to answer the study's research question. The chapter described the population, recruitment methods, participation criteria, consent, sample size, data collection tools, and trustworthiness. Ethical considerations were also described. Chapter 4 will present the results of the data collection including themes gathered from the responses.

Chapter 4: Results

The purpose of this study was to explain the experience of parents while managing their children's ASD symptoms during the quarantine prompted by COVID19. Participants were recruited using Facebook and support groups in the Northeastern Pennsylvania (NEPA) area. The potential participants were emailed the informed consent to review on their own, and they were prompted to ask any questions as needed. Informed consent was obtained by requesting the participant respond "I consent" to the email regarding informed consent. Once consent was obtained, semistructured interviews were scheduled and conducted. The interviews were audio recorded and stored on a locked flash drive to which only I had the password. The responses were then coded and analyzed to identify any themes in responses. The analysis of the data is presented in Chapter 4.

Setting

I recruited participants via social media on support group pages in the NEPA area to ensure the appropriate population was being recruited. The interviews were conducted via telephone calls. I facilitated the interviews in a private area where confidentiality could be maintained. Participants were also informed that they should be in a private area with no interference.

Demographics

The demographics of participants were not asked for the study due to demographics not being a specific part of the research questions. For participation, the only requirement was that the participants needed to be from NEPA and over the age of

18. In the recruitment process, five women and two men participated; however, this was unintentional.

Data Collection

Participant Recruitment

Participants for the presented study were recruited via convenience sampling on a small scale. The participants had to meet certain criteria. These criteria included having a child with diagnosed autism. Parents and/or caregivers also had to be active in the child's life. The participants were identified through intensive recruitment methods on social media. Participants were seeking support in ASD support groups on social media. The recruitment process occurred for approximately 4 weeks.

The study included seven participants who responded via email. These participants included five women and two men who were between the ages of 30 and 50. The participants were presented the informed consent form as well as asked availability for the interview. At the beginning of the interview, participants were reminded that the interview was voluntary, and they could end participation at any time. The telephone calls were recorded on a personal, password locked computer to ensure secure saving of the data. These interview times ranged from 25 to 30 minutes, and participants were asked if there was anything else they would like to add before the phone calls were ended. The number of interviews appeared to be sufficient due to similar emerging themes.

I transcribed the audio recordings on Word. The word documents were then printed and used during data analysis process. Similar themes were highlighted and colorcoded according to themes including *struggles*, *resources*, *supports*, *strengths*, and *suggestions*. This process did not vary from methods presented in Chapter 3, and there were no unusual circumstances witnessed or presented.

Interviews

The conducted interviews were semistructured and were conducted via telephone at the participants' convenience. The following questions were asked:

1. Tell me about parenting a child that has been diagnosed with autism.
2. Tell me about some of the resources you have utilized.
3. What are some things that were different during the quarantine?
4. What was the transition back to regular routine like?
5. Tell me about your experience as a parent including the good and bad things.
6. Tell me about some things that you would change.
7. What advice would you give others in regards to managing behaviors during any future quarantine?

Data Analysis

Bracketing and clustering were used throughout the data analysis process. For bracketing, I set aside own beliefs and ideas to best represent the experience of the identified population. My own beliefs were set aside and only the ideas presented in the data were presented. Only the ideas and beliefs of participants were recorded. Clustering allowed presented ideas to be organized into themes to represent and summarize the data. The data were then coded utilizing narrative analysis to present the story of the experiences the participants had.

Evidence of Trustworthiness

Effective representation of the data is important the validity of the study (Morse, 2015). For this to occur, it is important to note the trustworthiness, which includes identifying qualities that address the credibility, dependability and confirmability of the study.

Trustworthiness

Throughout the study, trustworthiness was maintained by addressing the credibility, dependability, and confirmability throughout the study. The interview questions were extensively reviewed by the dissertation committee and the semistructured interview allowed for the participants to address any concerns as well as share their experiences without leading.

Credibility

Credibility was maintained by reviewing the accuracy of the transcriptions. This was addressed by listening to the audio recordings separately one at a time to provide undivided attention. Then, the transcriptions were created through by listening to the transcriptions. The audio recordings were clear and the responses were recorded accurately. Participants were also able to review the responses to assure accuracy.

Dependability

Records of the entire methodology were recorded to assure dependability. The records of the study ensure that the study can be recreated to assess accuracy in the presentation of results. Accurate representation of the data can assure that other researchers was able to recreate the study with minimal difficulty. The sampling methods, data collection methods, and data analysis methods were recorded in great detail to keep accurate representation of the data. Coding and recording procedures were also documented to ensure ability to recreate the data.

Confirmability

Accuracy in representation of the data and results were shared with participants to achieve confirmability. Allowing review of the data allows participants to be able to confirm or further explain any potential misrepresented data and responses. The participants in the study reported that their ideas and experiences were accurately represented. Also, I had to check my own biases and ensure that own ideas and thoughts regarding the experience of the participants were not presented in the data. This was also confirmed by participants with accurate representation of their response.

Results

After the conduction of a qualitative research study, experiences of parents while managing the behaviors of their children with autism were explored and explained. The themes were developed by utilizing the exact words of the participants and organizing them into emerging themes. Due to struggles with socialization and routine, the quarantine presented many additional concerns for parents with children with autism. The quarantine had resulted in even more of a social boundary and a decrease in the support network for families.

The research question was answered by the participants through a series of interview questions. There were numerous themes that were repeated throughout each interview and between each interview.

Theme Narrative

Theme 1: Experience of Raising a Child With ASD

The first theme of the study addressed the overall experience of the parents with raising a child with autism in general not specifically during COVID. There were a mixture of struggles and adventures noted throughout all of the participants.

Struggles

All seven of the participants noted many struggles with raising a child with autism. For many of the participants, they reported it as a very unfamiliar experience. One of the interview interactions was as follows:

> Researcher: Tell me a little bit about what it’s like in general to parent a kid with autism.
>
> P1: To summarize, scary.

The participant then went on to explain that they did not want to do too much or too little for their child because they wanted the child to grow up and be able to function independently, but they also did not want their child to have a rough time and be disadvantaged with attempting to reach goals that neurotypical children of the same age were meeting. P5 also had a similar description reported, stating, “When you’re brand new at understanding ASD, it can be frustrating and upsetting, as well as scary.” Overall, parents reported that parenting a child with autism was an experience that they have never expected and could have never prepared for, making it difficult at times. They felt very conflicted because they wanted their children to succeed, but they also knew that they may not be able to function at a typical age level.

These struggles suggest that there is a significant need for resources to effectively assist these families in assuring that their children are the most successful that they can be. There have been many intervention methods that have been effective in treating symptoms of ASD such as CBT (Sapmaz et al., 2018), Lego therapy (Levy & Dunsmuir, 2020), and ABA (Taylor et al., 2019). If parents do not have access to these resources, their struggles can become overwhelming. Also, according to the Bowen's theory (Galloway, 2019), parental struggles can lead to additional stress for the family unit. These struggles can affect family dynamics and make treatment in the home less effective.

Supports

All of the participants reported that their families were their biggest supports throughout the entire quarantine. Five out of seven participants reported that they had significant others that were readily available, and it was a team effort to manage behaviors and meltdowns.

> P6: His dad is a truck driver, and with COVID, he was on the road a lot more. I rarely had him as a support, but I had my mom. Whatever I was struggling with, I'd call her up and she'd talk me through it or come over.

Family support appeared to be the most recognized resource in all participants whether it be support with managing the behaviors or the participant being a support for their child. Without family, love and dedication, the participants reported that they do not think they would have been as successful in the experience of parenting children with ASD.

The idea that family support was critical for success is supported by both the interdependence theory (Thibaut & Kelley, 1959) and Bowen's theory. According to Thibaut and Kelley (1959), humans are social creatures and rely on one another for support and guidance. Bowen's theory suggests that in families, the emotions of one member can affect the overall functioning of other members as well as the unit as a whole. Reaching out to family members and having positive guidance and support appeared to be an effective way of coping and managing daily stressors for parents of children with autism. During COVID-19 quarantine, many of these interactions changed, which may have resulted in less support.

Resources

All of the participants reported that it was very difficult to access resources to help their children be the most successful that they could be, though they eventually found the resources. One participant reported that it was more difficult than it should be.

> Researcher: Tell me about some of the resources that you were able to secure for helping you manage behaviors of autism.
>
> P1: As a parent who does what I do for a living, you know, I know what the resources are. I know how to, you know, navigate how to get, you know, I knew how to get, you know HRS, so my son did have the HRS services when he was younger, so you know, like I knew how to do that, I knew how to get him hooked up… and I wonder sometimes like, if this is this hard for me, what is this like for… families who don't have that knowledge or don't know those resources.

Participants also reported struggles with obtaining the appropriate supports in the school setting, even before COVID-19 quarantine.

> P2: They don't have that learning foundation to sit at a desk and work, but it's like they can't help it, and the school didn't want to work with him. I was able to hire a lawyer to get him into the proper school.

Other participants reported similar but less severe circumstances. For example, P6 stated, "They refused to give him an IEP at his school because he went to a private school, and the district wanted nothing to do with it." P4 reported that it was extra difficult due to not having any experiences with even neurotypical children, stating, "She was my first experience ever with a baby, no nieces or nephews, so everything was brand new. The diagnosis was tough, and life became very stressful and I became depressed." These struggles with attempting to find the appropriate supports and managing the behaviors of children with ASD were stressful financially, psychologically and even physically for some parents. They used their children as motivation to continue to attempt to achieve the best care that they could.

Most of the participants reported that speech, occupational and behavior therapies were all very helpful in managing the behaviors of their children and helping them function at a more age-appropriate level, and they reported that they were very passionate about finding the resources that their children need and making sure they get the appropriate supports. The participants all reported dedication to their children's behavioral and academic success.

Many of the participants reported that attempting to receive the appropriate resources for their children to be successful was very difficult, even when they knew how to find those resources. All of the participants reported that they had to take extreme measures to obtain resources, and all of them admitted that it affected their mental health. This again can affect the family unit and add more stress (Galloway, 2019). With the significant amount of effort that families must put towards securing sufficient resources for their children with autism, there is a negative impact on the parent's mental health as well as the child's success.

Siblings

It was noted by four out of seven participants that much of the struggles they experienced with their child with autism were also experienced with their neurotypical siblings. The other participants did not mention any other children.

Participants tended to treat their children with ASD similarly to how they treated their neurotypical children. They gave the same expectations that were age appropriate and just attempted to identify more effective and beneficial ways to meet the goals with their children with ASD.

> P2: His sister is a neurotypical twin, so she learns things, you know, reading was eye opening to me, the way she learned to read was, you know phonetically sounding out things where [child with ASD] has a photographic memory and he learns the words just by looking at the word, saying it loud, looking at again…

Parents admitted that once they adjusted their own responses and aid towards their child's needs, they were better able to help them be more successful.

Siblings are also affected by family dynamics when there is a child with autism in the home, and they can also be affected by parental stress (Galloway, 2019). Participants reported that it was beneficial to present similar tasks but set expectations in a developmentally appropriate manner. This allows the family unit to continue functioning while properly distributing the tasks. Siblings of those with developmental disorders will not feel as much stress due to varying expectations that they do not fully understand.

They can also help their sibling succeed by modeling typical behaviors.

Positives

Parents also reported that there are many positives in parenting a child with ASD. Many of the parents reported that raising children with ASD was an adventure and they would not change it. P6 put it this way: “Autism is fun. It is what you make it. If you want to make it a struggle, it was a struggle. If you want to make it an adventure, it was an adventure.”

Parents shared an overall positive experience and enjoying the parts of their children that other people may not understand. They spoke about their children to the highest degree and reported pride in parenting them. They reported that even though there were many struggles, they would not change the experience.

Despite the struggles and extra effort that goes into parenting a child with autism, all of the participants reported that they found ways to adjust themselves to make the best out of the difficult situation. Having a positive attitude and thinking about the journey as a learning adventure is something that helps these parents manage the more difficult times. This calls for more support groups and resources for the parents and caregivers to increase the positive views toward parenting a child with ASD. Having these supports can be beneficial to the parent (Thibaut & Kelley, 1959), which in turn can affect the children that they are raising (Galloway, 2019).

Theme 2: Differences with quarantine

The second theme identified ways parenting changed during the quarantine. Many of the parents reported various changes in routine and resources. Parents reported that every day, something different was happening, and everything was unknown. They could not prepare their children for what was happening next because they did not know themselves. Each parent reported that they made the best of the situation. P6: We

> started this thing where we did ice cream for lunch and breakfast for dinner just to switch things up. It led to us bonding more for an extended period of time because school wasn't in the way. It taught him that things change abruptly, and he needed to learn that.

Resources

Parents reported that many of the resources that they had available to them before quarantine were no longer available, especially schooling for the older children. As mentioned previously, resources were already difficult to secure, so when the quarantine occurred, many children and families did not receive the support that they needed. Although online resources were available to some, they were not as effective as face-toface interventions and are not made to replace face-to-face interventions (Maskey et al., 2019). Many children and families experienced a deterioration in progress due to the inability to access resources.

Adjustment

Adjustment appeared to be different depending on the ages and responsibilities of the children. Parents of younger children reported that they were able to adjust more easily because they had no idea of what school was supposed to be like yet, so there were no expectations. Parents continued to attempt to follow routine and have bonding time.

> P4: Even though she wasn't chatting and interacting with peers on a consistent basis, she was still around other kids her age and experiencing what they were experiencing in the classroom and mirroring their behavior, both good and bad. There was a lot of learning and growth happening. Virtual class became very frustrating, and we had a lot of meltdowns. We did still continue our adventures though, just in a different way.

It appeared that parents of smaller children attempted to maintain the same routines and make the at home experience mimic the school experience as much as possible; however, the parents of older children reported that their children enjoyed being home, though there were negative impacts noted.

> P1: He loved it because he could roll out of bed, get on the computer, you know? Um, but I do think it impacted his academics. I don't think he did as well as he could have if he'd have been in school.

Having freedom and limited expectations in regards to schoolwork set many of the children back academically. Parents reported that they tried as hard as they could to motivate their children to make the best out of virtual learning, but many of them were working parents, which made it difficult for them to keep an eye on their children at all times. They also took the quarantine as an opportunity to go on outdoor adventures and make the best out of a negative situation.

Overall, there were noted positives and negative changes that were presented by the quarantine. Families became closer and were able to interact with each other more, which resulted in a positive bond. The interdependence theory (Thibaut & Kelley, 1959) suggested that working together and exploring difficult situations can be effective for individuals. However, some of the children were setback due to the lack of structure, and that additional stress was spread to other family members, like Bowen's theory suggests.

Theme 3: Transition back to routine was successful

The third theme identified in the study involved what the transition back to routine looked like for these families. Many of the participants reported that they attempted to keep routines the same, they just attempted to continue the routine in the home setting. P4 stated, "With school, we continued the same schedule that the girls had, but just at home. So they got up at the same time, followed the same class schedule they had at school… she was ready to go back."

All of the participants noted that it was mostly a smooth transition as all of the children were ready to get back to regular life. It was a relief for them as they did not fully understand what was going on in the world around him. This suggests that children with ASD are most successful and happier when they have a routine and know what to expect. With the quarantine and consistently changing expectations, the entire family unit was affected negatively. Transitioning back to regular schooling and routine provided relief and allowed time for parents to destress. For example, P5 noted, “She didn’t understand why she had to be home if she wasn’t sick, and she would cry and be very upset.”

Parents also reported that upon returning to regular routine, a lot of fear left their children. With Bowen’s theory suggesting that family members are affected by the emotions of others, the reduction in fear for the child could significantly reduce the stress levels in the parents.

> P6: During COVID, one school that he was attending required masks at some areas but not at others, and he was getting into trouble for not wearing a mask in a zone that wasn’t mask free, and school put fear into him that he was going to die. Getting him back into a regular routine and making sure he was going to a place that wasn’t going to confuse him was critical with transitioning back.

Transitioning back to routine and daily life was easy for many of the parents because they attempted to keep things as similar as possible. They also attempted to calm any fears and anxiety in their children. A shift back into a routine that they were familiar with and that did not cause so much fear was beneficial to relieving stress that was presented to the parents.

Theme 4: Advice and changes for the future

The fourth theme addressed what parents would like to change and any advice they want to give for others in the future. Many of the parents shared similar bits of advice and changes that they would make in the future.

Never give up

All of the participants reported that their main advice is that parents and caregivers should never give up on their children. There are plenty of struggles, but there is always good that outweighs the bad. P5 put it this way: “I’ll never stop fighting for my son, but god I get so tired.”

Participants reported significant struggles and fears that they have experienced throughout parenting their children, but the one thing that they all reported that kept them motivated is the love for their children. They push them to strive to be the best that they can be. This suggests that participants have been exhausted by attempting to aid their children in being successful. They may have even thought about giving up. However, like previously mentioned, utilizing their families and loved ones as supports has been helpful in the continued growth and motivation to continue attempting to aid their children in being successful. Without this motivation, their children have very limited chances at leading a successful life.

Have backup plans

Another piece of advice is to always have numerous backup plans. Things change very quickly, as participants noted COVID-19 documented. According to the participants, it is important to have backup plans for the backup plans. For example, P6 said, “Have plan A, and B, and C, and if you run out of the alphabet, start using fruits and vegetables, because there will always be enough of those.”

Participants suggested that it is important to have plans and routine, but it is also very important to demonstrate that those plans and routines can and will change with minimal notice. It is important to think quickly and be able to change the plans. Due to children with autism having difficulty with change in plan and routine, a lot of the stress that arose from this fell on the parents, especially when they were attempting to avoid meltdowns. This suggests that parents require additional support and resources to maintain their own mental health.

Get rid of ASD

A wish reported by two of the participants that conflicted with the rest is that they wish ASD would go away. They reported that it has been a significant struggle in managing the behaviors, and P4 even reported diagnosed depression while attempting to manage the behaviors in the beginning. However, the other participants reported that they would not change anything. P5 said, “I wouldn’t change a thing about my son. He’s absolutely perfect the way he is.”

Participants appeared to love their children, but they also reported struggles with the behaviors that resulted in a decline in the participants’ mental health. They enjoy their children at their greatest but also report that the struggles are constant. They would like to take the struggles away from them. All of the parents reported that it was difficult to watch their children struggle with tasks any neurotypical child could complete without issue; however, with that said, they continued to identify qualities that autism made evident that make their children who they are. This suggests that it is important to help parents maintain a positive outlook and to identify the positives in the situation rather than only focusing on the negatives.

Change the process for resources/schooling

All of the participants reported a bad experience with obtaining resources, especially during COVID-19. It also was reported that schools appeared to be working against the families attempting to secure resources for their children.

> P2: The things we had to do to meet his needs is just horrific. Like I was a horrible person for six months when I was in a lawsuit, suing my district to get him into a special needs school. Like they were hodgepodging this program together for him with therapists that weren't qualified.

Participants reported significant struggles with obtaining outside resources, but they all identified their own dedication as motivation for their children to do better in life. This finding was the most prominent that requires attention. The lack of resources resulted in additional stress for the parents as well as the family. It is important to identify appropriate resources as well as make them easily accessible.

Summary

The study presented addressed the explanation of the experience of parent while managing the behaviors of their children with ASD. There were many themes presented throughout the data collection process. Theme 1 identified various struggles and adventures while managing the behaviors of children with autism as well as the availability of resources. Theme 2 identified what it was like for the families during the COVID-19 quarantine. Theme 3 addressed what the shift back to regular routine postCOVID was like. The final theme presented suggestions and areas in which parents would change their experience.

Chapter 5 is a summary of the current study. It addresses current literature and an interpretation of the findings of the study. Limitations of the study are presented as well as recommendations of any further or follow-up studies. The implication for social change is also addressed.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this study was to explore the parents' experience while managing their children's behaviors during the COVID-19 quarantine. Due to autism being a relatively new disorder, there is much knowledge that still has to be discovered. This study aimed at filling the gap in literature.

Findings

Children with autism struggle on a daily basis, and these struggles may appear to come out of nowhere (Burton et al., 2020). Per Bowen's theory, these struggles and negative emotions can play a significant role in a caregiver's emotional wellbeing. Throughout my study, participants reported much intense emotion over watching their children struggle and experience meltdowns over things that were beyond the caregiver's control. The parents also experience this additional stress, and it was difficult for them to manage and maintain their own mental health. Findings also suggested that parents continue to want the best for their children, even if access to the appropriate resources is difficult.

This study also suggested that there is a significant bond between humans and that they are interdependent of one another. All of the participants reported that they needed others to guide them and help them through difficult times. Attempting to keep as much social interaction as possible allows for appropriate development and continued growth. Parents identified their loved ones as their most positive support in difficult times. Even though COVID-19 prompted a quarantine that resulted in limited access to resources outside of the home, parents were dedicated to maintaining their positive support network. It is important to continue to build a strong, positive network for these parents.

This study also showed that there is a significant deficit in the available resources for children with autism. Though there are various effective types of therapy that has been helpful to children with autism such as CBT (Sapmaz et al., 2018), Lego therapy (Levy & Dunsmuir, 2020), and ABA (Tayor et al., 2019), many of these resources were unavailable during the quarantine. Parents reported significant struggles with the education system and school districts refusing to give accommodations as needed to help their children succeed. These struggles were difficult both emotionally and financially for the parents and caregivers, which resulted in heightened stress to the parents. Being unable to adequately provide support to their children resulted in additional stress.

Limitations

This study was a qualitative study that attempted to explain the experience of caregivers managing their children's ASD behaviors, especially during COVID-19. The study looked at a specific group of people and only included the caregiver's perspective. There were limitations throughout the study.

While completing this study, there were various parts in which follow-up studies would be beneficial. For example, though it was not directly related to quarantine, there was a significant report of lack of resources for children with ASD. A follow-up study should address where this lack of resources and aid is coming from and how it can be addressed in order to better serve the population. Until the change is made, the families will continue to struggle.

Another interesting concept and follow-up study would be a quantitative study addressing parental stress linked to behaviors of neurotypical children in comparison to their sibling with ASD. Many of the participants reported that there were similar struggles between their neurotypical and ASD diagnosed child. It would be interesting to see if data would support that determination.

Another approach would be to interview individuals with ASD about their experience during the quarantine. As noted by some of the participants, their children loved being home. Others reported that their children had severe anxiety and were very confused. It would be interesting to see what the experience was like for those children and/or adults struggling through the quarantine. However, this comes with its own struggles and limitations due to socialization deficits.

Finally, bias is always a limitation. I attempted to limit my own bias beliefs and presented information as it was given to me, but there is always a chance that the biases were presented. This can be reviewed throughout the process through the committee and extensive review process.

Recommendations

The main recommendation after conducting the study is that the system that provides care and resources for families struggling to support their children with ASD needs to be revamped. Many of the participants spent countless hours attempting to find resources to help their children, and often, they had to do everything on their own. Many families may have their own disorders that may result in the inability to dedicate as much time to researching autism and interventions. These resources need to be more readily available, especially in times of need.

Also, it is recommended that individuals working with children, especially schools, should be adequately trained on working with children with autism. These children appear to be missing out on a quality education due to refusal of services in the school. This process needs to be changed to better support the community.

Social Change Implications

This study was a representation of Walden University's mission to facilitate positive change. This positive change was witnessed throughout the study by allowing the participants to tell their experiences without interruption or judgment. They were able to report things that they believed were wrong with the system and allow their opinions to be heard.

One way that this study can affect positive social change is that it can lead to additional studies addressing specific changes that may be effective in addressing the concerns and struggles presented by the participants. There is an apparent need for more efficient and less difficult access to resources for caregivers of children with ASD. The study presented suggested that schooling and accommodations for their children were very difficult to achieve. This study can lead to additional research with specific suggests for change in the school system as well as obtaining resources for children with autism and their families.

This study also aids in filling a gap in research as there is limited research regarding COVID-19 due to the phenomenon being relatively new. Providing this data can give guidance as to where additional research can lead and what the overall experience was. Providing any additional data and knowledge to the public can be beneficial in reducing the stigma towards ASD. Along with calling attention to a lack of availability in resources, this study suggested that positive support is also necessary in growth for these families.

The study can also facilitate social change by providing knowledge and alleviating any biases in the community. Oti-Boati et al. (2020) suggested that stigmatization is often experienced by mothers caring for their children with autism, and this stigmatization is often linked to lack of knowledge. This study helps with closing the gap and expanding the knowledge, which can result in a significant decrease in the ignorance towards the autism community. A reduction in this ignorance can positively impact children with autism and their families because it is less stress and insecurities that the parents have to attempt to manage. A positive, supportive community can result in significant growth in success for these families. This study calls attention to that need.

Conclusion

In conclusion, much was learned from conducting this study. There were various themes identified throughout the study. Theme 1 addressed what it is like parenting a child with autism, Theme 2 identified the experience during COVID-19 quarantine, Theme 3 addressed the transition back into everyday routine post-quarantine, and Theme 4 included suggestions and guidance given by the participants to any other parent attempting to manage ASD behaviors.

The themes of this study are important because it addresses the struggles of a vulnerable population that appears to be begging for help but also attempting everything in their power to fight obstacles that prevent their children from success. It opens a door to many other opportunities for research in order to better service a community that is misunderstood and misrepresented.

As a final thought, in the words of P6, “Autism is fun. It is what you make it. If you make it a challenge, it was a challenge. If you make it an adventure, it was an adventure.”

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