Walden University

College of Education & Human Sciences

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April DeMasters

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Abstract

Help-Seeking and Stigma Experienced by Arab American Immigrant Parents of Children with Autism

by

April DeMasters

MA, University of the Rockies, 2013

BA, Ashford University, 2011

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

School of Psychology

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Abstract

Because of cultural and religious norms and associated stigma, some parents of a child with a mental illness or developmental disorder are hesitant to seek help for their child. The purpose of the study is to better understand how religious and ethnic culture reinforces stigma and its impact on a parent’s decision to seek help. This phenomenological qualitative study was conducted with Muslim Arab American immigrant parents, including first and second generations, in the United States who had a child diagnosed with an autism spectrum disorder (ASD) within the last 15 years. Semistructured interviews were conducted to gather data exploring these parents’ lived experiences and perceptions of stigma from their family and community. The social stigma theory provided a lens for understanding how culture can affect the decision to seek help for a child with an ASD. Findings of this study indicated that participant parents had an emotional experience coming to terms with the diagnosis of their child, difficulties telling family and community, and determining how to get the help they needed for their child. Significant positive social change areas relating to this study may include increased information and awareness of current difficulties for both consumers and providers of care for children with ASD in a group within the United States that has not significantly been studied.

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Dedication

I would like to dedicate this research to my three beautiful daughters Salaam, Sadeel, and Sara. They have been the reason I have pushed through this program and showing them what strength in the face of adversity looks like in the completion of my research means the world to me. I would also like to dedicate this to my parents Tom and Sara DeMasters who raised me to reach for the stars and beyond and stressed how life circumstances never dictate your future. Lastly, I would like to thank my other dad and mom Carlos and Barbara Quezada for the help and unconditional support they have shown me and my kids.

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Table of Contents

Chapter 1: Introduction to the Study

Introduction

Cultural beliefs and practices can shape knowledge, understanding, and the value of health and interventions of treatment for chronic conditions such as mental illness or developmental disorders. In some cultures, stigma is a learned response that surfaces as enacted stigma (i.e., shaming) with people blaming others for circumstances being experienced, and felt stigma (i.e., self-shaming), with people self-monitoring their behaviors (Napier et al., 2014). Associative stigma is also common among certain cultures, and abnormal behavior can bring social shame to a person and his or her family (El-Islam, 2008). More traditional cultures often encourage interdependence instead of independence. As such, health-seeking behaviors are influenced by the family, which may lead to shame or stigma, that potentially prevents health seeking behaviors (El-Islam, 2008).

This study focuses on Muslim Arab American immigrant parents in the United States and their lived experience in seeking help for a child diagnosed with an autism spectrum disorder (ASD) and the stigma they may have faced within their community or family. A better understanding of stigma within a culture can broaden knowledge of how stigma impacts someone's decision to seek help. If mental health professionals are better informed about how to address and reduce the stigma, health disparities in different communities may shrink. Chapter 1 contains the background, problem statement, purpose of the study, research questions, conceptual framework, nature of the study, definitions, assumptions, scope and delimitations, limitations, significance of the study, and a summary.

Background

Autism is a mental health disorder found worldwide. According to the *American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition ([DSM-5]*APA, 2013) an array of disorders falls in the category of autism spectrum disorders (ASD). Although there are insufficient data available to study presentation and occurrence elsewhere, researchers have found an increase in the last decade of diagnosis of ASDs in North America and Europe (Ramsey et al., 2016) Cultural and religious beliefs in Arab countries in the Middle East play a significant role in the diagnosis of mental health and developmental disorders (Zaroff & Uhm, 2012). Hence, the known prevalence of ASDs in children in the Middle East is lower than the United States and Europe (Zaroff & Uhm, 2012). Because of stigma and skepticism, parental attitudes, religious beliefs, and other sociocultural factors have influenced help-seeking patterns for children with a mental illness (Eapen & Ghubash, 2004). Additionally, Arabs stigmatize psychiatric or psychological interventions, with women being more likely the victims of stigma (Eapen & Ghubash, 2004). Mental health services are also often mistrusted, so these services are often underused and limited in Arab communities (Eapen & Ghubash, 2004).

Several hadiths, or sayings of Muhammad found in the Quran indicate that disabilities are a natural part of human existence, and certain Islamic principles address caring for someone with a disability (Al-Aoufi et al., 2012; Quran, al-Baqarah 2:195).

Yet Muslims' cultural and spiritual beliefs may vary because Islam is found across many ethnicities with differing views on illness and healthcare. Thus, some attribute a disability to themselves as a punishment from God. Other Muslims consider a disability to be a curse from God on the parents and family (Al-Aoufi et al., 2012). Additionally, some parents attribute a disability to envy (evil eye), black magic, or possession by evil spirits. To avoid embarrassment and stigma, parents tend to deny the child has a disability. Many parents will not allow the child to engage in social activities such as going to pray at the mosque. These beliefs can also inhibit use of mental health services, and parents may refuse treatment and early interventions despite their importance (Al-Aoufi et al., 2012).

Economic, political, social, and cultural factors also play a role in determining access and service to psychiatric help for people who live in Arab countries (Okasha & Karam, 1998). Despite a high income per capita in most Arab countries, mental health services available are limited (Okasha & Karam, 1998). Arabs, like many minority cultures, are new to the benefits of mental health services, but when they become aware of these benefits they can utilize them and achieve changes (McGoldrick et al., 2005). Members of Arab communities must have the ability to recognize problematic behaviors, as it is often the first step in the help-seeking process (AlAzzam & Daak-Hirsch, 2015).

Research regarding prevalence of ASDs is most often done in developed countries such as the United States and Europe (Samadi & McConkey, 2011). Thus, research on mental health stigma is often focused on Western cultures (Dardas & Simmons, 2015). But what is considered normal diagnostic approaches and treatment in one culture may not transfer well into another culture. This study is needed because little is known about how mental health stigma manifests in the Muslim Arab American immigrant culture. To address this gap in the literature, I designed this study to explore the decision-making process parents in immigrant Muslim Arab Americans used to seek help for their autistic child and the lived experiences they had when seeking help.

Problem Statement

At present, mental illness is one of the most stigmatized health conditions in the Middle East, making it difficult for people in these populations to understand and accept mental illness and find options for treatment (Ciftci et al., 2013; Sewilam et al., 2015). Stigma has also impacted the prevalence of studies on mental health and its treatment in certain regions. Thus, adapting psychosocial evidence-based interventions from one culture to another fails because of differences in culture preferences for service practices and treatment implementation (Gearing et al., 2013). Further, until as recently as 2017, tools used to measure performance and adaptive behavior such as the Preschool Activity Card Sort and the Vineland Adaptive Behavior Scale were not available in an Arabic version (Malkawi et al., 2017). Perceptions of stigma vary across cultures, as is seen in such differences as individualistic perspectives focused on oneself versus collective cultures, which focus on the greater good of the family or community(Vogel et al., 2013).

A child diagnosed with a disability significantly impacts a family. But the impact is not understood across cultures because most of the research has been conducted in Western Caucasian cultures (Venegas & Abdulrahim, 2016). Caucasian children in the United States are more likely than African American and Latino children to be identified with an ASD, and although the Arab immigrant population in the United States is amongst the fastest growing of ethnic groups, they are the least studied ethnic community (Habayeb et al., 2019). This is in part due to several factors such as lack of classification through the U.S. Census bureau, cultural protective factors, and religion (Habayeb et al., 2019).

Autism awareness and research is predominately found in economically developed continents such as North America and Western Europe. In low- and middle-income countries, ASDs have only recently begun to be recognized and diagnosed. Researchers in these countries were skeptical about ASDs and gave the subject little attention until only recently. Additionally, not much is known about cultural beliefs and autism among populations living in multicultural environments, which includes Arab immigrant populations living in the United States (Kang-Yi, et al., 2018). It is important to understand the knowledge and perceptions of immigrant families and the decisions they make regarding medical treatments. This will help to work more effectively with these populations and meet their needs. This study will help to fill the gap of how the stigma of mental illness impacts Arab immigrant families and if culture affects parents' decisions to access help and find options for treatment with ASDs.

Purpose of the Study

In the Arab Muslim immigrant culture, social, cultural, and religious beliefs and practices are factors when individuals make decisions regarding health care (Koenig et al., 2012). Parents in Arab American Muslim communities might delay or avoid seeking help for a child who might have a mental illness because of the fear and social stigma associated with having a child who could be sick both within their local community and abroad. Yet some parents do seek help for their children with autism despite its stigma, although how and why they make such decisions has not been well studied (Crabtree, 2007).The purpose of this study is to explore stigma and the extent to which it had an effect on parents in the Arab American Muslim community when seeking help for an autistic child, and these parents' lived experiences when trying to get help. Using a phenomenological approach through interviews will bring insight regarding the lived experiences of this population.

Research Questions

1. What are the lived experiences of Arab American immigrant (first and second generation) parents within their community when asking for help for their child with an ASD?
2. What are the lived experiences of stigma faced by Arab American immigrant (first and second generation) parents within their community when seeking help for a child with an ASD?

Theoretical Framework

Goffman's (1963) social stigma theory provides the framework for this study. The stigma faced by parents seeking help for a child with autism, the reasons for seeking help outside of cultural norms, and parents' lived experiences can be further examined using this theory. The social stigma theory is one of the dominant theories in social psychology. Stigma, according to Goffman, is based on the social construction of identity. Goffman's original theory included both psychological and social ideas about stigma and has been mainly used for analyzing the psychological impact of stigma. It is important to understand stigmatization and the role it plays in internalization, shaping a person’s behavior, decisions, and actions.

Social stigma theory is an appropriate framework for understanding a parent’s firsthand view of the relationship between stigma and the social impact of getting help for a child with an ASD. Data collection for this phenomenological study will occur through interview questions focusing on two research questions: (a) What are the lived experiences of Muslim Arab American immigrant parents when asking for help for their child with an ASD? and (b) What are the lived experiences of stigma faced by Muslim Arab American immigrant parents when seeking help for a child with an ASD? These questions allow insight into a parent’s perception on experience and stigma when seeking help and can further suggest the extent to which stigma is a barrier. The parents’ perceptions are important in the collectivist culture in which they live, which emphasizes the needs of the family rather than the individual in decision making.

Nature of the Study

This qualitative phenomenological study is designed to better understand the reasoning and motivation behind actions of the parents of children with an ASD. Specifically, I seek to explore the lived experiences of stigma faced by Arab immigrant parents, and why some parents sought help even when stigma about mental health presents itself within this culture (Crabtree, 2007).To better understand the phenomenon and complexity of culturally generated stigma and the role it plays in help-seeking, it is important to look at culture and stigma (Link & Phelan, 2014). Link and Phelan (2014) combined the labeling theory with Corrigan and Watson’s (2002) societal and self-stigma concept to better understand stigma. Such an approach gives a clearer perspective and better understanding of the parent's reluctance to seek help and other treatment for their child.

In the Middle East, social, cultural, and religious beliefs and practices affect many adherents' decisions, such as those relating to health care. This study was conducted through semi structured interviews with a purposive sample of Arab immigrant parents of children diagnosed with ASD who were in the age range of 3-15 years old. Interviews would have been conducted at a convenient location for the parents, such as home, school, or center in which the children attend, but due to the current global pandemic interviews were conducted through video chat such as Google Meet, Zoom, Skype or via telephone. Data was analyzed for context and personal lived experiences (Merleau-Ponty, 2004)

After the data had been gathered, I hand coded and analyzed the data with CAQDAS software. Once the data was organized, coded, and validated, the data was analyzed. Themes were identified, along with underlying structures of the experience (Moustakas, 1994). This provided information about participants' lived experiences and the stigma they may have faced. The results are discussed in later chapters.

Definitions

Autism Spectrum Disorders (ASD). A deficiency in social communication and social interaction with others demonstrated currently or in the past and considered a mental health disorder (American Psychiatric Association [APA], 2013).

Stigma. An attribute or behavior that is socially discrediting and can cause a person to become undesirable, rejected, stereotyped, and unaccepted by others (Goffman, 1963).

Phenomenology. The study of a phenomenon, or the appearances of something in one's experience, the way someone experiences things, thus giving meaning to an experience. Phenomenologists study an experience from the subjective or first-person point of view (Merleau-Ponty et al., 2010).

Assumptions

I am undertaking this study with the assumption that participants will understand the questions I pose and will be honest when providing answers. Other assumptions include that there is a stigma both culturally, and religiously, when seeking help for a child with an ASD, which can be a potential cause of reluctance for Muslim Arab immigrant parents seeking help. Because ASDs have been categorized by the American Psychiatric Association (*DSM-5*, 2013) as a mental illness, I assume it will be more difficult for parents to seek help outside their normal channels for their child. In light of the dearth of studies globally regarding mental health, I assume this problem is little discussed and remains a sensitive subject (Gearing et al., 2013). I also assume that because of the taboo of discussing mental health illness in children in Arab communities, and with ASD diagnosis on the rise elsewhere, more parents will need help for a child with this disorder.

Scope and Delimitations

The scope of this research of Muslim Arab immigrants is the descriptions provided by the participating parents about their individual lived experiences. This includes their perceptions of mental health screening, any reasons for hesitation to seek assistance, and any related implications within their lives. The specific focus of this research was chosen because of the lack of available research regarding autism and stigma within the culture and community. Inclusions for this study are English speaking parents with a child who has been diagnosed with an ASD, and who have sought health or psychological care for this child. Exclusions for this study are parents who do not have children diagnosed with an ASD, parents who have not sought help for a child, and parents who are not currently getting help for their diagnosed child.

Goffman's (1963) social stigma theory is a framework for the study. Tajfel and Turner's (1979) social identity theory was applicable but was not used because the main hypothesis of this theory is a "them versus us" mentality in which one group will find negative aspects of another group to enhance self-image. The social identity theory is more related to self-image and a sense of social identity rather than stigma. Goffman's theory emphasizes that stigma is a relationship between a person and a social setting such that a person can be in either role of stigmatized or stigmatizer.

Transferability refers to a type of external validity that can show that a phenomenon in one study is applicable or useful for future research and a larger population. This research may be transferable to other situations in which this group participates and may not be limited to autism but could include other social areas where stigma is found.

Limitations

Limitations for this study may include the assessment process. The interview responses relied solely on the participant’s recollection and perceptions of any stigma they may have faced. According to van Manen (2007), such lived experiences are reflective, yet they are still pre-reflective. The early 20th-century philosopher Husserl (1999) is credited with developing phenomenological research and defining it as reflection of one’s knowledge after an experience. It is only after reflecting on the lived experience that a person can interpret the effects of the experience that it has on one’s life.

Other limitations for this study include the sample size. Although qualitative analysis usually requires a fairly small sample, it must be large enough to collect sufficient data to show a phenomenon and address the research questions (Creswell & Poth, 2017). Because of the small sample size, the results may not be as transferrable as with a larger sample (Creswell & Poth, 2017). In addition, the process of qualitative analysis is time-consuming and can take weeks or months (Creswell & Poth, 2017).

Reliability in research demonstrates that the variable being measured is stable or constant and should therefore produce the same or nearly the same results with the same individuals and conditions if repeated (Givens, 2008).Validity in research is also important with study components well documented so that someone from outside the research would have the ability to follow and audit what was done in the research

(Givens, 2008).To maintain reliability and validity, I will clearly present the participant sample characteristics and my observations during data collection. I will also conduct interviews in a consistent manner, maintaining an audit trail to ensure dependability.

Phenomenology is an evolving methodology. Beginning in the early 20th century, researchers found data to be subjective, leading to difficulty in establishing the research findings as reliable and valid (Moustakas, 1994). Researcher-induced bias using phenomenology as the methodology could lead to a skewed perception in the interpretation of the data if the researcher is interpreting the data to support his or her personal beliefs or omitting data that do not favor a set of personal ideas (Moustakas, 1994). Bias is possible from the order or tone of interview questions, which can influence responses (Moustakas, 1994). Additionally, with the sample size being small, the outcome could be that the experiences were atypical (Moustakas, 1994). Other issues with phenomenological research include interference with interpretation of data when bracketing and the presentation of findings. The findings can be difficult to present because they are highly individual and sometimes impossible to explain. I plan to diminish these potential limitations by giving the participants the opportunity to articulate what they thought about their experiences, providing a rich view of their experiences.

Significance of the Study

Research is a critical tool for learning about the world around us. Psychologists seek a better understanding of behavior on a deeper level than just intuition. Different regional and cultural practices cannot be understood unless there is a deeper understanding of why people act and react in certain situations. Understanding stigma and raising awareness about Muslim Arab immigrant parents' experiences may help medical providers in multicultural areas offer a different approach or better services for this population.

This study is designed to address the link between stigma and culture. Gearing et al. (2013) found that most Arab countries relied on evidence-based practices and empirically supported treatments. However, these treatments were created and tested outside of Arab countries, and any adaptations or translations for these tests were given little attention within the Arab cultural context. Early intervention tests may not translate from one culture to the next, thus leaving at high-risk children requiring early intervention for the best outcomes. Obeid et al. (2015) found there are many regions around the world where ASDs are not assessed properly through psychologists, and cross-cultural research is needed to develop these services.

Misconceptions about ASDs are found worldwide. Thus, resources and services need to be available in culturally appropriate contexts that parents can get help for their children without feeling shame or stigma (Obeid et al., 2015). Additionally, parents of autistic children need resources at local hospitals and clinics where they will feel comfortable seeking help. Being able to identify reasons that contribute to parents not help-seeking could be useful to finding what impact stigma has on parents and how they chose to seek help. This would help physicians and clinicians increase the likelihood of parents overcoming the fear of stigmas associated with seeking interventions for their children.

Social psychology is a discipline about understanding a person's behavior in a social context and how human behavior can be influenced by those around us and the social setting we are in (Goffman, 1963). Culture plays a role in human behavior, and by studying social contexts on stigma within a culture, researchers can gain knowledge about how stigma plays a role with people with an ASD in different cultures.

This study is also significant because of the focus on stigma and lived experiences as the affected populations see it. Mak and Cheung (2008) developed their affiliate stigma questionnaire following their quantitative study of associative stigma. Their questionnaire was specifically used by the researchers to measure internalized stigma faced by caregivers of mentally ill individuals or those who are disabled. What Mak and Cheung found was that caregivers in different regions around the world felt they had experienced stigma as a caregiver of a child with an ASD. How people interpret the treatment they receive from their family and community can have a significant impact on future research within the culture and perhaps open a dialogue for other subjects that are considered stigmatizing to speak about and seek help for.

Positive social change regarding stigma and ASDs can stimulate societal well-being and can happen over time through change in social structure. It has been found that rather than conduct fact-based training to reduce stigma towards those with mental health issues or those with disabilities, that online training has been a positive strategy in fighting stigma (Massa et al., 2020). Recent evidence also shows that college students are improving attitudes towards peers with autism due to information and contact with peers who are autistic being more common (Massa et al., 2020). The suggestion is that high-quality contact with people who are autistic is a powerful way to reduce stigma towards autism (Massa et al., 2020). Changing social institutions and social behavior can help a community in the long term and can create social movements which can influence a social change. For all these reasons, this study can have a positive impact on the parents of children diagnosed with an ASD.

Summary

Autism is a mental health disorder found worldwide. An array of disorders falls under the category of ASDs (Kim et al., 2011). In the Middle East, prevalence of ASDs appears to be much lower than in Europe and North America. Religion, cultural beliefs, practices, and stigma are factors for under-reporting such a condition in the Middle East (Zaroff & Uhm, 2012). Resources, attention, and understanding of mental illness are inadequate compared to other regions, and mental illness remains one of the most stigmatized conditions in the Middle East (Sewilam, et al., 2015). By focusing on Muslim Arab immigrant parents in multicultural communities and their lived experience in seeking help for a child who has been diagnosed with an ASD, the role that this plays within a community or family can be better understood. Because perceptions of stigma vary across cultures, it is important to explore what factors deter or play a role in seeking help. The theoretical framework of this phenomenological study is Goffman's (1963) original social stigma theory, which addresses psychological and social ideas about stigma. Semi-structured interviews will be conducted with a purposive sample of 10 parents of children diagnosed with ASD who are in the age range of 3–15 years old.

Chapter 2 includes an introduction, literature search strategy, theoretical foundation, literature review related to key concepts, and a summary and conclusion.

Chapter 2: Literature Review

Introduction

Mental illness is one of the most stigmatized conditions in the Middle East (Sewilam et al., 2015). Stigma is one of the most common reasons for not seeking mental health help for individuals and families. In the Middle East, the Muslim Arab culture is collective, which tends to shape Arabs' perceptions and ideas about mental illness (Dardas & Simmons, 2015). The stigmatization is rooted in cultural beliefs about mental illness, such as demonic possession, black magic, and the evil eye (Okasha et al., 2012). Stigma has an impact on help-seeking, how psychological intervention is associated with stigma, and how mental illness is viewed within the cultural and religious perspectives. Researchers, too, are challenged by cultural beliefs in these regions and thus research relevant to this topic has been sparse. Because mental health services are a critical part of reducing mental illness, it is important to reduce the stigma that surrounds it. The purpose of this study is to explore stigma and its effect on Muslim Arab immigrant parents, on their decision making when seeking help for an autistic child, and these parents' lived experiences when trying to get help in a multicultural community.

One of the biggest challenges found in immigrant communities is that mental health treatments were developed by people in Western cultures (Dardas & Simmons, 2015). Because stigma is usually ingrained in social environments and societal norms are different from culture to culture, what is acceptable in one culture may not be acceptable in another (Dardas & Simmons, 2015). Because of the dearth of research on stigma that has been done in the Arab culture, it has been difficult to design and test methods of implementing acceptable interventions there (Dardas & Simmons, 2015). Nevertheless, in developing countries, it is important to study the concept of mental health stigma in order to improve the health and well-being of people with mental disorders (Dardas & Simmons, 2015).

Zolezzi et al. (2018) reviewed studies regarding stigmitizing beliefs, actions, and attitudes against people with mental illness in the Arab cultures. Of the more than 3,200 articles identified through database searching, the researchers identified only 34 articles that met the criteria of reporting stigmatizing beliefs, actions, and attitudes. In many of the articles, mental illness was portrayed in a negative way among various Arab populations. Among the stigmitizing beliefs were that mental illness is Allah’s punishment, Allah’s will, the evil eye, curses, magic, spirits, demons, and paranormal phenomenon, all being rooted in religion, cultural steroetypes, and family tradition (Zolezzi et al., 2018). Additionally, most of the studies suggested that Arabs sought help from religious faith healers or prayer as the first step in treating mental illness, and that stigmatizing beliefs or the social stigma of shame for the family kept people from seeking help and generated feelings of shame for having a mental illness (Zolezzi et al., 2018).

Studies conducted in other collective cultures found similar results regarding stigma. Minhaset al. (2015) found that similarly to the Arab culture, in South Asia a child who had ASD was considered to have it because of the “will of God,” and that caring for a child with a disorder was a divine duty for which the parents would be rewarded in the afterlife. Often, because of poor understanding by health professionals, a delay in diagnosis occurred, which led parents to seek treatment from a range of professionals and religious practitioners (Minhas et al., 2015). Community attitudes toward those with an ASD, especially those with visible behavioral and socially unacceptable presentatons, were a contributing factor in stigma toward the child with ASD and their family (Minhas et al., 2015). The stigma associated with ASD concerned parents to a point that they restricted societal exposure of their children for fear of harm to them from others.

Cultures that are individualistic, such as Ireland, have similarities to the collective culture and stigma. Although there is more awareness of ASDs in Ireland, parents with a child on the spectrum in Ireland face significant societal stigma (Byrne et al., 2018). As in other studies conducted in the United States (Myers et al., 2009), France (Chamak et al., 2011), and China (McCabe, 2008), parents in Ireland found it difficult to accept the autism diagnosis and felt loss, loneliness, difficulty to plan for the future, and lived on a day-to-day existance. Stigma was a prominent factor in the misperception by the public regarding the disability and its causes (Byrne et al., 2018).

In their study, Myers et al. (2009) asked parents in the United States and seven other English-speaking countries to answer an online questionnaire and a survey to address how their child with a condition in the autism spectrum affected their lives. Parents indicated that having a child with an ASD negatively affected both parents and the family, with pain and distress in marriages, for siblings, and for family members with the outside world (Myers et al., 2009). In France, Chamaket al. (2011) used mixed method research and found the most difficult part of having a child with autism was the length of time it took for their child to be diagnosed due to doctors’ hesitancy to give an autism diagnosis. Because research had suggested an early diagnosis of autism was associated with parenting stress, doctors did not want to interfere or cause undue stress to the parents (Chamak et al., 2011). Other research showed that parents of children who were diagnosed before the age of 4 years had negative feelings about the diagnosis such as disbelief, shock, and anger. Yet in most cases the parents were relieved the child's behavior had been diagnosed. Indeed, the delivery of the diagnosis to the parents was significant. Assistance to cope with the news and being given information and contacts to get help for their child reduced the stress parents felt with the diagnosis (Chamak et al., 2011).

McCabe (2008) conducted a qualitative study in China on the experiences of parents with a child who had autism. In answers to a questionnaire, most parents were shocked and devastated by the results, and had a lack of understanding about the disorder (McCabe, 2008). Some parents were in denial and hoped that the diagnosis was wrong. Overall, parents experienced devastation and despair, along with stress, anxiety, worry, and depression. All these responses were linked to stigma in Chinese society about children with disabilities (McCabe, 2008). Mothers' lives changed completely, and having a child with autism took up all of their time, limiting social interactions and activities, while the fathers' lives remained unchanged. Because of the absence of services, mothers had competing demands at work and at home and as a teacher for their child (McCabe, 2008).

Kang-Yi et al. (2018) conducted a qualitative study to try and understand cultural beliefs at community levels and how they affected the care for children with autism and developmental delays within the immigrant communities. The focus was to see if there were strategies that could identfy ways to assist in early intervention and to increase autism awareness within the Korean-American community. What was found was that cultural influences played a huge role in decisions regarding help-seeking. Additionally, how professionals' understanding within the community affected community beliefs and understanding of things such as autism, as well as approaches to the subject of autism and being sensitive to cultural beliefs (Kang-Yi et al., 2018).

The preceding background supports the need for continued study in relation to the experience of autism diagnosis within immigrant communities. The remainder of Chapter 2 contains an introduction, literature search strategy, theoretical foundation of the study, literature review, a summary, and conclusion. I review literature on the concept of stigma and how it is a factor in help-seeking, as well as how it applies to the target population in this study.

Literature Search Strategy

I conducted a thorough search of the peer-reviewed literature on stigma covering the past 5 years and using the Thoreau Multi-Database and the Psychology Databases combined search. The search databases included Google Scholar, PsycINFO, SAGE Journals, SocINDEX with Full Text, Taylor and Francis Online, PsycARTICLES, PsycBOOKS, andPsycEXTRA. Keywords and phrases used to search were *autism and stigma, autism stigma, autism immigrant stigma, stigma mental health Arab, mental health stigma Middle East, immigrant mental health help,*and *Arab immigrant autism help.*

The search revealed a pattern of articles that focused on stigma toward mental illness in general, but few that focused on stigma and autism within the Muslim Arab culture.There were a few comparative study on parents' perceptions of raising children with autism in the United States and Arab countries. Additionally, there were studies about community cultural beliefs and the impact it had on care for children with autism. Many of the studies had to do with acculturation and the impact it had on treatment for autism, touching on the subject of stigma, none focusing solely on stigma or lived experiences. This creates a gap in the literature as stigma is known to have an affect on help-seeking within other cultures.The articles on mental illness stigma in general helped to provide a more thorough understanding of how social factors in immigrants and in the Arab culture affect a person's willingness to seek help for a mental illness.

Because the specified keywords and phrases in the initial search yielded few findings, the search was broadened to include *perspectives, attitudes, beliefs, discrimination, stereotypes, cross cultural differences, sociocultural factors, racial differences, ethnic differences,* and *autism middle east.*The broadened search, which included *stigma or stigmatization or stigmatisation or shame or discrimination or predjudiceand autism,* yielded more findings pertaining to this research. Additionally, research from other cultures regarding autism and stigma was used to added insight into stigma and attitudes toward people with autism or mental illness.

Theoretical Foundation

The theoretical foundation for this study was Goffman's (1963) social stigma theory. I explored the stigma faced by parents seeking help for their children with autism.

Despite modifications to Goffman's theory, the orignal theory has remained a dominant theory for stigma in social psychology. Goffman believed stigma was based on the social construction of identity, and the theory is frequently used to analyze the psychological impact of stigma. Stigma shapes behavior, decisions, and actions, and therefore understanding the psychology of stigma can focus attention on the process of the role stigma plays on human interaction and help-seeking.

Finding the relationship between stigma and the social implications as to why some people do not seek help is important. Understanding the parent's first-person experience can help to comprehend why some people do not pursue professional help. Countries all over the world are seeing a rise in the diagnosis of ASDs (Centers for Disease Control and Prevention [CDC], 2019). Factors such as culture, the lack of available resources, and the lack of understanding about ASDs are predictors in the diagnosis of autism (Mandell & Novack, 2005). Because of the dearth of qualified mental health professionals, access to services, support, and medical treatment is lacking in most Middle Eastern countries, the stigma and attititude toward those who seek psychological help make it difficult for those who would like to see a professional (Dardas et al., 2018).

Goffman's (1963) theory has had a great influence on today's concept of stigma. Goffman identified four types of stigma: visible, public, obtrusive, and relevant. Although variations of these categories are not mutually exclusive, they are often found to overlap one another due to perception, individual choice, and other external factors. Children on the spectrum display such subtle signs as ticks and repetitive actions, and others display more overt signs such as sudden outbursts and uncontrollable reactive behavior, which may affect the stigmas experienced.

Studies Relating Social Stigma, Culture, and Mental Illness

Experiences of stigma can manifest differently in differing settings. Weaver and Trainer (2017) used a mixed method strategy and examined two instances of stigma in two different cultures and drew from Goffman's (1963) concept of stigma as a single social process. Status incongruity was examined as a way to measure stigma. Weaver and Trainer measured food insecurity, that is, the lack of consistent access to food to stay healthy (U.S. Department of Agriculture, 2019) in rural Brazil and obesity in the UAE. Certain foods in Brazil are a sign of luxury, such as pizza and salty snacks, while other foods carry a stigma because they show an impoverished way of life. Weaver and Trainer found that many people were unaware of food insecurity within their own community, which could have resulted from shame and self-stigma regarding food insecurity. This then motivated people to hide that they did not have enough food. In the UAE, the exploration of stigma focused on regional behaviors and norms and the stigma associated when someone deviates from these norms.Weaver and Trainer noted that the socioeconomic, structural, and cultural changes over the past 20 or 30 years have changed food, eating patterns, and bodies, in cities such as Dubai and Abu Dhabi. Despite the great wealth in the UAE, poverty and food insecurity remain. Similarly to Brazil, the authors found that in the UAE there was stigma-associated social pressure to hide poverty and hunger. The bigger issue in the UAE was not food insecurity but obesity and the associated co-morbitities which have increased in the last 30 years. In the past, heavy body weight was a sign of wealth and considered desirable. Now, being perceived as too fat or too thin is stigmatized and a larger body is an indication of laziness while being thin is interpreted as being too Western-influenced. In this study stigma was internalized by the participants, as Goffman's original work indicated is most often the case. Additionally, in both populations stigma was experienced because of a nonconformity to a social norm, and social isolation was a result.

Turning to stigma relating to the proposed research topic, Munroe et. al. (2016) studied the lived experiences of African immigrants integrating into a new culture in the United Kingdom while parenting a child who had been diagnosed with an ASD. The participants were all mothers who had a son diagnosed with an ASD and a learning disability. The results indicated parenting a child with an ASD was all-consuming, demanding, emotional, worrisome, and stressful, and mothers found it was difficult to balance life due to prioritizing a child with special needs. Additionally, the participants found it difficult to find support because they did not want anyone knowing about their child. The families did not want others to speak ill of them or their child. The mothers felt shame, embarrassment, judgment, and rejection. Many of the participants thought if they had stayed in Africa they would have had more support and tolerance of their child from their extended families. The participants seemed to be mourning the loss of a "normal" child and an envisioned life they had for themselves. In some cases, they were in denial of the diagnosis. All participants had felt marginalized by the cultures around them and experienced shame and alienation. Mothers' feelings were connected to the experiences they had of stigma linked to cultural beliefs, and to deal with this different participants assimilated, integrated, or separated with UK society.

Obeid et al. (2015) used a quasi-eperimental design for their research into stigma and culture. The study compared stigma of ASD between the United States, a country with many resources for autism, and Lebanon, which has limited awareness and resources for autism. College students from both countries were assessed online before and after an online ASD training (Obeid et al., 2015). The students from Lebanon had less knowledge and a higher stigma toward ASD compared to those students in the United States (Obeid et al., 2015). Yet, the students from Lebanon knew more about people having less access to care and other disparities for availibility to care compared to the U.S. students. The study suggested unequal information is distributed on an international level and that this may impact how cultures respond to such conditions as autism.

Meier (2017) found that although the United States is one of the largest and most developed countries in the world, barriers still prevented adolescents from accessing mental health help because of stigma. Literacy about mental health disorders and interventions available were low, which contributed to incomplete mental health treatments. Guided by Goffman’s social stigma theory, Meier explained that the high levels of stigma associated with mental health and help-seeking could be internalized at an early age and solidified in adulthood. Further research was recommneded to address mental health in adolescents and what could be done to get help when stigma is high.

Summary

As demonstrated in the preceding studies, social stigma theory is appropriate for this study in relation to cultural connections. Fear of public stigma, self-stigma, stigma by association, and structural stigma can influence choices regarding help-seeking. Little research is available regarding stigma in the Arab immigrant populations because of societal constraints and stigma within the culture. Additionally, although Arab Americans are one of the fastest-growing ethnic groups, they are among the least-studied ethnic communities in the U.S. especially when it comes to mental health. Applying the stigma theory can help better understand why parents do and do not seek help and answer the two research questions: (a) What are the lived experiences of Muslim Arab American immigrant parents when asking for help for their child with an ASD? and (b) What are the lived experiences of stigma faced by Muslim Arab American immigrant parents when seeking help for a child with an ASD?

Literature Review Related to Key Concepts

Different variables contribute to stigma. Traditional sociology emphasized stigma as feeding on the inequality that is found between class, race, and gender, but sociologists now include other types of social stigma, such as mental illness (Tyler & Slater, 2018). In this study, culture, Islam, and stigma are examined in relation to parents' help-seeking for their children with ASD.

Culture

Culture is the shared attribution and belief system of a group of people and is important when it comes to mental illness and treatments. Cultural anthropologists have found relationships between mental illness stigma and the cultural values and attitudes toward mental illness for people in various cultures (Abdullah &Brown, 2011). Abdullah and Brown (2011) found that studies of American Indian, Asian, African, Latino, Middle Eastern, and European cultures have all yielded comparable results.

Cultural values have played an important role with regard to stigma and can play a key role in the perception of mental illness in various cultures (Dardas & Simmons, 2015). Abdullah and Brown (2011) noted that Americans in the past have not wanted someone with a mental illness to marry into their family, work closely with them, or spend an evening socializing with them. Similarly in the Arab culture, a set of values, beliefs, and traditions are shared and have a heavy influence on mental illness perceptions and management (Dardas & Simmons, 2015). Putul et al. (2018) also found that mental health is understood and interpreted differently in various cultures. Consequently, treatment-seeking behavior varies among cultures. The treatment of racial and ethnic minorities is attended to at a much later stage in illness due to reluctance for treatment, coming from the stigma attached to mental illness within minority cultures (Putul et al., 2018).

Dominant culture status does not prevent stigma attached to mental illness, however. In a qualitative study on autism in China,Tang and Bie (2016) analyzed coverage of autism in five leading newspapers and found that the reporting was often biased. Stigma was attached to many different health conditions. Parents of autistic children and those with autism were often discriminated against and stigmatized, with low awareness of the disorder, lack of resources, and lack of programs for children with autism in China.

In the face of the influx of Middle Easterners in the United States, pediatric psychologists have noted a unique challenge (Hilliard et al., 2012). These researchers found little guidance regarding the provision of culturally relevant care to children and families from the Middle East, with cultural adaptions of evidence-based treatments sparse. Culture is not the only factor in mental health treatment. Religion for people from the Middle East was seen to play a large role in how mental health was viewed and treated (Koenig et al., 2012). Religious psychotherapies within faith traditions have been developed, refined, and used in clinical trials as a way to develop an integration of patients' religious resources into treatment. Integrating religion into mental health treatment may or may not be as effective as conventional therapies in relieving the symptoms of disorders such as depression and anxiety (Koenig et al., 2012). Although more research is needed, Koenig et al. (2012) found through observational and clinical studies that the more involved in religion and faith traditions, the better a person's mental health (Koenig et al., 2012).

In the Middle East, psychological treatments and interventions remain low,even in countries that are experiencing social and economic growth. Despite the prevalence of mental illness and treatments, stigma has been one of the biggest barriers to negatively impact help-seeking (Vally et al., 2018). The UAE is one country experiencing significant growth over the last 20 years. But despite the growth and need for mental health services, there are few trained and licensed mental health professionals in the UAE

(Vally et al., 2018).The UAE is a predominately Muslim Arab country, and there are both religious and cultural influences upon perspectives of mental illness. Within the culture stigma is related to mental health problems, which can lead to self stigma and the fear of public stigma which relates to help-seeking (Vally et al., 2018). Social identity to some can be devalued in certain social contexts if that person is seen in a negative way and therefore label avoidance is active. Any negative labels associated with mental health problems will be avoided because of public stigma and people who help-seek can be seen as inadequate, inferior, or weak which can negatively affect one's self-worth (Vally et al., 2018).

Strengths and Weaknesses of the Literature

Abdullah and Brown (2011), Tang and Bie (2016),Putual et al. (2018), and Vally et al. (2018)showed that a significant amount of research and awareness is still needed in many cultures. These scholars suggested the stigma of mental illness exists and affects not only the child but the family. Moreover, culture plays a role in how mental illness is viewed.There is often a lack of awareness for conditions and insufficient resources for treatment of families in need. Little research has been undertaken on Arabic Muslim culture and stigma. Although it cannot be said one culture is more stigmatizing than another, patterns of beliefs are repeatedly seen to show that culture plays a role in stigmatizing attitudes.

Culture, Help-Seeking, and Intervention

Cultural influence on stigma research has shown that help-seeking can be difficult when faced with the dominent ideas about what mental illness is and is not within a culture. In a qualitative study, Tzouvara and Papadopoulos (2014) found that although there was sympathetic feeling among Greeks toward people with mental illness, there was also a high stigmitizing attitude toward them. Improving general knowledge about mental illness was suggested to help improve attitudes within the culture, making help-seeking easier. Also suggested was that an anti-stigma campaign needed to be culturally tailored to be effective (Tzouvara & Papadopoulos, 2014).

Al Jabery et al. (2014) explored why parents in Jordan had difficulty when seeking help for a child with autism. At times the services that were needed required traveling to multiple places with different providers. Issues also arose because of the cost of treatment and quality of service; thus, parents were dissatisfied with what they could access for their children. The challenge of finding a provider connected with the challenge of cultural and social perceptions of disability, with both the stigma of having a sick child, and lack of qualified professionals to help. The researchers noted that this poses a great challenge in Middle Eastern countries for children with disabilities.

Alotaibi et al. (2016) and interviewed 15 male teachers between the ages of 27–40 years in special needs schools in Saudi Arabia. The researchers explored the effectiveness in the classroom of "Social Stories", a comic strip type of informational guide designed to help autistic people develop greater social understanding and skills. Many of the Social Stories used in Saudi Arabia came from other countries and were found inappropriate for use, such as clothing guidelines, and were found to confuse the children instead of assisting them (Alotaibi et al., 2016). The authors noted that, as might be expected, Saudi culture influences parents of autistic children, their parental expectancies, and how they choose to treat their children and the facilities they attend. Alotaibi et al. recommended modifying the social stories materials to suit cultural and traditional contexts for the country the comic is being used in and including parents in the evaluation of the content prior to their use.

Strengths and Weaknesses

Al Jabery et al. (2014) focused on the perception of the parents and what they experienced trying to get a diagnosis for their child with autism. The authors also examined avaliable services post diagnosis. Although the researchers offered excellent suggestions for improving comprehensive services, they offered no implementation strategy for providers. Alotaibi et al. (2016) made a strong case for their research and the impact of culture and the effectiveness of several educational products, including Social Stories, and how they are presented. It was the first of its kind regarding a specific tool, and the authors suggested that the tool should be personalized according to culture and region, but implementation strategies were not developed.

Tzouvara and Papadopoulos (2014) identified high levels of stigma among healthcare professionals and law enforcement working with people with mental illness. Yet there was no plan offered for educating those in the public sector and training them how to interact with people who suffer from a mental illness.

Islam and Mental Health

In the holy Qur’an, and in Islamic teaching, people have a social responsibility toward people with disabilities, both physical and mental (Al-Aoufi et al., 2012). Al-Aoufi et al. (2012) concluded that mixing culture with religion can lead to false attribution of abnormalities to religion such as having a child with a disability and trying to explain why the child is disabled. Other Islamic teaching seems to uphold culturally-held stigma for those seen as mentally ill.

The Qur'an is a guide not only for social responsibilities which could include assisting those with disability but is considered the divine source for all Islamic beliefs and guidance for behavior (Islam & Campbell, 2014). Often times in Islam mental illness is believed to be caused by a person being possessed by an evil spirit. In Arabic it is called a "Jinn," or supernatural being, which happens as a punishment from God because of a person's weakness or sins, and are seen as a punishment from God (Islam & Campbell, 2014). Islam and Campbell (2014) found that a culture of silence in Islam has been embedded within religious communities, which have underreported and underdiagnosed mental illnesses because of fear of stigma relating to its perceived cause.

Supernatural forces being blamed for mental health issues is not restricted to Islam but can be found in other religions, such as Buddhism, Hinduism, Judaism, and Christianity (Islam & Campbell, 2014). Pre-Islamic Arabs believed in spirits as guardians who were protectors. Those beliefs changed during the medieval Islamic State to manipulate and enforce religious and certain political ideologies (Islam & Campbell, 2014). Influenced by the Greeks, later Islamic medicine began treating mental illness as a physical illness with a more holistic approach connecting healing to the mind, body, and spirit (Islam & Campbell, 2014). Mental illness in Islam was treated as a somatic or physical illness. Over time, this perspective waned and modern Muslims learn from a young age that the devil is the cause of mental illness and that spiritual health is more important than physical health (Islam & Campbell, 2014).

Hashim, Yussof, and Bahrin (2017) used a hybrid methodology with 20 participants examining Islamic religious perceptions of technology in using robots for rehabilitating children with mental disabilities. They found that despite scientific advances being used and encouraged in Islam there are still constrictions. For example, the Nao humanoid robot, a type of artificial intelligence, has been used all over the world and on children with special needs. Yet, because of the Islamic perception of the sin of idolatry, religious and spiritual beliefs have made it difficult to make a decision on whether it is appropriate to use this robot because of its human-like facial features (Hashim et al., 2017). The authors concluded that because of religious, spiritual, and cultural implications, teachers and parents were not ready and did not want to use humanoids with autistic children. Parents of autistic children were more protective of their children with ASD and did not want the children interacting one on one with the humanoid. They would, however, allow short interactions as entertainment if there were groups of children.

Strengths and Weaknesses

Hashim et al. (2017) took into consideration the current climate of technology. These researchers noted that technology was seen as useful in Islamic culture, with many teachings used for religious practices available via computer, tablet, and phone. However, they also noted the difficulty when one’s religious beliefs were perceived to become affected by using a tool that may or may not align with religious provisions. The weakness in this study was that the authors did not indicate what technology the parents would be willing to use that could help their child and align with religious beliefs.

Religion can guide many beliefs, including those regarding mental health. Tzouvara and Papadopoulos (2014) found in their qualitative study that the religious Greeks they studied were more authoritarian, followed more traditional values, and had a more conventional attitudes toward psychiatry than those who did not have traditional values. Religiosity could also be linked to stigmitizing attitudes and a higher level of authoritarian attitudes (Tzouvara & Papadopoulos, 2014). This does not mean that this is true of all religious groups, but evidence shows that religiosty and mental illness stigma can be associated.

Stigma and Society

Revisiting Goffman's (1963) theory on stigma, Pescosolido (2013) argued stigma is fundamentally a social phenomenon rooted in social relationships and shaped by the culture and structure of society. Therefore, stigma is produced from culture and social relationships. To understand and change how stigma is negatively associated with mental illness, social relationships and the structures that shape them must change. Although there is an increase in research into mental health interventions in non-Western cultures, and treatment in the past few decades has become more tailored toward cultural norms, research in these regions continues to be sparse and methodologically limited (Gearing et al., 2012).

Stigma, a social phenomenon, can be exacerbated by a clinical diagnosis. Linton (2014) used a phenomenological design and found that a diagnosis of an ASD often leads to stereotypes, prejudice, and discrimination. In Hollywood, characters on the spectrum are often portrayed as mysterious, savant, or having extraordinary cognitive abilities.

Stigma can be harmful to people with mental illness and can lead to blocked life opportunities, limited work, and negative stereotypes (Linton, 2014). Stigma against those with autism is found everywhere and is often linked to a lack of awareness and understanding within a culture. It can be difficult for parents to get an exact diagnosis in areas where there is little to no knowledge of autism among the general population. This is stressful not only for the child but the parent or caretaker of the child and creates stressors taking away from the needs of siblings, and straining relationships with friends, family, and neighbors.

Al Jabery et al. (2014) found that parents in the Arab Muslim community had trouble finding help for a child with health conditions such as autism. The problem is found socially, culturally, and religiously, which makes decisions about healthcare options harder for parents. Setting aside culture and religion, the social stigma that is attached to having a child with any medical condition is difficult for parents in this region. The stigma of mental illness is significant around the world and can vary culturally (Zolezzi et al., 2018). Mental health conditions are the same cross culturally but can manifest in different ways and are shaped by stigma within that culture (Zolezzi et al., 2018). Stigma in religion has been linked to social and extrinsic motives of looking for social support via engagment in religious community, social conformity, or respect for traditional beliefs (Johnson-Kwochka et al., 2020)

Islam and Campbell (2014) found that Muslims often face a double stigma with self and community/family, because of the idea that the devil is what causes mental illness. This type of shame or fear of stigma leads to the underutilization of mental health care, which leads to a range of social consequences, including suicide. Similarly, Scull, Khullar et al. (2014) found in their research in Kuwait that seeking mental health treatment was extremely stigmatizing among Arab populations. Psychological disorder was so stigmitizing that few would turn to formal therapy if they experienced a psychological problem. Additionally, the stigma associated with seeking mental health care was known to cause problems interpersonally in areas such as marriage and prospects of marriage. Therefore, alternative means of support for mental health treatment were sought (Scull et al., 2014).

Stigma is found not only in the general population but can occur in the medical field as well. In their mixed method study, Soliman et al. (2016) explored the attitude toward psychiatric patients and mental health disorders among 300 fifth-year Egyptian medical students on their psychiatric rounds. Those with a positive attitude about psychiatry to begin with had neutral attitudes after their 3-week rotation, and those with negative attititudes to begin with also had neutral attitudes after their rotation. The lack of interest in psychiatry had to do with the attitude that it is less important than other branches of medicine. There was insufficient time for students to get comfortable with their patients, and inefficient teaching failed to correct already associated perceptions of psychiatric illness (Soliman et al., 2016).

Strengths and Weaknesses

Al Jabery (2014), Islam and Campbell (2014), Scull et al. (2014), and Soliman et al.(2016) all reiterated Goffman's (1963) fundamental idea that stigma is a social phenomenon rooted in social relationships and shaped by the culture and structure of society. Weaknesses of these studies included lack of recommendations for battling stigma. There was no clear path for this region to engage and reduce the stigma for mental health disorders or a way for cultural and religious leaders to engage with a campaign to fight stigma.

Summary and Conclusion

Little is known about autism in the Middle East, but the prevalence of autism has been suggested to be comparable to that of the Western world (Sopaul, 2019). Autism is often overlooked and misdiagnosed because of the lack of knowledge and methodical use of appropriate tests, measurable scales (Sopaul, 2019).With the Muslim Arab American immigrant population being one of the fastest growing in the United States it is important to research this group. Additionally, future qualitative studies should examine the lived experiences of immigrant parents with a child who has autism and explore their rationale and decision-making processes for the child's care within the new community away from their home country.

This chapter consisted of an introduction, literature search strategy, theoretical foundation, a literature review related to key concepts, and a summary and conclusion. A major theme that surfaced in the literature review was the impact of culture on stigma. More than one culture from continent to continent has the same preconceptions about mental illnesses. Although an array of literature (e.g. Abdullah & Brown, 2011; Dardas &

Simmons, 2015; Putul, 2018; Tang & Bie, 2016) has addressed stigma and different cultures, there is little regarding stigma and help-seeking within the Muslim Arab American immigrant culture specifically. Researchers have found that those who were more religious tended to have more stigmatizing views on mental illness. Sopaul (2019) found in the Arab World mental health was an emerging field. While several researchers (Al-Aoufi et al., 2012; Eapen & Ghubash, 2004; Gearing et al., 2013; Okasha & Karam, 1998; Samadi & McConkey, 2011; Sewilam et al., 2015; Zaroff & Uhm, 2012) have examined the effectiveness of special education and teaching interventions, there is little research on the impact of a disability, such as autism, on individuals and families. Reform has been inhibited by politics, strict culture, and tradition, which oppose adopting international guidelines in the region (Sopaul, 2019).

Stigma is a social phenomenon shaped by culture. The relationship between culture and stigma can be seen in various cultures (Byrne et al., 2018; Chamak et al., 2011; McCabe, 2008). Research of immigrant populations is greatly needed in order to help a new generation of parents and children who are struggling with the conditions of autism. Additional research is needed on the topic of mental health conditions and how culture affects treatment. Understanding the stigma that is found within the Muslim Arab American immigrant culture can help those in search of mental health, as well as their providers to have less fear of negative attitudes from their community and family.

In Chapter 3, I explain why a phenomenological study is appropriate for addressing the research problem. Chapter 3 provides the research design and rationale for the study, my role in this study, the methodology I plan to use, issues of trustworthiness, and a summary.

Chapter 3: Research Method

Introduction

Healthcare decisions and options vary depending on factors such as social and cultural norms. The purpose of this phenomenological study is to explore stigma and the decisions Muslim Arab American immigrant parents make while seeking help for an autistic child or children, and their lived experiences when seeking help. Specifically, the study is intended to better understand help-seeking behaviors. The results may bring information helpful to developing different approaches and services from medical providers for people in this region.

In this chapter, I will explain the research design and a rationale, researcher bias, explanation of the methodology chosen, participant criteria, population, sampling strategy, sample size, data analysis plan, addressing the issues of trustworthiness, ethical procedures of the study, and a summary.

Research Design and Rationale

Research Questions

The research questions guiding this study were:

1. What are the lived experiences of Muslim Arab American immigrant parents when asking for help for their child with an ASD?
2. What are the lived experiences of stigma faced by Muslim Arab American immigrant parents when seeking help for a child with an ASD?

The relationship between research questions and interview questions can be found in the sections below and in the data analysis plan.

Central Concepts of the Study

Although psychiatry has had a place in the Middle East for centuries, the stigma attached to mental health is still apparent in the region (Sewilam et al., 2015). A central concept of this study is that stigma is faced by parents when seeking help for a child with an ASD because of the community they live in and how mental health is viewed in that community (Ciftci et al., 2013). To avoid stigma from the community, parents may avoid seeking professional help or visiting mental health clinics to avoid diagnosis and any stigma they could face (Ciftci et al., 2013).

Another central concept is that stigma affects help-seeking behavior of the parents. Zeina, Al-Ayadhi, and Bashir (2014) found that serious psychological distress was experienced by parents of a child with an ASD, more than that of a child with other psychological or developmental disorders. The reasons for added distress included stigma, blame, and lack of social support (Zeina et al., 2014). Although mental health care has seen an improvement in Middle Eastern regions over the last decade, many Middle Easterners still choose not to seek help or prematuraly terminate treatment (Ciftci et al., 2013).

Research Tradition

Generally, the two approaches to research are quantitative or qualitative traditions. I have chosen a qualitative inquiry approach for this research topic. Although there is a long-standing debate about which approach is best used for research, the debate is centered around two fundamentally different schools of thought (Mayoh & Onwuegbuzie, 2015). Quantitative methods use experimental methods to test hypotheses, while qualitative methods use phenomenological inquiry and naturalistic approaches to understand human behavior (Mayoh & Onwuegbuzie, 2015).Within the tradition of qualitative research, a phenomenological approach was best suited for this research study because the naturalistic approach, which suggests that reality is not fixed but subjective to human experience, would create a better understanding of the experience being researched (Reiners, 2012). A transcendental phenomenological approach was used in the analysis process.

Rationale for Chosen Tradition

A phenomenological approach (Husserl, 1999) was best aligned with the research questions, purpose of the study, and methodology. The study was guided by two research questions: (a) What are the lived experiences of Muslim Arab American immigrant parents when asking for help for their child with an ASD? and (b) What are the lived experiences of stigma faced by Muslim Arab American immigrant parents when seeking help for a child with an ASD? As indicated in the main question, the central phenomenon was to understand the lived experiences of parents in immigrant communities when asking for help for a child with an ASD. Phenomenology investigates how knowledge happens as it explains the essence of a person’s experience and sheds light on assumptions made. This approach contributed to current research on stigma in the Muslim Arab American immigrant parent population. Additionally, the goal was to provide a better understanding of stigma. To provide an unbiased perspective and to focus on the essence of the phenomenon, a transcendental phenomenological approach was chosen over a hermeneutical phenomenological approach. A hermeneutical phenomenological approach would have been a fit for this study if the intention of the study were to personally engage and interpret experiences and to then provide an interpretive analysis of the information that was collected. But the goal was not to interpret experiences; rather, I aimed to look at the scope of lived experiences of stigma.

Role of the Researcher

In this phenomenological approach, my role is an observer/interviewer. As an observer I will be able to see the participants and how they react to the questions they are answering. The purpose is to elicit and understand the lived experiences of stigma parents in the Muslim Arab American immigrant community have experienced within their community when they seek help for a child with an ASD. My role as a researcher combines all aspects of research including recruiting participants, conducting interviews, transcriptions, analysis of data, and reporting the findings. This process will include myself and the research participants, with whom I have had no previous personal or professional relationships.

My goal as the researcher is to conduct a bias-free interview focusing on personal experiences as they pertain to the study or knowledge of the topic during the study. Personal bias may be introduced through my having in-laws who are Arab and who have children with an ASD. Smith and Noble (2014) found that regardless of research design, bias is found in all research, is difficult to eliminate, and can happen at all stages of research. Bias affects dependability, which establishes the study’s consistency and ability to be repeated (Patton, 2015). Data can be misinterpreted, which can have negative consequences such as the credibility of the research and the authenticity of the findings.

Bias can happen when there is poor study design, when selecting populations, in data collection, analysis, and in publication (Smith & Noble, 2014). Measures for decreasing and controlling effects of personal bias are detailed below.

It is my goal as the researcher to have an authentic relationship with the participants, avoiding power differentials in the interactions. To better manage bias, ethics, and power in relationships as the researcher, it is my duty to be honest with myself and the participants and explain and clarify any questions the participants may have throughout the research. According to Karnieli-Miller and Strier (2009), there are ways to protect one's ethics and power balance before, during, and after the study. Karnieli-Miller and Strier suggested that, before the research begins, researchers should examine the goals and reasoning of the research thoroughly. While conducting research, researchers should do no harm, be familiar with the culture and history of the population, be clear and open with the research, and protect the privacy and anonymity of the participants.

During the interview, a researcher must tailor the language to the interviewees, show awareness of developing power relationships, such as being alert to and mindful of personal feelings that may impact the research, and be open to criticism and objection from the participant (Karnieli-Miller & Strier, 2009). Researchers should remind participants of the nature of the study and intended publication, make sure there is a balance between benefits and burden for the participants, and verify at different stages of the research the information that is being collected. Lastly, once the study has concluded the researcher should check that no personal information that may identify participants has been exposed or made public, avoid representing the researcher's rather than the participant’s view, protect anonymity, recognize strengths within the participant group, use the language used by participants in the writing, use substantial descriptions, be transparent and accountable for methodology and the limitations, and present any factors that contributed to interpretations and the findings (Karnieli-Miller & Strier, 2009).

The epoche process allows a researcher to identify and set aside many biases the researcher may have and allows the researcher to focus on the participants’ views of the phenomenon being studied (Moustakas, 1994). Moustakas (1994) found the challenge of the epoche process is within oneself and the inability to see things clearly and openly with new eyes and naivety. To achieve epoche one must allow a phenomenon or experience to present itself as is and leave behind anything that has been put into one’s mind previously.

Ethical implications for this study can include beneficence and non-maleficence and informed consent. Beneficence is the practice of researchers making sure the welfare of the participant comes first while non-maleficence is the practice of researchers making sure that the research being conducted does not cause harm to the participants (APA, 2013). Informed consent provides the participants with information about the research being conducted prior to the interview and then again before the interview is conducted. Participants can then anticipate topics and questions that may arise. Because the participants will come from a different culture and country from my own, I must respect the participants’ values and any decisions they make regarding the study, such as the participant wanting to drop out of the research. I must also make sure with informed consent that the participants are competent, understand, and consent voluntarily to their participation in the research. The research is not being conducted in my work environment. I will not be working with or know the participating volunteers prior to the study, and I will not use incentives for this study.

Methodology

Participant Selection Logic

Following the recommendation of Moustakas (1994), participant selection will be based on the following criteria: participants experienced the phenomenon, were interested in discussing and the phenomenon, were willing to participate in an interview, and granted me permission to publish the findings in my dissertation. I will interview parents with children diagnosed with ASD who are in the age range of 3 to 15 years old. I will be asking parents to reflect on their experience of the diagnosis process and to consider whether stigma was a factor in whether they sought help.

Patton (2015) found that with purposeful sampling researchers can select more information-rich cases to study and allow the questions of the study to be answered in more depth. Creswell (2013) noted that a participant number of 3 to10 is best for a phenomenolgical study.The goal should be to attain saturation in the research, which occurs when the addition of participants does not add new perspective or information (Moustakas, 1994). The sample for this study will be 8 Muslim Arab American immigrant parents with children initially diagnosed with an ASD who are in the age range of 3–15 years old. The sample will be solicited from Craigslist. Other avenues of recruitment can include a notice of this study on appropriate Facebook pages. A Participant Invitation letter, which includes specifics of the study, will be given to parents. Those who are interested in participating may contact me at the given email address.

An analysis tool called the cultural consensus model (CCM) developed by Romney et al. (1986) sought to identify common characteristics within communities and cultural groups. The model suggested that every culture shares a world view and therefore ascribes to a "cultural consensus." Although consensus on different topics varies, Romney et al. found there was a limited set of characterisitcs or views, and because of this the views can be analysed to produce a model of cultural views on particular topics. This analysis tool has been used to estimate minimum sample size. One example is Atran et al. (2005), who used this analysis model and suggested in their study that as few as 10 participants were needed in order to establish a reliable consensus. This model would be appropriate for this study as it could give a possible deeper understanding of help-seeking through cultural consensus. This could also be used as a predictor, noting characteristics of those who would and would not seek help for an autistic child.

A purposive sampling strategy will be used as this will provide qualitative information related to a specific phenomenon. The sample taken should be information-rich in order to establish the phenomenon of interest (Hunt, 2011). Purposive sampling allows a researcher to study a group within a population who have similarities. It is cost effective, and time-effective (Hunt, 2011). The purposive strategy was used for recruitment of Muslim Arab American immigrant parents of children in Kansas City, Missouri with ASDs.

Instrumentation

My initial consideration was to conduct participant interviews face-to-face, but planning was influenced by the pandemic and online interviews were selected as the method thereafter. Semi-structured interviews (Moustakas, 1994) with parents who meet the study's criterion (Muslim Arab American immigrant parents with a child diagnosed with an ASD within the last year who are in the age range of 3–15 years old). The interview questions (Appendix A) will be open-ended and broad in order to facilitate gathering rich, vital, and substantive information from the participants (Moustakas, 1994). An interview protocol will be used to prepare for the interview to ensure the overall questions the participants are being asked are relevant to the research questions and to make sure no key points are forgotten in the interview (Patton, 2015) and that the same lines of enquiry are used for every interview. A protocol was developed using current phenomenological literature by van Manen (2007) and Moustakas (1994).

A Participant Invitation Letter was used to recruit English speaking participants for my study along with contact information for the researcher at the early education school for children with special needs in Kansas City, Missouri, via email. If not enough English-speaking participants are recruited, the study will be stopped and the Institutional Review Board of the university will be contacted to seek approval of changes needed for the study. A second wave of recruitment will then occur allowing those who only speak Arabic to participate, and a translator will be brought onto the study. The translator will be present to ask the interview questions and to translate the answers. Following initiation of contact by volunteers, each participant will be screened, offered an informed consent form to sign, and an interview time. Interviews with the participants will not occur face-to-face because of the current pandemic and travel restrictions; instead, they will take place via telephone, Skype, Zoom, or Google video. The interview questions (Appendix A) will be asked by the researcher. Each entire interview with participants will be audio recorded.

I used Moustakas's (1994) modification of the Stevick, Colaizzi, Keen (Moustakas, 1994) method to organize and analyze the phenomenological data. The steps of the Stevick, Colaizzi, Keen method follow:

1. Use a phenomenological approach to get a comprehensive description of interviewee's experience with the phenomenon.
2. From the interview transcript data, gather a list of significant statements from the interviewee's experience. Consider the significance of the statements and list nonrepetitive and nonoverlapping statements.
3. Group the statements that are significant into larger themes or meaningful units.
4. From the descriptions of the interviewee's descriptions of experiences, create a composite "textural description" of "what" was experienced. This is done through verbatim examples.
5. From the descriptions of the interviewee's descriptions of experiences, create a composite "structural description" of "how" the experience happened. This is done by integrating individual meanings and essences of one's own experience.

6. Create a composite description of the phenomenon integrating both textural and structural descriptions.

A semi structured interview is the best way to gather data because the participants can express their experiences of the phenomenon in their own words. Asking interview questions enables a more thorough, explicit, and flexible investigation. Additionally, a semi-structured interview can present more reliable and comparative qualitative data.

Researcher Developed Instruments

Using Van Manen's(2014) criteria, I developed the research questionnaire. The basis for using the instrumentation of interviewing in phenomenological research according to Van Manen (2014) is to see how someone perceives their experience as an individual. The empirical procedures of phenomenology are not used to explore the psychological life but to understand the human experience (van Manen, 2014). I intend to elicit a specific experience from the participants by asking them to describe their experience as it occurred. The goal is to gather their lived experiences rather than personal stories. People tend to share an opinion, view, or perception of an event rather than sharing an experiential account about a sensitive subject (van Manen, 2007).

In qualitative research there are several ways to gather data such as through observation, interviewing, audio recording, and documentation (Creswell, 2013). For a phenomenological study to have validity, the research findings must be well-supported and well-grounded. Polkinghorne (1989) suggested that if a researcher can convince the reader that a logical thought process has occurred, then the steps from data collection to data anlysis and synthesis can be viewed as stable and dependable. Concerns about stability and dependabilitycan be alleviated by identifying certain considerations such as the following: Did the interviewer influence the subject's answer? Is the transcription accurate, and did it portray the interview correctly? When analysing the transcipts ,did the researcher identify alternative conclusions? Can a general description of the transcripts make connections and identify specific content in the original content? Is the structural description specific for certain situations, or is it the same for other experiences in varied situations? Content validity generally refers to whether a measurement tool is measuring the construct of interest correctly and if the interview and observation techniques were used effectvely and relevently for the research (Collingridge & Gantt, 2008). To establish content validity,the researcher must first use verification to establish validity in the research, define what is being represented using specific constructs, outline what is being represented in the research, and evaluate whether the outline captured the content being sought.

In my interview protocol, I recognize that an interviewee may not directly respond to the given question. I will write notes as the participants speak (Creswell & Poth, 2017).The protocol will provide a framework. Thus, research questions are more organized and perhaps further developed into more in-depth questions and touching on other topics, which could help other useful themes emerge.

Van Manen (2014) explained that questions that are abstract, theoretical, conceptual, or asking for perceptions, views, or interpretations, lead to phenomenological exploration or reflection, but questions that ask about immediate experience and human experiences do not. Additionally, Van Manen explained that phenomenological questions are not aimed at empirical or descriptive generalizations, scientific law, testing hypothesis, opinions, ethnographic or other explanations, theory development, or moral judgment, or to describe certain people. It is important to elicit specific experiences from the participants and focus on a single concrete moment within a particular lived experience.

Procedures for Recruitment, Participation, and Data Collection

I advertised for volunteer parents of children with ASD aged 3 to 15, from an early education center for children and local schools, or from an appropriate Facebook page. Following contact from volunteers, consent to participate and an interview time was offered. Each interview lasted from 60 to 90 minutes. The participants conducted the interviews via video chat. The goal was to have a location for the interviews that is free of distractions and private. The privacy and confidentiality of the participants was important and must be protected. At the beginning of the interview, I reviewed the informed consent, assured confidentiality, and ensured that participants are participating voluntarily. The participants were also reminded they have the right to withdraw from the study at any time and were asked to sign a consent form, a copy of which they may keep for their records. A consent form was sent to the participants via my Walden email with a request from participants to reply back to this email with “I consent.

The interviews were be conducted over a 2-week period. All interviews were audio recorded, which, along with my handwritten notes, were later transcribed verbatim. I used only first names during the interview. For the privacy and confidentiality of the participants, they are identified only by a number in the published study (e.g., the first participant will be known as P1). A purposeful sampling procedure was used when recruiting participants. If my initial outreach to a school is unsuccessful, I will contact other schools, or I will seek out parents on a Facebook page, or through Craigslist. After the interview, the participants were debriefed, and I answered any questions and thanked them for their participation. After the data was collected and transcribed the participants were given a summary of their responses via email, as a member check for any clarification, thus ensuring the findings of the study are accurately portrayed. The data was then analyzed (Patton, 2015). There should not be a need for a follow-up interview, as any clarifications will be requested during the interview.

Data Analysis Plan

I will gather information specific to my research questions with two sets of semi structured questions.

RQ1. What are the lived experiences of Muslim Arab American immigrant parents when asking for help for their child with an ASD?

1. Tell me about your experience as a parent raising a child with an ASD in Kansas City.
2. How old was your child when he or she was diagnosed?
3. When did you find out your child had an ASD?
4. What were the emotions you felt when you found out your child had an ASD?

RQ2. What are the lived experiences of stigma faced by Muslim Arab American immigrant parents when seeking help for a child with an ASD?

5. What is your perception and experience of the way family and friends reacted to your child being diagnosed with an ASD?
6. What support have you received from friends and family?
7. Tell me about how your relationships with family and friends and any changes that have occurred since your child was diagnosed.
8. How does having a child with an ASD affect your family?
9. What kind of support have you received as a parent with a child who has an ASD?

The interview data was transcribed verbatim in order to familiarize myself with the data gathered.

Because the number of participants for this study is small, the data analysis was hand coded. Analysis software, such as NVivo (2020), can be used as a back-up for tagging and retrieving data and to ensure credibility of the research. The hand-coding was done using data analysis techniques by Moustakas (1994) for transcendental phenomenology. Moustakas's process consists of epoche, transcendental-phenomenological reduction, imaginative variation, and synthesis of meanings and essences. The epoche process, as I described above, allows a researcher to set aside biases and prejudgments so that the researcher may pay attention to and focus on the participants views of the phenomenon being studied (Moustakas, 1994). The transcendental-phenomenological reduction, the essence of the phenomenon, is seen in a fresh way and the information can then be bracketed and horizontalized (Moustakas, 1994). Bracketing is placing the focus on the research, knowing one's biases, setting everything else aside and focusing specifically on the topic and question, and horizontalizing is done by treating every statement with equal value (Moustakas, 1994). Once the data are bracketed and the data horizontalized, they will be evaluated. The third step in the research process is imaginative variation, which is done to look for possible meanings through imagination and looking at the phenomenon from different perspectives and roles. Imaginative variation is used to find the main structure of the phenomenon (Moustakas, 1994). The final step in Moustakas's (1994) process is synthesis of meanings and essences, which are the main textural and structural descriptions gathered to form the meanings and essence of the research.

Participants' opinions of the phenomenon will vary, and there may be negative or discrepant cases that oppose the overall theme of the research (Creswell, 2013). I will examine the data looking at all elements and perspectives, so they have equal weight. I will then organize them into meaningful clusters. Any discrepant cases will be further reviewed and analyzed, and they will be included in the findings. Including the discrepant cases can show a representation of contradiction or alternative responses that do not fit the emerging pattern

Issues of Trustworthiness

There are four different elements of trustworthiness in qualitative research: credibility, transferability, dependability, and confirmability. These are described in relation to the proposed research in the sections below.

Credibility

Credibility must be established in a study, linking the research to reality (Patton, 2015). Patton (2015) noted that credibility and quality go hand in hand and are crucial in a study. In this study, credibility will be established by using appropriate strategies, which include triangulation, researcher reflexivity, and engaging with the participants and data.

Transferability

Transferability is what allows application of research to other studies or settings (Patton, 2015). Patton (2015) considered the concept of transferability to be a generalization and that research goes beyond the replication of an exact study. Instead, transferability is a logical, thoughtful, and useful way of gathering information from information-rich samples and designs from similar conditions that can produce relevant information for both present and future studies. Transferability for this study can be attained by providing detailed information about the study such as settings, procedures, characteristics of participants, and my role as the researcher.

Dependability

Dependability describes the stability of the data with time and differing conditions (Patton, 2015). Patton (2015) found dependability can be achieved through detailed documentation of activities, processes, data collected, and other elements that pertain to the study. Dependability can be established through triangulation. There are four types of triangulation in qualitative studies: methods triangulation, triangulation of sources, analyst triangulation, and theory/perspective triangulation (Patton, 2015). Methods triangulation considers the consistency of findings achieved through varying data collection methods. Triangulation of sources looks at how consistent data sources are in the same method. Analyst triangulation reviews findings through various analyses. Theory/perspective triangulation interprets data by using several theories or perspectives(Patton, 2015). The common misconception about triangulation is that if it occurs with different data sources or inquiry, an approach has yielded the same results as previous inquiries, when the point of triangulation is to test for consistency (Patton, 2015). This study will use and describe triangulation for establishing dependability of outcomes.

Confirmability

Confirmability refers to how results can be corroborated by others (Patton, 2015).The source of data for this study is face-to-face interviews with various participants along with handwritten notes that will be taken during the interviews. Moustakas's (1994) phenomenological process will be used to establish confirmability. Throughout the research, documentation such as a self-reflective diary will be kept in order to stay aware of personal thoughts, biases, and preconceptions I may have. Reflexivity is an approach used by researchers to be more aware of personal biases, assumptions, and preconceptions of research being conducted, and will be employed in the proposed research (Patton, 2015). In addition, participants will be offered the opportunity of member-checking the data prior to analysis.

Intracoder Reliability

Intracoder reliability refers to how consistent my coding as a researcher is and could be applied to my research (Patton, 2015). Intercoder reliability does not apply to this research as I am the only researcher coding the data and would require at least two researchers coding the data independently to apply to this research. However, data and data analysis will have oversight of the research committee members through the course of the research process.

Ethical Procedures

Ethical standards are provided by the American Psychological Association (APA) (2016) which guides all facets of psychological work including research. APA ethical standards will be adhered to with this research by obtaining consent from the participants to be recorded for the research, informing participants prior to the research the nature of the study, and reminding participants that participation is voluntary and that participants have the right to withdraw from the study at any time without any repercussions (American Psychological Association, 2016). Approval from the univeristy's Institutional Review Board (IRB) will be obtained prior to recruitment of participants and will address purpose of the research, risks, confidentiality, possible benefits of participation, and contact information (Appendix B).

Because of the pandemic present at the time of research, the data collection will not be done in person but via video conferencing such as Skype, Zoom, and Google video. To recruit participants, I contacted several schools in Kansas City, Missouri that provide service for children with ASDs and get permission to advertise the research opportunity to parents who might be interested in participating in my research. In case this avenue does not draw participants, I will find participants through appropriate Facebook pages, or on Craigslist. In the invitation letter I will explain who I am, the purpose of my study, participation criteria, and confidentiality.

As the researcher, I must be careful with recruitment methods and take privacy concerns into consideration, give participants time to think about being part of the study, make sure the information presented to the participants is clear and does not have complicated, technical or scientific wording, does not mislead participants by making the study sound more attractive than it is, and make sure the participant knows this study is not a form of health care or a treatment of any kind and will not directly benefit them.

When I collect the data, I will protect the interest of the participants and protect them from mental harm, and I will be culturally sensitive. If a volunteer declines to participate or withdraws from the study early, he or she needs only to inform me of their decision without explanation. If too many participants withdraw from the research, I will need to reevaluate the research. In cases where predictable adverse events occur such as a participant becoming visibly upset when discussing an event, I will stop the interview and ask the participant if he or she would like to continue, take a break, and then continue, or stop the interview. The incident will be documented and reported to the IRB. Other ethical issues such as conducting a study within one’s own work environment, conflict of interest or power differentials, and justification for use of incentives are not applicable to this study.

For privacy and confidentiality of the participants, all data such as audio recordings, transcripts, and anything pertaining to the study that could identify participants will be kept in a locked cabinet in my home office. Additionally, no names will be associated with the data; rather, their names will be replaced with an identification number. After the study is complete, the data will be kept for 5 years and will then be destroyed using a shredder.

Summary

This chapter provided a detailed description of the research design and methodology, researcher's role, issues of trustworthiness, ethical procedures for the study, and a summary. The purpose of this study is to use a phenomenological approach to explore the lived experiences of Muslim Arab American immigrant parents when asking for help for their child with an ASD. I discussed how the steps of phenomenological processes by Moustakas (1994) will be followed. The video or telephone semi-structured interviews will be guided by the two research questions: (a) What are the lived experiences of Muslim Arab American immigrant parents when asking for help for their child with an ASD? and (b) What are the lived experiences of stigma faced by Muslim Arab American immigrant parents when seeking help for a child with an ASD? Issues of trustworthiness were also discussed, as well as how as the researcher I can establish credibility, transferability, dependability, and confirmability in the study. Additionally, I addressed APA ethical standards for conducting research, obtaining appropriate approval from the IRB, participant confidentiality, data collection, data analysis, and data storage and management. Chapter 4 will provide information regarding the study’s setting, describe participant demographics, data collection, data analysis, evidence of trustworthiness, results, and a summary of the findings.

Chapter 4: Results

Introduction

The purpose of this study is to explore stigma and the extent to which it influenced parents in the Muslim Arab American community when seeking help for an autistic child, and these parents’ lived experiences when trying to get help. Recognizing experiences while help-seeking and facing stigma within an immigrant group can increase awareness within this population and help to increase the understanding of ASDs.

This study was designed to understand the lived experiences of Muslim Arab American immigrants in the United States and help-seeking for a child with an ASD, and the research paradigm used was qualitative and phenomenological (Husserl, 1999). Using this paradigm allows the researcher to have a better understanding of the participants’ personal experiences in their own environment (Creswell, 2013). For this study it was important for the participants to be in an environment that was comfortable for them because of the nature of the topic and the sensitivity of the topic for some parents. This chapter will consist of an introduction, data collection, research setting, data collection and analysis, and results.

Data Collection Changes

Data collection was originally planned as face-to-face interviews, but because of the COVID-19 pandemic, changes in data collection were necessary. Instead interviews with participants were conducted using semistructured interviews using the Google Meet video meeting application. The original recruiting plan was to recruit parent participants from an early learning facility in the Middle East, in particular the country of Jordan, but due to cultural beliefs there were no parents interested in speaking about their children diagnosed with autism. Other avenues of recruitment included a local early learning facility in Kansas City, Missouri, using Facebook parent groups, and other social media outlets. Unfortunately, there were no parents interested in participating in the study at the early learning facility, and there were no responses from Facebook and social media. A change of procedures was submitted to the Walden IRB to include recruitment from Craigslist and to add a payment for participation. After posting an ad on Craigslist there were immediate responses and saturation was met with eight participants.

Research Setting

My home office was the research setting and where all interviews were conducted. The interviews were conducted between October 18, 2022, and November 10, 2022. A consent form was sent to the participants via my Walden email, and I requested participants to reply back to this email with “I consent” after reviewing the consent form that was approved by the Walden University IRB. My home computer was used for interviewing the participants using Google Meet. I recorded all the interviews using voice recording software on my phone, which was then downloaded to my home computer. The interviews were then transcribed by dictation with corrections made as needed. Member checking was conducted after the interviews were transcribed and all participants agreed no changes were needed. All interviews conducted lasted between twenty minutes and thirty minutes. None of the participants reported feelings of discomfort speaking with me at the time of the interviews.

Demographics

The demographic characteristics of participants for this study were as follows: Two participants were female, while the other six were male. Two of the participants were first generation immigrants, while the other six were immigrants themselves. All eight participants were fluent enough in English to participate in the study and express their experiences.

Table 1

Demographic Characteristics of Study Participants

Code Name	Gender	Generation	Age Child Diagnosed
P1	Female	1st Generation	2 ½
P2	Male	1st Generation	1 ½
P3	Female	Immigrated	5
P4	Male	Immigrated	3
P5	Male	Immigrated	4
P6	Male	Immigrated	8
P7	Male	Immigrated	4
P8	Male	Immigrated	5

Data Collection

After making the changes that were necessary in order to recruit participants, permission from the Walden University IRB was given (study #06-21-0485182) to begin recruitment for the study (Apendix B). I posted an ad on Craigslist and offered a $20 Walmart gift card to participants. I was immediately contacted by three people interested in participating in the study who met the inclusion criteria. I then used snowball sampling asking the participants who I interviewed if they knew anyone in their community who would also be interested in participating. I was then contacted by several people to participate in the study bringing my total to 8 participants.

I was able to interview all participants between October 18, 2022, and November 10, 2022. The interviews were recorded on my phone using a voice recording program in my home office over Google Meet with permission from the participant. The interview was then downloaded onto my computer and transcribed using Microsoft Word Transcription and corrections were made by me when needed. Interviews lasted between 20 minutes and 40 minutes. I found saturation was reached after eight interviews as data from the interviews was yielding similar themes. The only variation in data collection happened with the difficulty in recruitment of participants. There were no unusual circumstances encountered in data collection.

Data Analysis

The data for my study was collected through semi-structured interviews. I implemented my data analysis plan by organizing and interpreting the data collected from the interviews to develop themes and shed light on the lived experiences of Arab American immigrants, including first and second generation parents regarding help-seeking for their autistic child. Moustakas (1994) described phenomenological research as a way to analyze a participant's statements to find a deeper meaning, while Creswell (2013) described the purpose of data analysis as trying to make sense of information gathered during an interview. Interviews have layers that must be peeled back in order to get a deeper understanding of what is being expressed.

At the completion of the interviews, each interview was transcribed by myself verbatim. Accuracy of the interviews was checked by listening and rewinding the audio until I was sure the words had been transcribed correctly and to the best of my ability. The names of the participants were then coded for anonymity and privacy and transcribed as P1 through P8, representing each of the eight participants. After completing the transcripts, a copy of their interview was sent to each participant for member checking.

As data is being coded researchers can begin to see themes emerging from the coding. After printing the transcripts I read and reread through them. I then analyzed them and looked for themes and began coding. I bracketed the data, then horizontalized it and then evaluated it. After handcoding the data I used the NVivo 12 Pro software to upload the interview transcripts to start the data analysis, tagging and retrieving data to ensure credibility of the research. After reading through the data I looked at the questions for specific topics. I then organized the themes and coded them.

After reviewing the data, certain themes emerged which were congruent with the social stigma theory. Most noticeable was seeking help for their child being impacted by community and culture. Themes included (a) high emotions, feelings of shock, sadness, disbelief, devastation, and fear for their child; (b) services offered, not sure of where to go, not knowing what services are available; (c) family, questioning diagnosis, denial, pity; (d) perception, maybe things will get better, maybe it is a wrong diagnosis; religion, religious beliefs impacted how parents looked at the diagnosis in a positive way, and faith helped them accept the diagnosis; culture, denial of diagnosis within the culture, pretending that the child is not atypical, refusal of services, putting stigma on any illnesses children suffered from. There was no discrepant information found as all the respondents felt hesitation in seeking help for their child due to cultural stigma. Other information was found in participant answers and will be discussed further in the results section of this chapter.

Evidence of Trustworthiness

In qualitative research, reliability is found in answers given by participants and transcription, while validity in a qualitative study is found through carefully recording the findings and continually verifying the data that has been gathered (Creswell, 2013). As a qualitative researcher it is important to ensure that credibility, transferability, and dependability is found in the research, each of which this study shows.

Credibility

Credibility was established in this study by linking the research to reality and using the appropriate strategies to gather information for this study. By engaging with the participants, I was able to associate the data and the findings with my research questions.

Transferability

Transferability is what allows application of research to other studies. Transferability is a logical, thoughtful, and useful way of gathering information from information-rich samples and designs Although it can be difficult for a researcher to generalize their findings, the information obtained from the interviews conducted for this study found many shared experiences within this group. This in turn will make it easier for future researchers to replicate similar investigations using the lens of this study.

Dependability

Dependability is the stability of the data with time and differing conditions, and can be found through detailed documentation of activities, processes, data collected, and other elements that pertain to the study (Creswell, 2013). Triangulation, as evident in this study, looks at how consistent data sources are in the same method of a study, and triangulation of sources looks at how consistent data sources are in the same method. Although variation was needed from the initial plan for data collection in this study, the strategy for the research plan did not change.

Confirmability

Confirmability refers to how results can be corroborated by others (Patton, 2015).The source of data for this study was a video interview with participants. After speaking to each participant, I used the reflexivity approach to write down personal thoughts and assumptions so as to stay aware of personal thoughts, biases, and preconceptions I might have had. After the interviews the participants were offered the opportunity of member-checking the data prior to analysis.

Results

The results section of this chapter identifies the findings of the research that are relevant to the research questions;

1. What are the lived experiences of Arab American immigrant parents within their community when asking for help for their child with an ASD?
2. What are the lived experiences of stigma faced by Arab American immigrant parents within their community when seeking help for a child with an ASD?

To answer the research questions, I looked for themes developed from the participants interviews.

Theme 1: An Emotional Time

When speaking to the participants the themes that emerged when it came to the diagnosis of autism were an array of feelings such as stress, grief, sadness, depression, feeling heartbroken, regret, confusion, feeling lost, shocked, and devastated. P1 explained:

> I was devastated. Just devastated. I just cried and cried and cried honestly. I just cried. I was so upset because you want your child to be able to like function and know that they're going to be able to take care of themselves and I worried about that. And like looking back I feel like I was grieving because you know, especially in our culture, they're like oh your son. You know when you have three girls and then. Well, I had two girls and a boy at that time but still they're always like it's your son it's your son and then to have that was really that was difficult. That was difficult and you know when we're with others you can tell there's a difference you know?

Participants shared the emotional ups and downs of the diagnosis with the immigrant participants blaming themselves for the diagnosis. Six of the eight participants felt worried about diagnosis and how their child would have a foreseeable future with normality such as having friendships, personal relationships, the future of marriage, and having children of their own.

Theme 2: Accepting the Diagnosis

Many participants' emotions settled down after the diagnosis with many stating that they followed doctor's suggestions and began to seek services for their children such as speech and play therapy. Participants often felt there was something different about their child but were hesitant to seek help. One participant explained that he had no idea what to expect from the diagnosis since he knew nothing about autism. This prompted him to research what autism was so that he could provide the best life for his child. Another participant said she felt like this was a time to make her a better mother for her child and it was a way to learn more about autism and give her child what she needs to be successful. P5 stated:

> I felt that he's not normal, and disappointed for a while then you feel something come over you and you kind of come to terms with it.

Participants stated that after speaking with health professionals and therapists they learned more about autism and what they could do to help their child. Many stated the number of services available helped them cater to their child and their family's needs.

Theme 3: Family and Community

While trying to understand and accept the diagnosis of autism, many participants felt hesitant to tell their family and community. The main reason for this was due to cultural beliefs and stigma about having a child with a medical condition, especially one that is not often discussed. P1 said:

> Well, I told my mom, and you know a lot of times in Arab culture they'll be like the doctors they don't know what they are talking about. Pray harder. I'm like OK

> I don't think like that, but that's the tools they have like that's all they know so it can be difficult telling especially if you're going through something it's always pray harder, you’re not praying right you're not praying hard enough.

Participants often took their time to tell their family for fear of their reactions to the diagnosis. P4 stated:

> I think culture personal beliefs affect it. Yeah so, it's culture, religion yeah, I think it's cultural perception. They think that having an autistic child is a curse, they think it's not a good sign. I found it hard at first of course not to tell people. My wife was uneasy telling my parents and also telling her parents. It was our first kid, and you are quite terrified because of the religious beliefs of some of our family members. I thought who I can call? They're still archaic. Yeah, their thinking is still archaic and backward. So, I decided to not tell them all because they think it passes from person to another.

Participants often stated that culture was a big reason they were hesitant to tell their friends and family. Many chose to wait months before discussing it with people outside their immediate household. But when they finally decided to share the diagnosis, it was for the betterment of their child. P6 stated:

> One of my friends found us a very good doctor in our neighborhood who helped us very much and the right medication. Since the doctor was certified with dealing with autism they helped us find a therapist that could help us.

Theme 4: Help

In the acceptance process of the medical diagnosis from their child’s care provider many participants stated that they fell into depression while trying to cope with everything. P4 expressed:

> I was depressed in a way. I was not myself in the very first days, and I don't think I've ever gone back to the normal me. Even right now speaking about this I think there are some negative thoughts. I have a lot of negative thoughts. Some are negative about autism and me being among parents of autistic children.

Participants stated that they were able to receive the help that they needed for their child and found that they needed to seek help as well. Many parents chose to get therapy for themselves because they often felt overwhelmed by the emotional and financial burden they were facing. Participants stated that they had to start medications and change their child’s diet to accommodate the diagnosis. With some participants stating they were able to get financial services from programs and from family to help them with the increase in medical and food bills.

Theme 5: The Future

Participants have found after some time that the future is not as bleak as they had predicted. Many participants feel like they understand their child better now, and they have tools for success after seeking professional help. Some feel their families are more supportive, while others state their families are still in denial.

P3’s thoughts on the future:

> Life is normal. People don't have to really regret having a kid who has autism. I say OK I have a child with autism! I always watch several videos on Instagram I follow a woman who has an autistic child and I see how she loves her child. That really motivates me. So, I could just advise parents to autistic children to treat their kids normally. Just to give them a conducive place to live life.

P6 stated:

> Time has changed my perspective on people living with autism and how to relate to them. At least for now I live with my daughter, and we have a good relationship since I understand her needs and the activity of living with that person. You have a better outlook.

Most participants felt that paying attention to your child at an early age can help with early diagnosis, and that this is important not just for the child but also for the parent.

Discrepant Findings

This study was conducted to explore the lived experiences of help-seeking and stigma among Arab American immigrant parents of children with autistic spectrum disorders, and discrepant findings did not emerge. Each participant experienced the same dilemma and hesitation of seeking help and telling friends and family about their child's diagnosis. This was identified as being due to culture and how the Arab culture looks at children with illnesses and disabilities.

Summary

This chapter consisted of an introduction, data collection changes, research setting, demographics, data collection, data analysis, evidence of trustworthiness, results, discrepant findings, and a summary. The lived experiences of Arab American immigrant parents within their community when asking for help for their child with an ASD was consistent. The parents felt their child would benefit from a diagnosis but did not want their community to know the diagnosis. Most participants did not let people within their community know about the diagnosis for fear of judgment, but opened up once their child had started some sort of therapy. The lived experiences of stigma faced by Arab American immigrant parents within their community was mainly found within their own family and aligned with cultural beliefs about the medical diagnosis of autism.

Chapter 5 will have an introduction, interpretation of findings, limitations of the study, recommendations for further research, implications for social change, and a conclusion.

Chapter 5: Interpretations and Conclusions

Introduction

The purpose of this phenomenological study was to explore stigma and the extent to which it affected parents in the Arab American Immigrant Muslim community when seeking help for an autistic child, and these parents' lived experiences when trying to get help. The contributions for this study are significant as the focus is on a population that is not generally studied. It raised awareness about Arab American immigrant Muslim parents' experiences and helped to identify reasons that contribute to parents not help-seeking. This can be useful to finding what impact stigma has on parents and how they choose to seek help and could help physicians and clinicians shape their practice to increase the likelihood of parents overcoming the fear of stigmas associated with seeking interventions for their children.

Of the 8 interviews conducted for this study, there were common themes that were identified. These themes included the diagnosis being an emotional experience, the parent having to accept the diagnosis, dealing with family and community, getting help for their diagnosed child and themselves, and what the future held for their child. All participants described similar feelings and experiences and the many emotions felt about the diagnosis and how it was mainly sadness and shock they felt. Most participants took time to absorb the diagnosis and well as delaying telling anyone they knew that their child had been diagnosed with an ASD. All participants followed up diagnosis with different therapies for their child, while some sought therapy for themselves to help cope with the stress. All participants felt optimistic about the future for their child, with many saying their child had improved with therapy, medication, and diet changes over the years.

Interpretations of Findings

A phenomenological approach was used to explore the perceptions of Muslim Arab American Immigrants and help-seeking behavior. While this population has had less research conducted, the population is one of the faster growing populations in the United States, but still one of the least studied. The goal of this study was to contribute to a better understanding of the population and how stigma influenced help-seeking. The sample included both men and women who were all recruited online through a dedicated advertising site for research. Of the eight participants only two of them were first generation immigrants, while the other six had immigrated to the United States. As stated earlier one of the biggest challenges found in immigrant communities is that mental health treatments were developed by people in Western cultures, and although they are living in the United States (Western culture) there are cultural beliefs and practices from their home country that remain within their community.

As stated in Chapter 2 other collective cultures have similar ideas when it comes to diagnosis of illness in children. Most participants found that it was the "Will of God" for their child to have an ASD, which is what Minhas et al. (2015) similarily found within South Asian culture. Immigrant parents in the United States like those in studies conducted in France (Chamak et al., 2011), China (McCabe, 2008), and Ireland (Byrne, et al., 2018) found it difficult to accept the diagnosis of autism and felt extreme emotions such as depressions, loss, loneliness, and difficulties in planning for the future for child and family.

Social Stigma Theory

Goffman's social stigma theory was an appropriate framework for understanding these parent's firsthand view of the relationship between stigma and the social impact of getting help for their child with an ASD. Because this theory is based on the social construction of identity, both psychological and social ideas about stigma were supported in conceptualizing this study. These were both found in the data. Two participants that were born in the United States had earlier diagnosis for their children than did others, around the age of 2. Other participants' children were older when they were diagnosed. With the 2 participants who were born in the United States there was still some hesitation in seeking help for their child due to culture and stigma from within their family and community.

Goffman's idea of stigma generally focused on social life and the complications faced by those who are stigmatized by the community they live in with people who do not share the same attributes. Those who are stigmatized generally are wary of engaging with those who do not share the same attributes. This study found this to be true, with parents not taking their children to public or family functions due to the stigma they may have faced because of how their child might behave or interact with others. There are negative implications on self-esteem and mental health when coping with stigma which many of the participants found to be true after the diagnosis.

Limitations to the Study

For this study my biggest limitation was that I was not able to meet face to face with my participants due to the restrictions due to Covid 19 and the recommended social distancing. Reliability and validity were present in the study as I documented the participant sample characteristics and my observations during data collection and interviews in a consistent manner and maintained an audit trail to ensure dependability. Although phenomenology is an evolving methodology my perception was not skewed in the perception of the data to support my own beliefs. Additionally, the data showed similarities to what has been present in studies across other cultures. The purpose was to see if parents in Muslim Arab American communities might delay or avoid seeking help for a child who might have a mental illness because of the fear and social stigma associated with ASDs. This was found to be true as participants who were immigrants did not seek help immediately, but rather waited for their child to get older to seek help.

Recommendations

Studies regarding stigmitizing beliefs, actions, and attitudes against people with mental illness in the Arab cultures can be identified when reading research about this culture. Mental illness is most often portrayed in a negative way among various Arab populations, and those who are immigrants and first or second generation immigrants in the United States continue to hold these stigmitizing beliefs. Because there is little research done with this population the scope of this study is limited to the sample taken for this particular study. Recommendations for this study are for more research to be conducted on this group. Future research could include prenatal and postnatal questionarres for expectant parents of this population to introduce them to ASDs. The participants for this study were open to answering questions and allowing me as the researcher to delve into the beliefs held by their culture and how help seeking was done. The ability to reach these groups and look at the needs of these communities can help for further research.

Implications

As stated, the potential impact for this research for positive social change is significant. Children with an ASD struggle with social interactions and communications skills such as failing to respond to their own name, seeming not to hear when being spoken to, feeling aversions to touch such as cuddling and holding, usually preferring to be alone or seeming like they are in their own world. Immigrating from one's own country is difficult, and having access to specialists and mental health professionals who understand culture and fit the needs of family and social aspects can encourage earlier diagnosis and intervention.

Families who have a child or children with an ASD face many challenges that can have a negative impact on not just the parents, but the family as a whole. It is often overwhelming when dealing with a diagnosis, but the experience of facing the diagnosis often creates stress and an increase in mental and physical health issues for caregivers. Families would have the ability to access help for themselves and for their family without feeling the burden of stigma if they were able to see other families similar to theirs facing the same issues. This could open a dialogue for those families to know that they are not alone.

Finding adequate healthcare can be difficult when it comes to disorders such as autism and the spectrum disorders because there is no medical test which can identify ASDs on a biological level. A provider must be able to make a diagnosis by gathering a patient's history, observations, and through speaking with the patient's caregiver. Treatment options for ASDs vary and adequate care often depends on socioeconomic and cultural factors. Finding providers who are trained and educated in diagnosing ASDs is beneficial for the communities they serve.

Theoretical and empirical implications for this research were evident in the answers the participants gave and the finding of the research. Goffman's theoretical framework helped to explain the social impact of stigma and this was borne out in the empirical evidence of the findings of this study, showing how stigma impacted parents' help seeking behaviors. Stigma was validated as a reason for parents to not seek help right away and to wait for their child to get older or have more difficulty.

Conclusion

ADSs are diagnosed all around the world and in recent years have become a common diagnosis. Breaking the cycle of stigma for mental illness is important not just for current generations, but for future generations within the United States as a melting pot of cultures and communities. Many immigrant communities are not being included in the fight to stop mental health stigma and it is imperative to include those communities. This can help early intervention and treatment which helps the patients and the families to live happier and healthier lives.

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Appendix A: Interview Questions

1. Tell me about your experience as a parent raising a child with an ASD?
2. How old was your child when he or she was diagnosed?
3. When did you find out your child had an ASD?
4. What were the emotions you felt when you found out your child had an ASD?
5. What, if any, services were offered to help with the diagnosis?
6. How do you feel about the diagnosis now?
7. How did you tell your family?
8. What changes have you seen in your child since diagnosis and treatment?
9. What is your perception and experience of the way family and friends reacted to your child being diagnosed with an ASD?
10. What support have you received from friends and family?
11. Tell me about your relationships with family and friends and any changes that have occurred since your child was diagnosed.
12. How does having a child with an ASD affect your family?
13. What kind of support have you received as a parent with a child who has an ASD?
14. How has time after your child's diagnosis changed your view on Autism?
15. What has happened over time with your family post diagnosis?
16. How has time affected your view on Autism?

Appendix B: IRB

Dear April Al-Mahdawi,
This email is to notify you that the Institutional Review Board (IRB) has approved your application for the study entitled, " Experiences of Help-Seeking and Stigma Among Arab American Immigrant Parents (1st and 2nd Generation included) of Children with Autistic Spectrum Disorders."
Your approval # is 08-06-21-0485182. You will need to reference this number in your dissertation and in any future funding or publication submissions. Also attached to this e-mail is the IRB approved consent form. Please note, if this is already in an on-line format, you will need to update that consent document to include the IRB approval number and expiration date.

Your IRB approval expires on August 5, 2022 (or when your student status ends, whichever occurs first). One month before this expiration date, you will be sent a Continuing Review Form, which must be submitted if you wish to collect data beyond the approval expiration date.

Your IRB approval is contingent upon your adherence to the exact procedures described in the final version of the IRB application document that has been submitted as of this date. This includes maintaining your current status with the university. Your IRB approval is only valid while you are an actively enrolled student at Walden University. If you need to take a leave of absence or are otherwise unable to remain actively enrolled, your IRB approval is suspended. Absolutely NO participant recruitment or data collection may occur while a student is not actively enrolled.

If you need to make any changes to your research staff or procedures, you must obtain IRB approval by submitting the IRB Request for Change in Procedures Form. You will receive confirmation with a status update of the request within 10 business days of submitting the change request form and are not permitted to implement changes prior to receiving approval. Please note that Walden University does not accept responsibility or liability for research activities conducted without the IRB's approval, and the University will not accept or grant credit for student work that fails to comply with the policies and procedures related to ethical standards in research.

When you submitted your IRB application, you made a commitment to communicate both discrete adverse events and general problems to the IRB within 1 week of their occurrence/realization. Failure to do so may result in invalidation of data, loss of academic credit, and/or loss of legal protections otherwise available to the researcher.

7/29/2022
Dear April,

This e-mail serves to inform you that your request to have an extension for the study # 06-21-0485182 has been approved. You thus have one year to gather the data for your study and your new expiration date 7/28/23. One month before this expiration date, you will be sent a Continuing Review Form, which must be submitted if you need to collect data beyond the new approval expiration date. Also attached to this e-mail is the revised consent form which contains the new IRB expiration date. If this consent form is already in an on-line format it will need to be revised to reflect the new expiration date.