Graduate Theses and Dissertations   Graduate School

December 2017

Perceptions of Arab American Mothers of Children with Autism Spectrum Disorder: An Exploratory Study

Haifa Alsayyari
University of South Florida, haifa@mail.usf.edu

Perceptions of Arab American Mothers of Children with Autism Spectrum Disorder

An Exploratory Study

by

Haifa I. Alsayyari

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy in Curriculum and Instruction
with a concentration in Special Education
Department of Teaching and Learning
College of Education
University of South Florida

Major Professor: Ann Cranston-Gingras, Ph.D.
Daphne Thomas, Ph.D.
Brenda Townsend Walker, Ph.D.
Jennifer Wolgemuth, Ph.D.

Date of Approval:
January 31, 2018

Keywords: Arab American Parents, Arab Families, Arab Culture, Disability, Qualitative Interviews

Dedication

I dedicate this dissertation to all individuals and families affected by autism. My special dedication to the five parent participants, who graciously allowed me into their lives and bravely and willingly shared their unique experiences.

To my homeland, the Kingdom of Saudi Arabia, for giving scholarship and opportunity to study abroad, and for all the support throughout my nine-year journey, far from home.

To the United States of America, for welcoming me as an honored guest and providing me with a valuable personal and educational experiences which I appreciate and will keep in my heart when I return home.

Acknowledgments

In the name of Allah (God), most gracious, most merciful, "O' my lord increase me in knowledge" (The Holy Quran, chapter 12, verse 114).

"If anyone pursues a path in search of knowledge, Allah will thereby make easy for him a path to paradise" (Prophet Mohammed, ﷺ).

First and foremost, I would like to thank Allah; with his help everything becomes possible.

This work would not have been possible without the support of several individuals. I would like to express my extreme appreciation to my beloved parents; Ibrahim and Mashaeel. Their unconditional love, prayers, support, and encouragement have continuously helped me to overcome the challenges that I encountered, not only throughout this endeavor, but also throughout my life.

My deepest gratitude to my partner, Ahmad, who sacrificed much of his time to support me and see me complete this journey.

My special thanks to my little angel, my daughter, Shaha, who was patient with me being busy and not giving her much of time that she deserves. There are no words that can express how grateful I am to have her in my life.

I would like to express my sincere gratitude to my major professor, Dr. Ann Cranston-Gingras, for the continuous support of my Ph.D. study and related research, for her motivation, and immense knowledge. She steered me in the right direction whenever she thought I needed it. Her guidance helped me while researching and writing this dissertation.

Table of Contents

ii

List of Tables

List of Figures

Abstract

A gap exists in the literature regarding the needs, concerns, and overall experiences of Arab American parents of children diagnosed with Autism Spectrum Disorder (ASD) (Al Khatib, 2017; Goforth, 2011; Haboush, 2007). This study explored the experiences of five Arab American mothers of children with ASD. A qualitative interview approach, utilizing in-depth interviews, was used in order to investigate Arab American parents' experiences of caring for children with ASD, their cultural beliefs and understandings of their children's ASD, and their concerns and needs regarding their children. Six themes emerged from the interview data, which offered insight into Arab American parents' unique experiences of caring for a child with ASD, including (1) parents' journeys toward the acceptance of the diagnosis of ASD, (2) beliefs about the cause of autism, (3) concerns, (4) needs, (5) coping techniques, and (6) unanticipated positive effects. Findings of this study and aspects related to Arab cultural beliefs with the ASD diagnostic process are discussed in detail, as well as implications of the findings for the field of special education and recommendation for future research.

Chapter One

Introduction

A gap certainly exists in literature examining the needs and concerns of Arab American parents regarding their children with Autism Spectrum Disorder (ASD) (Al Khatib, 2017; Goforth, 2011; Haboush, 2007). This is despite the fact that the Arab population in the US increased dramatically by more than 72% between 2000 and 2010 (Arab American Institute [AAI], 2010). According to Brown, Guskin, and Mitchell (2012), the Arab demographic is one of the fastest-growing ethnic groups in the US. The US population, in general, has become more racially and ethnically diverse over time (U.S. Census Bureau, 2010). Between Fall 2014 and Fall 2025, the enrollment of racial/ethnic minority students, such as Hispanic and Asian/Pacific Islander students is projected to increase, while the number of White students enrolled in public schools is projected to continue decreasing from 25.0 million to 23.5 million, accounting for 46 percent of total enrollment in 2025 (The National Center for Education Statistics [NCES], 2016).

Consequently, the number of diverse students has increased, and teaching and serving them has become one of the most challenging tasks in today's schools. As diversity in the classroom has increased, it is important to acknowledge students with disabilities, especially in light of the growing trend of inclusion. In the US, 19 percent of the population has a disability; nearly 1 in 5 people (U.S. Census Bureau, 2010). In the school year of 2013-14, the number of children and youth ages 3-21 receiving special education services was 6.5 million, or about 13 percent of all public school students (NCES, 2016). Recently, the number of students in the US who presented with ASD increased to 1 in 68, a 30% increase over previous rates in 2012, which

1

was one in 88 (Centers for Disease Control and Prevention [CDC], 2016). Children and youth with ASD accounted for between 5 and 8 percent of students served under the Individuals with Disabilities Education Act (IDEA) (NCES, 2016).

The prevalence of ASD in children is similar, regardless of race and ethnicity (Fombonne, 2003). However, the perception, interpretation, and acceptance of disability varies and may be influenced by culture, socio-economic class, educational level, and religious beliefs (Zhang & Bennett, 2003). Cultural factors influence parents' beliefs on the cause of disabilities, their reactions to diagnosis, their help-seeking behaviors, and their ultimate expectations of their child (Donovan, 2013). According to Ennis-Cole, Durodoye, and Harris (2013), "The decisions families make about autism diagnosis and treatment are directly influenced by the family's cultural background" (p. 279). There is evidence suggesting that parents' cultural backgrounds have a noticeable influence on how they interpret and accept their child's disability, and also play a basic role in providing various approaches to child rearing (Tincani, Travers, & Boutot, 2009).

For instance, African American mothers report lower levels of perceived negative impact of having a child with ASD than Caucasian mothers (Bishop, Richler, Cain, & Lord, 2007). Further, Rogers-Adkinson, Ochoa, and Delgado (2003) found a variety of interpretations of disabilities exist across Native American, Puerto Rican, Mexican, and Colombian cultures. Some families from Puerto Rican, Mexican, and Colombian cultures believe that disability is a result of genetic and environmental factors. On the other hand, the Navajo tribe views a person with a disability as teacher for the clan, and as an individual that maintains a sixth sense or a unique gift. Accordingly, a person with a disability does not receive specialized intervention in the Navajo tradition, as doing so could interfere with the delivery of his or her message to the tribe.

In fact, children with disabilities in the Navajo culture do not receive any segregated services. Instead, they are active recipients of all traditional parts of child rearing (Rogers-Adkinson et al., 2003).

Seung (2013) reported that parents from Asian cultures are sensitive to the perceptions of others. The conflict between perceptions of the parents and others regarding their child's disability may result in shame to the family. Accordingly, Asian parents of a child with a developmental disability prefer to disconnect from other family members, in order to either hide their child's disability or to avoid the resulting pressure stemming from non-acceptance of their child's disability when disclosed. Similarly, Shin (2002) examined the effects of culture and social support on maternal stress for families of children with mental retardation in Korea and the United States. Results showed that Korean mothers experienced more stress than Euro-American mothers. They express feeling trapped because of the lack of a social support network and the negative attitudes of society toward disabilities, which prevented them from being open and sharing their experiences about their children's disabilities.

Research demonstrates that different cultural variables may affect a family's desire to seek professional services for their children with disabilities. For example, Al-Busaidi (2010) noted that many people in the Arab world do not seek mental health services and assistance of their own choice, due to the fact that they generally see seeking help as a sign of weakness or insanity. In other cultures, parents perceive that it is critical to consult elders or community leaders in order to make wise choices for their children before accessing any professional services (Zhang & Bennett, 2003). While many cultures chose to avoid professional services, in other cultures, such as Asian culture, parents "rely on the professional's perspective, because professionals are perceived as those who have the knowledge" (Seung, 2013, p. 16).

This cultural standpoint could also lead families to prefer therapies that closely reflect their cultural perspectives. Here, Shin (2002) found differences between Korean and American mothers in using supplemental private services. The general cultural practice in Korea is to rely on after school private tutoring centers for supplemental education, despite the fact that doing so poses a financial problem for many families. Korean American parents with limited financial resources similarly rely on tutoring services when attempting to provide assistance to their children with disabilities. They do so due to their comfort with tutoring services in aiding typically developing children and, as such, neglect to provide professional services, such as speech language therapy, to their children with disabilities. Here, Shin (2002) asserts that American mothers are much more likely to advocate for private speech language pathology services. The fact that Korean mothers prefer to use tutors reflects their perspective on the importance of traditional academics.

Furthermore, a study by Yeh et al. (2005) demonstrates that the beliefs of Latino parents regarding the nature and severity of their children's developmental disabilities suggests a lower likelihood that they will seek mental health services. The study asserts that in non-Hispanic Whites and African American populations, the parents' beliefs that disability is the result of biopsychosocial causes (such as relational issues, prejudice, physical causes, and trauma) subsequently caused a greater likelihood of pursuing mental health services while Asian/Pacific Islander American and Latino children were less likely to be provided with mental health services. These findings highlight the ways in which cultural variables impact a parent's willingness to attain professional services for their child.

In the US, health and other care services are oriented and rooted in White Western culture (U.S. Department of Health and Human Services, 2001). This can have implications when health

professionals/service providers utilize "established normative group-based theories" to individuals from different cultural backgrounds, and ignore cultural, ethnic, and linguistic diversity (Donovan, 2013).

Additionally, when comparing non-immigrant White families with immigrant families, immigrant families reported a more than two times greater lack of access to health insurance coverage, a usual source of care, sufficient clinician time, and extra help with health care coordination (Lin, Stella, and Harwood, 2012). Ennis-Cole et al. (2013) noted that,

> A cultural group's history can be filled with trauma—unfair treatment,
> devaluation, experimentation for medical purposes, discrimination, political and
> economic disenfranchisement, and other negative factors that can make it difficult
> for members of the cultural group to fully trust mainstream health care and
> service providers. (p. 283)

Consequently, one of the common problems between healthcare providers and patients is the lack of awareness of a family's cultural beliefs. This may lead to an inaccurate understanding and assessment of the family's needs and concerns and may create barriers in building a trusting relationship with families (Flores, 2012).

Statement of Problem

As illustrated above, culture has a significant impact on the perception and acceptance of disabilities. Therefore, it is imperative for service providers to be conscious of the implications of culture in diagnosing and treating disorders like ASD. However, unfortunately, the literature on children with ASD from diverse backgrounds is limited (Jegatheesan, Miller, & Fowler, 2010; Welterlin & LaRue, 2007). In fact, research including cases of Arab Americans or immigrant Arabs in the US is even more limited. There is a manifest lack of published literature on this

minority group (Goforth, 2011; Haboush, 2007). Al Khatib (2017), in his recent review of literature, reported that there are only three empirical studies regarding disability among Arab American children. The lack of sufficient information on Arab American students with disabilities makes it difficult for special education and related service providers to work properly with these children and their families.

In general, the lack of such knowledge of cultural values and perspectives on children of diverse cultural, ethnic, linguistic, and religious backgrounds results in several issues, including a large gap between minority students and their White peers in academic achievement, graduation/ dropout rates, and suspension and expulsion rates (NCES, 2011; Office for Civil Rights [OCR], 2014; Walker, 2012). Also noticeable among these issues, is the disproportionate assignment to special education, which results in overrepresentation of minority students in special education programs (Albrecht, Skiba, Losen, Chung, & Middelberg, 2011; Artiles, Kozleski, Trent, Osher, & Ortiz, 2010; Skiba, 2013; Zhang, Katsiyannis, Ju, & Roberts, 2014).

Overall, cultural relativism and the ingrained nature of culture could make addressing the particular needs of children with disabilities challenging. This is largely due to the fact that accepted understandings of disability and methods of addressing it differ immensely amongst cultures. Here, it is important for educators and service providers to acknowledge the differences in understanding and levels of acceptance that characterize parents' willingness to promote and participate in intervention. Thus, a one size fits all approach to introducing and utilizing services for children with disabilities of varied backgrounds is not effective. Instead, giving attention and respect to the cultural and religious beliefs of parents and their children with disabilities allows for the design of treatment plans that best suit the family in question. Additionally, despite the fact that Arab Americans represent a relatively small minority in the American public school

system, the rapid growth of this demographic calls for more research. Moreover, the fact that the needs of this ethic group are so diverse suggests the importance of developing and analyzing more research based information regarding culturally sensitive approaches to meeting the needs of Arab American children with disabilities (Donovan, 2013).

Purpose of The Study

Given the fact that the number of children who present with ASD is increasing, along with the population of Arab immigrants, and there is a gap in literature examining the needs and concerns of Arab American parents regarding their children with ASD, research that offers insight into Arab American children with ASD and their families is needed. This study aims to understand the experiences of Arab American families and their children with ASD to inform the practices of the institutions and the organizations (Newman, Ridenour, Newman, & DeMarco Jr., 2003) to work in a more culturally relevant manner with Arab families. Therefore, the purpose of this study is to explore Arab American parents' experiences of having a child with ASD, and to determine their needs and concerns, in order to provide sufficient information for special education and related service providers to develop cultural awareness and the necessary skills for working with these families and their children. A qualitative interview approach utilizing in-depth interviews was used in order to investigate the experiences of Arab American parents of a child with ASD, and to address the following research questions:

1. How do Arab American parents make meaning of the experience of having a child with ASD?

    a. How do their cultural beliefs affect their understanding of their child's ASD?

    b. In what way(s) does their understanding of their child's ASD affect their help-seeking behaviors?

c. How do Arab American parents adapt to raising a child with ASD?

2. What are the concerns and needs of Arab American parents of children with ASD?

3. What are the social support systems that assist Arab American parents in raising their children with ASD?

Conceptual Framework

After synthesizing the literature regarding multicultural perspectives and disability, I collected a number of linked concepts that influence families' perspectives of having a child with disability, and their decisions regarding their children's education. This conceptual framework provided me with a basis and direction for pursuing a productive review of literature, analyzing and interpreting the findings of this inquiry, and a broader understanding of the phenomenon being studied (Imenda, 2014). The collected concepts represent factors that predict or explain the differences in how parents raise their children, view disability, respond to their children's diagnosis, access health care, and are involved in their children's education and intervention. These concepts include: religious beliefs, education level, socio-economic status, acculturation, and English language proficiency.

Thus, there appears to be no one single factor that influences families' perspectives of having a child with disability and their decisions regards their children education. Instead, these differences are likely due to complex interactions across social and cultural factors. The influence of each factor is discussed in detail in Chapter Two. A summary of the conceptual framework is provided in Figure 1.
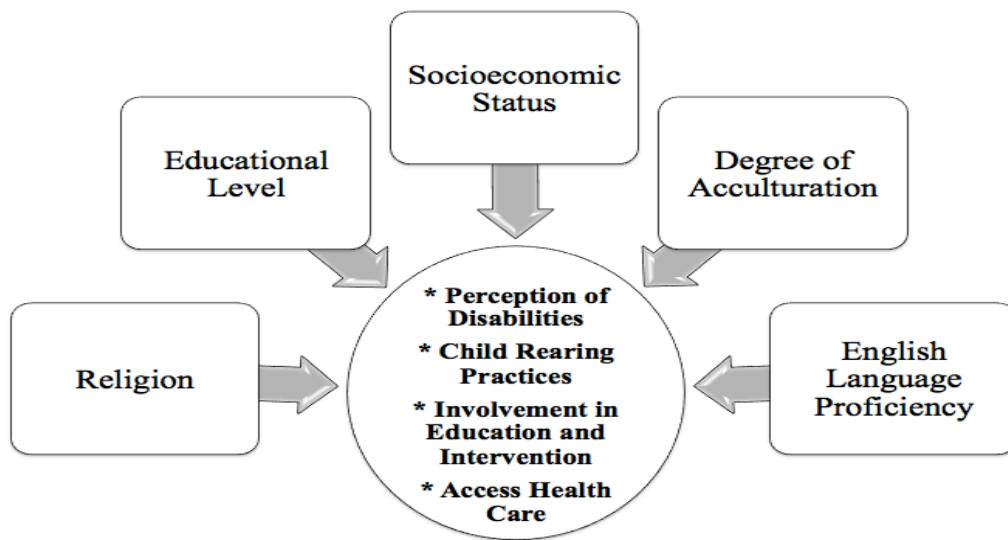
Figure 1. Conceptual Framework

Delimitations

Participation in this study is delimited to Arab American parents who (a) have at least one child who had been diagnosed with ASD; (b) have received special services related to their child's disability within the last year; (c) at least one of the parents were an immigrant (not born in the US); and (d) were not a recent immigrant, and have been in the US for more than one year. Families who met all the qualifications, but who were recent immigrants, and have been in the US for less than one year were excluded from the study. They were excluded because recent immigrants or refugees at this stage may experience difficulties in the process of adjustment, which could result in developing a hostile and aggressive attitude toward the host country (Oberg, 2006). Moreover, at this stage, they may not have enough experiences in the US to share, and/or they may not be willing to openly share their experiences.

In addition, this study is delimited to the examination of parents' experiences with special

education and related services, as this study aims to understand the parents' experiences in order to inform the practice of special education and related services to provide culturally appropriate services to these families. A qualitative interview approach utilized in-depth interviews in order to investigate the parents' experiences. This research design was chosen from among other qualitative designs because it provided the data I needed to answer the research questions.

Definition of Terms

Arab American: a diverse community of immigrants and the descendants of immigrants who have come from throughout the Arab world, from North Africa to Southwest Asia (AAI, 2014).

ASD: is acronym for Autism Spectrum Disorder. It is defined by the US Department of Education as a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

Special Education: defined by the US Department of Education as specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability, including (a) instruction conducted in the classroom, in the home, in hospitals and institutions, and in other settings; and (b) instruction in physical education.

<div align="center">

Summary

</div>

There is a gap in current literature, which largely fails to examine the needs and concerns of Arab American parents of children with ASD. This is a problem for numerous reasons, not the least of which being that a one size fits all approach to services for children with disabilities does

not take into consideration the cultural needs of these children and their families. ASD is diagnosed in children across racial or ethnic lines at similar rates, but the way in which children, parents, and communities respond to this diagnosis and access services can vary because of underlying cultural factors that should be addressed to improve services. There are numerous cases in extant literature that examine the ways in which different populations respond to having children with disabilities, but few cases that discuss how Arab American parents respond to having a child with ASD. Arab Americans, in particular, are one of the fastest growing populations in the country. The Arab population in the United States grew by 72% from 2000 – 2010 (AAI, 2010). The lack of current literature on Arab American parents of children with disabilities, ASD specifically, and the fact that they are such a fast-growing segment of the US population, demonstrates a need for further scholarship and the study I carried out so institutions and organizations can more adequately understand and meet the needs of this population.

Through qualitative interviews with Arab parents, I examined Arab parents' responses to receiving a diagnosis of ASD, and determined their needs and concerns in order to offer sufficient information to special education professionals and service providers. In order to better interpret these interviews, I built a conceptual framework that seeks to understand the variety of cultural inputs that influence families' perspectives on having a child with a disability. The study was limited to Arab parents who have at least one child who has been diagnosed with ASD, who have received special services related to their child's disability for at least one year, and couples in which at least one parent must be an immigrant. This population specifically excludes recent immigrants, who may not exemplify the typical concerns of Arab Americans given the hostile immigration climate, and families who have not yet engaged with the special education process or received special services related to their child's disability.

Chapter Two

Literature Review

This synthesis of available literature regarding multicultural perspectives and disability aims to support a conceptual framework that provides a direction for pursuing a productive review of literature. This review includes discussion of numerous linked concepts that represent factors that influence parenting style, families' perspectives of having a child with a disability, families' accepted methods of seeking care and health services, and families' decisions about, and involvement in, their children's education and intervention. These factors include religion, educational level, socio-economic status (SES), degree of acculturation, and English language proficiency. Such factors explain the range of differences between different cultures as well as within a given cultural group. These factors do not stand alone; each is influenced by the others.

In addition, this review provides an overview of Arab Americans, including their country of origin, population, religions, classification, education, and occupations. It also examines Arab cultural characteristics that distinguish Arab culture from Western culture, which manifest in family structure and relationships, approaches to child rearing, and conceptualization of disabilities. Disabilities research on Arab Americans is also discussed in this review of literature. The intent of the discussion of these topics is to highlight the importance of considering the family's cultural influences when discussing disabilities and providing services.

The databases searched to locate literature include ERIC, EBSCO, ProQuest, JSTOR, PsycINFO, Google Scholar, and SAGE. The key terms used to locate literature related to this inquiry include multicultural perspectives and disability, multicultural perspectives and culture

and disability, religion and disability, educational level and disability, socio-economic status (SES) and disability, acculturation and disability, Arab culture, Arab American, immigrant Arab American, Arab and disabilities, immigrant Arab and disabilities, and immigrant Arab and ASD.

Conceptual Framework

Religious beliefs. The influence of religion on beliefs regarding disability is widespread and global. In research on children with disabilities, the perception that religious beliefs can play a significant role in the interpretation, explanation, responses, and acceptance of disability is consistently recognized (Jegatheesan et al., 2010). For instance, many Muslim Pakistani families believe that having a child with disability is the will of *Allah* (God), and that if they care for their child appropriately, *Allah* will reward them (Mirza, Tareen, Davidson, & Rahman, 2009). Similarly, South Asian Muslim immigrant parents express happiness over the fact that they believe they have been chosen by *Allah* to raise a special child. Here, religious beliefs lead the parents in question to believe that raising a child with autism is a test from *Allah*, one put in place to assess their morality vs. their immorality (Jegatheesan et al., 2010).

In the same vein, research asserts that Indian Hindu immigrants in the US, who subscribe to Hindu beliefs about reincarnation and karma, believe that disability is a sign from God, bestowed as a result of sins committed in a former life (Gabel, 2004). Similarly, some families from Puerto Rican, Mexican, and Colombian cultures believe that having a child with a disability is a result of sins committed by the parents (Rogers-Adkinson et al., 2003). In contrast, other families from Puerto Rican, Mexican, and Colombian cultures with strong religious beliefs show greater acceptance of a child's limitations (Rogers-Adkinson et al., 2003). Likewise, ultraorthodox Jewish Israeli families show positive interpretations of disability. Jewish families

13

view their children with autism as having a spiritual status or as chosen to fulfill a religious mission (Shaked, 2005).

In the Republic of Ireland, Coulthard and Fitzgerald (1999) conducted interviews with 60 parents of children with autism and found that 66% reported that they trusted God to take care of the situation and sought comfort through prayer. Here, prayer was identified as a resource and a coping strategy. Other research examined the experiences of families of children with disabilities in their spiritual communities. Findings indicate that families rated their children's participation and family support in their spiritual communities as positive and important to coping with disability. In addition, families reported positive experiences with religious education/activities, and religious leader support (O'Hanlon, 2013).

Researchers in several studies shed light on the religious beliefs of families of children with visual impairments. Erin, Rudin, and Njoroge (1991) used a survey to examine the religious perceptions and practices of 161 parents of children with visual impairments. Researchers found that most of the parents held positive beliefs and maintained their general belief system and association with their religious community. In contrast, 20% felt that having a child with a visual impairment was a punishment from God. However, this percentage decreased, and only 5% held that view later (Erin et al., 1991). In Morocco, where 99% of the population is Muslim, it is a widely held belief that blind individuals are closer to God (Lawson, 2015). Similarly, Bazna and Hatab (2005) explain that blindness is viewed as neither a curse nor a blessing amongst Muslims. Here, it is simply a part of the human condition. As such, "The Qur'an removes any stigma and barrier to full inclusion of people with physical conditions" (p. 24).

The previous examples show the strong influences of religion on the perceptions of disability, regardless of the particular culture. The next section discusses families' educational

level and its effect on their level of acceptance of their children's disability, and involvement in their children's education and intervention.

Education level. Parents' education levels have a great influence on their perception and acceptance of disability, their help-seeking behaviors, and their expectations and involvement in their children with disabilities intervention and education. Studies have shown that higher levels of parental education were associated with earlier diagnosis, greater satisfaction with the diagnostic process, more involvement in child intervention and education, and overall satisfaction with professionals and services (Deslandes & Bertrand, 2005; Garland, Brookman-Frazee, & Gray, 2013; Fishman & Nickerson, 2015; Jones & Gansle 2010; Halsey, 2005; Hidalgo, McIntyre, & McWhirter, 2015).

Lack of education may limit a family member's ability to understand the child's diagnosis and intervention options. Parents with higher education are more able to locate support and informational resources, more likely to be informed and aware about best practices, services, and intervention, as well as challenges and barriers to their children's education (Hidalgo et al., 2015). For example, Shin (2002), in his comparison study between Korea and United States, found that regardless of culture, both American and Korean mothers with higher education were more likely to receive professional support and had more informational support from informal sources.

In addition, the parents' education level predicts how much participation in school is observed. Research on parents of children with disabilities indicate that parents with higher levels of education are more likely to participate and be involved in school activities than are parents with lower levels of education (Deslandes & Bertrand, 2005; Fishman & Nickerson, 2015; Jones & Gansle 2010; Halsey, 2005). Studies also found that the parents' education level

15

significantly predicted postsecondary enrollment and degree-attainment. Youths of parents who have no college experience are less likely to attend college, and confront difficulties in navigating the college application and enrollment process and procedures (Harrell & Forney, 2011; Mudge & Higgins, 2011; Perna & Thomas, 2008; Peterman, 2016).

In general, research suggests that highly educated parents form more reasonable expectations about their children's performance and educational outcomes (Alexander, Entwisle, & Bedinger, 1994; Halle, Kurtz-Costes, & Mahoney, 1997), have more ability to foster their children's adjustment and produce a cognitively motivating home environment (Davis-Kean, 2005; Wang, Deng, & Yang, 2016), are more motivated to seek help for their children (Garland et al., 2013), showed lower levels of anger, and coped with barriers and stress more efficiently (Parkes, Sweeting, & Wight, 2015; Shokoohi–Yekta, Zamani, & Ahmadi, 2011) when compared to parents with a lower education level.

As the role of parents' education contributes to their perception, expectations, and involvement in their children with disabilities intervention and education, a family's income has a great influence, as well. The next section discusses the impact of families' SES in providing support services, intervention, and education to a child with disability.

Socioeconomic status (SES). The discussion of families' socioeconomic status (SES) in this section is intended as the family's income. A family's income affects their ability to access health care, which directly impacts their children's early diagnosis and identification, planning of intervention, technology utilization, and specialized training and support services provided to their children with disabilities (Ennis-Cole et al., 2013; Gibson, 2007; Lin et al., 2012). Consequently, families who are low-income may have difficulties accessing health care due to a lack of health insurance, may face additional barriers, experience greater difficulties in locating

16

support and informational resources, and may find transportation to program and services unaffordable (Hidalgo et al., 2015; Lin et al, 2012; Reichard & Turnbull, 2004).

Literature shows that families from higher SES backgrounds are more likely to report being satisfied with the special education process, show more positive attitudes toward mental health services, and face fewer barriers to accessing services than families with lower incomes (Goin-Kochel, Mackintosh, & Myers, 2006; Hidalgo et al., 2015; Moh & Magiati, 2012). Moreover, there is a significant relationship between a family's income and the types of the services they receive. Higher income families are more likely to receive more types of services than lower income families (Irvin, McBee, Boyd, Hume, & Odom, 2012) because families with higher incomes were found to be more likely to report a lack of services available, and advocated for additional and different types of services for their children than families with lower incomes (Hidalgo et al., 2015).

In addition, the parents' SES have been shown to be associated to how much parents engage in their children education. Studies reported that low-income parents are typically less involved in their children's education and school activities than are parents of high-income families (Camacho-Thompson, Gillen-O'Neel, Gonzales, & Fuligni, 2016; Deslandes & Bertrand, 2005; Jones & Gansle, 2010; Halsey, 2005; Wang et al., 2016). A family's SES also significantly impacted their children's postsecondary enrollment and finding competitive employment. Youth from low SES backgrounds are less likely than their peers from higher SES backgrounds to enroll in postsecondary education and to be employed (Newman et al., 2011; Wagner, Newman, & Javitz, 2014). Also, during high school, employment experiences among low-income youth with disabilities have been shown to be significantly lower than their peers with higher income (Wagner et al., 2014).

17

The connection between families' economic statuses and their ability to access health care and participate in their children's intervention and education was clear. Other aspect that could influence parents' help-seeking behaviors and involvement in their child intervention and education is the family degree of acculturation to midstream culture, which is discussed in the next section.

Acculturation. Acculturation has been defined as "a complex process of psychological and cultural change resulting from the contact of two different cultures, with one group of people being dominant and the other forced to modify or adapt some of their original cultural patterns and to absorb some of the dominant culture's in order to accommodate to a new environment" (Rodriguez, 2010, p. 83). Acculturation is a complex and multidimensional processes that involves several domains, including identity, behaviors, attitudes, values, and cultural beliefs (Matsudaira, 2006; Sun, Brockberg, Lam, & Tiwari, 2016; Yoon, Langrehr, & Ong, 2011). The multidimensional process of acculturation indicates that individuals adopt both cultures and do not necessarily give up one or the other (Pak, 2006). The function of acculturation can differ by cultural group, and some domains of these dimensions can be more significant for certain groups compared to others (Sun et al., 2016).

Research literature shows that the degree of acculturation with mainstream culture changed families' perceptions, motivations, and behaviors from similar cultural and linguistic backgrounds, including changing in their child rearing practices, perceptions of disability, help-seeking attitudes and behavior, and involvement in their child's intervention (Al Khateeb, Al Hadidi, & Al Khatib, 2014; Dinh & Nguyen, 2006; Guerrero, & Leung, 2008; Sklar, Pak, & Eltiti, 2016; Venza, 2002). However, change and adaptation to new culture is never easy, particularly if the family's values contrast with the mainstream culture (Guerrero, & Leung,

18

2008). The process of acculturation also may be negatively impacted by historical or sociopolitical events (Guerrero, & Leung, 2008). Immigrant parents in the US may encounter acculturation stressors in the context of negative context of reception, maltreatment, acculturative stress, lack of economic opportunity, and discrimination (Guerrero, & Leung, 2008; Leon, 2014; Tran, 2014). This, in turn, interferes with positive family functioning, can lead families to reject mainstream cultural values, make them skeptical of mental health professionals or school personnel, and cause them to be unwilling to collaborate with educators, which negatively impacts the mental health and well-being of their children (Guerrero & Leung, 2008; Leon, 2014; Lorenzo-Blanco et al., 2016; Tran, 2014).

Acculturation can predict factors to recognize variability among racial and ethnic minority groups, such as an individual's well-being and adjustment, help-seeking attitudes, intervention preference, counseling styles, and mental health outcomes (Yoon et al., 2011). Several researchers have shown that higher levels of acculturation to host cultures has a positive effect on psychological and sociocultural adjustment (Swagler & Jome, 2005; Wang & Mallinckrodt, 2006), benefits the well-being of individuals (Yoon et al., 2013), fosters more positive help-seeking attitudes, and results in a greater likelihood of seeking help from mental health specialists and psychological services (Venza, 2002).

Additionally, parent-child relationships and parenting styles can change due to adaptation of attitudes and behaviors of mainstream culture. Dinh and Nguyen (2006) found that children of immigrant parents, who are acculturated to mainstream American values, may adopt these values as well as their parents. Research also reports that immigrant parents' acculturation to mainstream culture may change their parenting style (Bornstein & Cote, 2004; Farver & Lee-Shin, 2000). For example, research found that Chinese immigrant parents who are highly

19

acculturated to American culture change their authoritarian parenting to a more authoritative

parenting style, while those who maintain a higher acculturation to Chinese culture associated

with a more authoritarian parenting style (Yu, Cheah, & Calvin, 2016).

Based on previous research, acculturation has been identified as playing a significant role

in parents' child rearing practices and educational involvement, as well as in understanding the

health and well-being of immigrants in general. Learning the language of the host culture is

considered as a part of the acculturation process, which is, in our case, the English language.

Thus, the impact of the English proficiency on families' function is discussed in the next section.

English language proficiency. Scholars found that immigrant families' English language

ability affects their ability to understand their children's disability, and to communicate,

advocate, and access appropriate services for their children with disabilities (Al-Hassan &

Gardner III, 2002; Al Khateeb et al., 2014; Hornby & Lafaele, 2011; Sentell, Shumway, &

Snowden, 2007). Parents with poor English language skills face more barriers and difficulties

that limited their ability to access resources and needed services, communicate effectively with

professionals, and obtain clear information on intervention and treatment (Hornby & Lafaele,

2011; Mui, Kang, Kang, & Domanski, 2007; Sentell et al., 2007).

Limited English proficiency has been shown to a barrier to most parents' involvement at

school, and subsequent withdrawal from participating in school activities (Geenen, Powers, &

Lopez-Vasquez, 2001; Hornby & Lafaele, 2011; Lai & Ishiyama, 2004; Tumey & Kao, 2009).

Parents with limited English proficiency may lack of confidence and feel they cannot

communicate effectively with school personal due to languages differences (Al-Hassan &

Gardner III, 2002; Hornby & Lafaele, 2011). Moreover, the language barrier not only

unfavorably affected the parents' involvement at school; it also restricted parents' ability to assist

their children with their education at home (Jones & Gansle 2010).

Additionally, there is an association between immigrants' English language ability and their income. English-speaking ability is found to be critical to determine the earnings of immigrants in the US. Immigrants' proficiency in English language increases the likelihood of employment and the range and quality of jobs they get, which in turn increases their income (Bleakley & Chin, 2004). Lack of English proficiency may limit employment and training opportunities of immigrants in the US labor market, as well as hinder their ability to obtain information about available jobs (Park, 1999), which negatively affect their income. This in turn, affects their access to appropriate intervention, health care, and related services for their children with disabilities.

To sum up, there seems to be no one solitary factor that contributes to families' perception of having a child with disability, and their decision regarding their child's education and intervention. Instead, these differences are likely due to complex interactions among social and cultural aspects including families' religion beliefs, education level, SES, degree of acculturation, and English language proficiency. These factors are not operating dependently; each is influenced by the other. Such factors can clarify the variety of differences between different cultures as well as within given cultural group. The next section is an overview of Arab American population.

Arab American

Before discussing Arab culture and disability, it is crucial to explain the traits characterizing this demographic. This section provides basic information about Arab Americans, including their origins, population size, religions, classification, education and occupations.

Origins. The Arab world consists of 22 countries in West Asia and North Africa; including Algeria, Bahrain, the Comoros Islands, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Mauritania, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, the United Arab Emirates, and Yemen (AAI, 2014). The term *Arab world* refers to this geographical and linguistic region. There are also other geographical terms that refer to parts of the Arab world. For instance, the term *MENA,* which is an acronym for Middle East-North Africa region, refers to 17 of the Arab world countries, in addition to Iran and Israel (U.S. Census Bureau, 2015). Moreover, the term *Middle East* refers to the region that includes a number of Arab countries, as well as other non-Arabic-speaking countries, such as Cyprus, Turkey, and Iran.

Population. Arab immigration to the United States began during the1880s. Arab immigrants, who are citizens or residents of the United States, mainly came to the US from Middle Eastern countries under particular social and political factors (Suleiman, 2001). The Arab population in the US increased dramatically over the decades: 41 percent in the 1980s, 38 percent in the 1990s (U.S. Census Bureau, 2000), and by more than 72 percent between 2000 and 2010 (AAI, 2010). Today, the US Census Bureau estimates that at least 1.9 million Americans are of Arab descent; however, the Arab American Institute Foundation estimates that the number is closer to 3.6 million (AAI, 2010). The majority of Arab Americans are native-born, and nearly 82% of Arabs in the US are citizens (AAI, 2010).

The Arab community in the US traces its roots to every Arab country, though the majority of Arab Americans, roughly 37%, have Lebanese or Syrian roots. Since 1990, significant increases appear in the number of Arab Americans of Iraqi, Egyptian, and Somali descent (U.S. Census Bureau, 2000). Arab Americans live in all 50 states, but more than two

thirds of them live in just ten states: California, Michigan, New York, Florida, Texas, New Jersey, Illinois, Ohio, Pennsylvania, and Virginia. Moreover, up to 94% live in metropolitan areas. Los Angeles, Detroit, New York, Chicago, and Washington, D.C. are the top five metropolitan areas with Arab American populations (AAI, 2010). Americans of Lebanese decent represent a large segment of the overall number of Arab Americans living in most states. Egyptian Americans are the largest Arab group residing in New Jersey, while the majority of Arab Americans in Rhode Island are Syrian Americans. The Palestinian population mainly live in Illinois, and the Iraqi community is concentrated in Michigan, California, and Illinois (AAI, 2010).

Religions. In the Arab region, the majority of Arabs are Muslim, and only a small number of individuals practice other religions, such as Christianity and Judaism (Sharifzadeh, 2011). In the US, the majority of Arab Americans are Christian, 63%, Muslims represent 24%, and the rest are adherents of Judaism or undeclared (AAI, 2010). Earlier Arab immigrants were predominantly Christian; however, recent Arab immigrants are generally Muslim (Sharifzadeh, 2011). Today, Arab American Muslims represent the fastest growing segment of the Arab American community (AAI, 2010).

Classification. According to the 2008 American Community Survey, Arab Americans who identified themselves as "Arab/Arabic" included individuals from: Lebanese, Syrian, Egyptian, Iraqi, Jordanian, Palestinian, and Moroccan. Other individuals who classified themselves as "Other Arab" claimed the following as their countries of origin: Algeria, Bahrain, Djibouti, Kuwait, Libya, Oman, Qatar, Saudi Arabia, Tunisia, the United Arab Emirates, and Yemen. In addition, there are Arabic-speaking persons, such as those who identify as Somali or Sudanese, identities that are not aggregated as Arab in Census reports (AAI, 2010).

Arab Americans are racially classified as White on the US Census. This is due to the fact that the first Arabs immigrating to the US were light-skinned, thus, based on their appearance; they were classified as White (Cainkar, 2006). Consequently, the White classification denied them the status of a minority group; hence, Arab Americans do not receive protection under anti-discrimination laws (Hassan, 2002). At the same time, a White classification does not protect members of Arab communities from discrimination and racial profiling (Sharifzadeh, 2011). Such protections would be valuable, as Arab Americans' vulnerability to discrimination, negative distortions, and even hate crimes are more than other ethnic groups (Cainkar, 2009; Khan & Ecklund, 2012). In addition, the media plays a huge impact in reinforcing stereotypes against Arabs. Arabs and Muslims are usually negatively depicted, and the term "terrorist" has become synonymous with Muslim or Arab (Awad & Amayreh, 2016; Shaheen, 2003; Suleiman, 2001). This negative stereotype causes discrimination with respect to education, housing, employment, immigration, and misconduct of police (Awad & Amayreh, 2016). It also has harmful consequences on Arab American students, as many became subject to verbal and physical harassment by their peers (Suleiman, 2001).

Education. A large percentage of Arab immigrants are highly educated, where most of the second wave immigrants have come already educated, and seek higher education (Adeeb & Smith, 1995; Sharifzadeh, 2011). According to the Arab American Institute Foundation (2010), 89% of Arab American adults hold at least a high school diploma. Arab Americans who have a bachelor's degree or higher embody 45% of Americans of Arab descent, compared to 27% of Americans as a whole. Arab Americans who obtain a postgraduate degree represent 18%, compared to the American average of 10% (AAI, 2010). In terms of school age population, Arab American children in preschool and kindergarten represent 12%, while 56% of Arab American

24

children are in elementary through high school, and 32% are pursuing college or graduate studies (AAI, 2010). Arab Americans think very highly of education and the impact that it has, not just on individuals, but on families and communities as well. For this reason, Arab Americans, in particular, are likely to value and prioritize education for their children (Suleiman, 2001).

  Occupations. Arab Americans participate in the workforce at similar rates as other adults, and have similar unemployment rates; however, fewer Arab Americans work in service sector jobs than the national average. Only 14% of Arab Americans work in the service sector, compared to a 17% average for Americans overall. A large number of Arab Americans work in the private sector, 88%, compared to 12% who are government employees (AAI, 2010). Arab Americans also have a higher median income than the average American household, by approximately $56,331, and the mean individual income amongst Arab Americans is 27% higher than the national average of $61,921. On the whole, 13.7% of Arab Americans live below the poverty line, about one percentage point lower than the national average. An outlier in that group are single Arab American mothers, 28% of whom live below the poverty line (AAI, 2010).

  Lastly, represented in the previous section was a summary about Arab American population in the US, including basic information on Arab American origins, religions, classification, education, and occupations. Discussed next is Arab culture.

Arab Culture

  Understanding the role of culture in family interactions and child rearing practices is essential when working with families and students from different cultural backgrounds. Given that Arabs are a heterogeneous group and have a diverse cultural heritage that includes different religions, nationalities, education levels, Arabic dialects, and social classes (El-Khadiri, 2009), describing Arab culture in few pages is difficult. Therefore, the information presented in this

section is very brief regarding some of the different characteristics of Arab culture, and should be used carefully to prevent stereotyping Arab families or culture.

Family structure. Arab culture is characterized by hierarchical and interrelated family relationships, and emphasizes interdependence rather than individualism (Dedoussis, 2004; Dwairy, Achoui, Abouiserie, & Farah, 2006). In Arab culture, individuals tend to view themselves, and be viewed by others, in the context of their familial kinship group, a process that is reinforced by family socialization (Ajrouch, Hakim-Larson, & Fakih, 2016). Traditionally, the Arab family structure is extended rather than nuclear. Strong family ties represent a central aspect in Arab culture, and the extended family is the most important institution (Britto & Amer, 2007; Cainkar & Read, 2014; Sharifzadeh, 2011). Thus, we can often see the prominent role of the extended family in Arab culture in the close proximity in which families decide to live; it is common for several generations of a family to live together and to have extended relations living nearby.

Be that as it may, family members who are geographically distant are nevertheless loyal to their relations (Sharifzadeh, 2011). The familial and social bonds of the typical Arab family play an important role in society (Ajami, Rasmi, & Abudabbeh, 2016; Sharifzadeh, 2011). The extended families provide care and support to young, elderly, and people with disabilities amongst themselves rather than seeking outside services from governmental or nongovernmental organizations as is common for Euro-American families. Not only do these family bonds provide support, but the family also provides much of the entertainment and recreation (Ajami et al., 2016; Sharifzadeh, 2011).

The basics of family relations and interactions are formed by religion, with Islam being the major religious inspiration amongst most of families from the Arab countries (Ajami et al.,

2016; Amer & Kayyali, 2016; Sharifzadeh, 2011). Arab Families share several well-known

cultural characteristics, such as hospitality, generosity, and respect for guests and the elderly (Al-

Omari, 2008; Donovan, 2013; Harb, 2016; Nydell, 2012). Inhospitable behaviour is a source of

shame that can harm a family's reputation, and become a possible cause of marginalization

(Harb, 2016; Nydell, 2012). The elderly are highly respected, and the care of them is the family

responsibility, which is considered a debt children owe their parents, with special emphasis on

elderly parents (Elsaman & Arafa, 2012). The idea of nursing homes and social services for the

elderly does not gain support in Arab societies (Soliman, 2013). These fundamental values

cannot be underestimated in Arab societies, in which they are culturally socialized and

continuously strengthened through the family (Dwairy et al., 2006).

Marriage is highly valued in Arab culture (Gregg, 2005; Inhorn, 2012). Having children

is essential (Ajrouch et al., 2016), and not having children is a cause for sadness (Sharifzadeh,

2011). With this said, in Arab culture, the intention of most of marriages is to have children,

which is often a stronger marriage value than love or intimacy (Ajami et al., 2016; Sharifzadeh,

2011). Similar to how individuals tend to view themselves in the context of their relationships,

marriage is viewed not just as a joining of two individuals, but also as an agreement between two

families (Al- Krenawi & Jackson, 2014). Thus, the extended family may remain involved in the

couple's life after marriage, and plays an important role in providing guidance, as well as

emotional and potentially financial support (Ahmad & Reid, 2008; Chapman & Bennett-

Cattaneo, 2013). Among Arab families, a strong desire for having many children is prevalent,

with preference for male children (Abel, 2003; Sharifzadeh, 2011). The birth of children in Arab

families requires parents to fully attend to their children's care and upbringing, and parents may

sacrifice everything in the process, even their personal interests (Elsaman & Arafa, 2012;

Sharifzadeh, 2011). Child neglect and lack of care and love is extremely despised in Arab societies (Sharifzadeh, 2011).

In Arab culture, patriarchy is dominant. Fathers are usually the head of family, the primary agent of discipline, the ultimate authority within the family, and the main agent of socialization with the outside world (Ajrouch et al., 2016; Stephan & Aprahamian, 2016). Fathers seldom engage in caregiving procedures, and see themselves as responsible for providing the family with material needs and expenses, but not engaging in day-to-day caregiving (Ajrouch et al., 2016; Sharifzadeh, 2011). Mothers are typically responsible for aspects of household management, such as cleaning and cooking, as well as providing the majority of the day-to-day caregiving for children (Ajrouch et al., 2016; Ajami et al., 2016). However, extended family members provide a network of support to the Arabic mother, and help alleviate the need to tend to every moment of childcare by herself (Ajami et al., 2016; Sharifzadeh, 2011).

Child rearing. As noted previously, children are highly valued in Arab culture, and the intention of most of marriages is to have children (Ajami et al., 2016; Ajrouch et al., 2016; Sharifzadeh, 2011). Mothers have the primary duty of the day-to-day caregiving. Thus, in the case of immigrant Arabs, the mother's burden of caring of children alone with the absence of an extended family can be a great source of pressure and tension for the mother and the family (Ajami et al., 2016; Sharifzadeh, 2011). In Arab culture, a child's identity is gleaned from the parent-child relationship (Beitin & Aprahamian, 2014). The interactions between and among members of the family vastly influences the children's identities. Some of the central interpersonal relationship values that children learn are to treat their parents and other elders and adults with greatest respect, and to engage in generous and polite behaviors in the presence of guests (Nydell, 2012).

In the Arab family context, children regularly begin to learn male and female identities, which is a central component of the socialization of Arab children because of the patrilineal social structure of most Arab families (Beitin & Aprahamian, 2014). In the patrilineal structure, family affiliation is guaranteed through the father, and family members have access to different rights based upon their genders. The patrilineal structure both privileges and places an onerous burden of responsibility on men, who must ensure the security of the family, provide a sense of belonging to those around them, and carry on the family line. Women in patrilineal families learn a sense of responsibility to the family, and that their actions can either confirm or challenge the reputation of the family. This often results in women being viewed as valuable and needing protection (Ajrouch et al., 2016).

One of the main differences in the child rearing practices between Arab families and Euro-American families is the nature of parent-child attachment "independence vs. nurturing." Euro-American families place great emphasis on early independence of the child from the parents, and hold high expectations for self-help and self-reliance (Hanson, 2014). Children are socialized to attain and sustain their independence (Ajami et al., 2016). Thus, families in American culture usually do not expect to have very close relationship with their children as they become adults, as it accepted that their children, at the age of 18 or soon afterward, will leave the family home to start their own residences (Hanson, 2014).

In contrast, in Arab families, the emphasis is on attachment and parent-child bonding. Children in Arab culture are socialized to maintain a strong allegiance to their extended families as they become adults, as well as being imbued with the expectation to care for their elderly parents (Ajami et al., 2016; Sharifzadeh, 2011). Children do not leave their parents' home until they get married. It is also common for sons to live in their parents' home even after they are

married (Sharifzadeh, 2011). In summary, in Arab families, separation between mother and child is minimized, and in general, children are dependent on their parents for longer than most Euro-American children. Therefore, there is less parental concern about developing independence skills and self-help skills (i.e. early toilet training, self-feeding, self-dressing), which are taught early for children in American culture (Gregg, 2005; Sharifzadeh, 2011).

Another different practice between Arab families and Euro-American families is the "authoritative vs. authoritarian" style of child rearing. American culture is child-centered, and most of Euro-American parents adopt an authoritative style, in which parents encourage children's self-sufficiency, empower them to regulate their own actions, to make their own choices, and do not care to be seen by their children as an authoritative figure (Dwairy et al., 2006; Sorkhabi, 2010). For instance, children have opportunities to be involved in family decision-making, or consulted about their preferences for the family's purchases, vacation plans, or activities (Hanson, 2014; Sorkhabi, 2010).

On the other hand, Arab culture is parent-centered. In a typical Arab family, parents practice an authoritarian parenting style, in which they embody a figure of authority and socialize their children to heed their word (Kayyali, 2006). Arab parents typically determine what is, and what is not, appropriate for their children, and emphasize obedience and control. Arab parents prefer enforcing discipline, raise their children to listen to their wishes, and expect children to follow their orders unquestionably and immediately (Dwairy et al., 2006). Communication is usually more vertical with Arab parents, who are more prone to commanding or lecturing their child rather than engaging them in discussion or justifying their position (Ajami et al., 2016; Dwairy et al., 2006; Sharifzadeh, 2011). Though these childrearing techniques are not favored and may be considered undesirable in Western countries, they do not necessarily

result in negative outcomes for the children of Arab families in America or elsewhere (Ajami et al., 2016; Dwairy et al., 2006).

In addition, the "individuality vs. interdependence/collective" rearing style represents different characteristics between Arab and Euro-American families. Individualism is central to the life of Western societies (Davis & Gordon, 2010). Individualistic societies, such as American society, endorse and value independence, autonomy, identity, individual achievement, and self-reliance (Ajami et al., 2016; Davis & Gordon, 2010; Sharifzadeh, 2011). Parents in American culture taught their children from an early age to be self-reliant, self-determined, and responsible about their personal actions (Hanson, 2014).

In contrast, in collectivistic societies, such as Arab society, harmony, loyalty to the group, cooperation, tradition, extended families, and respect for elders and authority are highly valued (Ajami et al., 2016; Ajrouch et al., 2016; Davis & Gordon, 2010; Goforth, 2011; Sharifzadeh, 2011). Mutual commitments, interdependence, and reciprocal relationships are endorsed in Arab culture (Al Khateeb et al., 2014). In Arab families, child socialization fosters a collective identity, in which an individual's socioeconomic status is greatly associated with the family's status, and an individual's decisions are made taking all family members into consideration (Ajrouch et al., 2016; Goforth, 2011). Arab families view interdependence and sharing as significant; consequently, they promote them as socialization goals for children. Individuality may be viewed as selfish and interpreted as a rejection of the family. Generally, Arab parents favor raising their children as interdependent members of the family rather than as independent individuals (Sharifzadeh, 2011).

Conceptualization of disabilities. The discussion of disability in Arab culture is challenging due to the fact that literature on this subject is minimal, and statistics are not only limited, but have questionable reliability (Gharaibeh, 2009). According to Al Thani (2007), the two major challenges facing individuals with disabilities in the Arab region are the lack of awareness of the rights of people with disability and the lack of clear legislation to protect those rights. Further, in Arab societies, the causes of disability are consistent with beliefs held by to the rest of the world. However, several characteristics of Arab countries contribute to high levels of disability, such as the rate of consanguineous marriages, higher maternal and paternal age, large family sizes, armed conflicts, and terrorism (Gharaibeh, 2009).

Due to the cultural and religious differences characterizing Arab societies, the interpretations of disabilities are varied. For instance, Al-Krenawi and Graham (2011) found significant differences regarding attitudes towards mental disabilities among a cohort of students representing three major religious minorities among Arab communities: Christians, Druze, and Muslim. Some explanations for mental disabilities include it being a test from God, while other explanations attribute disability to supernatural entities, such as the evil eye, witchcraft, and possession by the demon "*jinn*" (Al- Krenawi & Graham, 2011). Additionally, Ahmead, Rahhal, and Baker (2010) found professionals' attitudes toward patients with mental illnesses are divided between psychological and medical understandings of the causes of mental disabilities. While 66.7% of the participants suggested genetic causes, 78.2% suggested stressful situations and adverse social circumstances (Ahmead et al., 2010).

In Arab societies, stigma and social attitudes toward disabilities vary and depend on the kind and severity of disability. Visual impairments, blindness, and deafness are less stigmatizing than other disabilities, yet may arouse compassion for the individual and empathy for the family

32

(Bazna & Hatab, 2005; Gharaibeh, 2009; Lawson, 2015; Sharifzadeh, 2011). Disabilities with no obvious physical signs (i.e. mild mental disabilities, learning disabilities) mostly result in a near typical life under strong protection of the family. Severe mental disabilities and mental illnesses are more stigmatizing than physical and sensory disabilities, and lead to strong negative stereotypes and often result in families' isolation (Ahmead et al., 2010; Al Thani, 2007; Gharaibeh, 2009; Sharifzadeh, 2011).

Additionally, females with any disability are more likely to be stigmatized and institutionalized than males with a disability (Gharaibeh, 2009; Sharifzadeh, 2011). Females with disability are considered unmarriageable, and incapable of fulfilling the primary role of marriage and childbearing (Al Thani, 2007; Wehbi & Lakkis, 2010). In Lebanon, for example, Wehbi and Lakkis (2010) explores the intersections of gender and disability, and found that several females with disabilities were not officially registered in municipal records, and faced ongoing barriers to education and employment.

In the family context, as it exists in other cultures, Arab parents experience a series of responses and feelings upon their child diagnosis of disability, such as shock, disbelief, guilt, anger, shame, and stress (Al Khateeb et al., 2014; Donovan, 2013). However, shame and guilt are the most common reactions when a child with a disability is born in an Arab family, which mostly results in overprotection and isolation (Donovan, 2013; Kuaider, 2005; Sharifzadeh, 2011). Some Arab parents feel that having a child with a disability is a test or punishment from God, which they must go through (Kuaider, 2005). Different attributions to the cause of disability are also found among uneducated Arab mothers, such as a previous abortion, eating a specific type of food, lifting heavy objects, unsuccessful attempts at abortion, or being punished for some wrongdoing committed during or before pregnancy (Sharifzadeh, 2011).

In several Arab countries, childbearing issues tend to be blamed on mothers, in which mothers are usually considered responsible for the birth of a child with a disability (Donovan, 2013; Sharifzadeh, 2011). Crabtree (2007) explored the perceptions of mothers of children with developmental disabilities in relation to family acceptance and social inclusion issues. Findings indicate that some mothers tend to hide their children's disabilities because of their fear of divorce, or concern that husbands would be allowed to marry a second wife due to childbearing issues. In such cases, the mother's isolation and restricted contact with other adults makes the burden of caregiving stressful and challenging for the mother. Moreover, members of the extended family may be less willing to participate in raising a child with a disability. They fear such a responsibility, as they may not know how to respond to the child's special needs (Sharifzadeh, 2011).

In addition, an individual's disability not only affects the individual, but also extends to the entire family (Goforth, 2011). Sisters are most notably affected, as they tend to face reduced marriage opportunities (Al Thani, 2007; Turmusani, 2003). Consequently, in the Arab world, it is rare to meet an individual with a disability in public, as family members with a disability might be kept hidden from the public (Al-Kandari & Al-Qashan, 2010; Al Thani, 2007; Crabtree, 2007). This negative social implication could be correlated with a family's reluctance to obtain disability-related services and personal support, the absence of accessible facilities and transportation for individuals with disabilities, as well as ignoring individuals with disabilities as important members of society (Donovan, 2013; Goforth, 2011; Haboush, 2007; Reilly, 2011).

In summary, literature indicates that Arab societies, in general, negatively perceive disability more than Western societies do, and that Arab parents are less ready than most Euro-American parents to accept the reality of having a child with disability (Al Khateeb et al., 2014;

Al Thani, 2006; Gharaibeh, 2009; Haboush, 2007; Sharifzadeh, 2011; Turmusani, 2003).

However, overgeneralizations should be cautioned, as it is not uncommon for Arab families to show positive attitudes toward their children's disabilities based on parental love and affection, as well as religious parity (Al Khatib, 2017; Crabtree, 2007). In addition, Arab society's perceptions and attitudes toward disability have changed over the decades. Parents are starting to advocate for their children with special needs, and individuals with disabilities have become more visible in public. Accessibility, special education services, and inclusive education have developed and become more popular (Al Khatib, 2017). This illustrates that determining how to best address disability-driven service provisions in the Arab world is complicated. This is due to the fact that Arab culture is heterogeneous, and there are several impressions of disability. The next section discusses disability research pertaining to Arab American families.

Disability Research on Arab Americans

Research, including cases of Arab Americans or immigrant Arabs with disabilities in the US, is limited. Arab Americans with disabilities are a neglected sub-minority of arguably the most stereotyped and marginalized minority in the US (Al Khatib, 2017; Campbell-Wilson, 2012). Whether in literature related to ethnic minorities with disabilities, or in literature pertinent to Arab Americans, individuals with disabilities with Arab ancestry have generally been overlooked (Al Khatib, 2017).

To this date, there are only three empirical studies regarding disabilities among Arab American children (Al Khatib, 2017). In the first study, Kuaider (2005) utilized the Ecocultural Family Interview model (Weisner, Coots, Bernheimer, & Arzubiaga, 1997) in order to examine the daily routine and adaptation of Arab American families who had children with disabilities living with them. Nine Arab American mothers of children with disabilities participated in this

study. These mothers came from different Arab origins, had been in the US for at least six years, and hold at least high school diploma. The ages of their children with disabilities ranged from 5 to 18 years old, and had different types and degrees of disability (genetic disorder, Down syndrome, autism, Prader-Willi syndrome, developmental delay, visual and hearing impairment). Findings of this study indicated that religion and spirituality were significant factors that influenced the lives of these families, and gave meaning of having a child with a disability. Further, families were generally satisfied with the services provided to their children. However, low family involvement with child disability groups/activities was observed.

The second study examined perceptions of Arab American parents of children with special needs regarding communication with the school and professionals who work with their children (Abadeh, 2006). A survey was used as the primary data collection tool. A random sample of 100 Arab American parents was selected from a list provided by the school district. Of this number, 77 parents completed the survey for a response rate of 77.0%. Participants had children with special needs in the first through fifth grades. Results of this study showed there are mixed outcomes and differences in responses that exist between Arab American parents who have been in the United States for a long time in comparison to those who are recent immigrants. The language barrier was the main factor that impeded parents' involvement and communication with schools. Further, most Arab American parents held the belief that schools are the authority in their child's education back in their homeland. Therefore, they assumed a passive role during the IEP meeting.

The third study was a phenomenological qualitative study that investigated Arab American parents' experiences of the special education process (Donovan, 2013). Six American Arab parents (five mothers and one father) of children with special needs from a large city in the

Midwest were interviewed. Of the six parents, four parents were born and educated in the Arab world, and two were American-born. All parents who participated in this study were Muslim; however, they were diverse in terms of their children's gender and type of disability. The ages of children with disabilities of these parents ranged from 8 to 15 years old, and they had different types and degrees of disability (genetic disorder, autism, specific learning disability, speech or language impairment, and attention-deficit/hyperactivity disorder). The findings of this study revealed that some parents had positive and supportive experiences with spouses and teachers during the special education process, while others reported unsupportive relationships with husbands and with school personnel, and that the special education process had negatively affected their relationships with their spouses.

In addition, empirical information on the prevalence of disabilities among Arab Americans is absent (Abadeh, 2006; Campbell-Wilson, 2012; Donovan, 2013). The prevalence of disability has been documented for different ethnic and racial groups in the US, yet slight attention has been paid to Arab Americans (Campbell-Wilson, 2012). There is only one published study by (Dallo, Al Snih, & Ajrouch, 2009) on the prevalence of disabilities among Arab Americans. This study only addressed older individuals and excluded school-aged children. In this study, researchers analyzed data from the 5% Public Use Microdata Samples of the 2000 US Census. The sample included 4,225 individuals, 65 years of age and older, who identified with an Arab ancestry. Results showed that immigrant Arab Americans had a higher prevalence rate of disabilities compared to US-born Arab Americans. The absence of sufficient information on the prevalence of disability among Arab Americans, and the lack of literature on Arab American students with disabilities in general makes it difficult for service providers to develop cultural awareness and the necessary skills for working with these children and their families.

Further, Al Khatib (2017), in his recent book *Arab American Children with Disabilities: Considerations for Teachers and Service Providers*, adds to the literature pertaining to Arab American families with disabilities. Al Khatib (2017) offers an overview of Arab people, cultural values, disability issues, and culturally appropriate services for Arab American families with disabilities. The book is divided into five chapters. Chapter 1 provides basic information about Arab Americans characteristics, as well as cultural traditions and practices. Chapter 2 discusses the prevalence rates of disabilities among Arab Americans and provides information about Arab American families of children with disabilities, prominent Arab Americans with disabilities, and disability within the Arab culture. Chapter 3 presents a concise description of special education services in the US, and possible obstacles to the use of these services by the Arab American population. Chapter 4 offers guidelines for providing culturally appropriate special education and related services for Arab American children with disabilities. Lastly, Chapter 5 highlights the gap in published literature pertaining to Arab Americans families with disabilities, and provides some directions for overcoming this gap. In summary, this book provides context and direction for researchers, teachers, and service providers working with the Arab American community, as well as helps Arab American families understand the special education process and how to advocate for their children.

Summary

In this chapter, factors that could influence families' parenting style, perspectives of disability, methods of seeking care and health services, and involvement in their children education were discussed. These factors included religion, educational level, socio-economic status (SES), degree of acculturation, and English language proficiency. In addition, this chapter provided an overview of the Arab American population, including their countries of origin,

population, religions, classification, education, and occupations. It also examined the Arab cultural characteristics that distinguish Arab culture from Western culture, which manifests in family structure and relationships, approaches to child rearing, and conceptualization of disabilities. Disabilities research on Arab Americans was also discussed in this review of literature. The intent of the discussion of these topics is to highlight the importance of considering the family's cultural influences when discussing disabilities and providing services. In the next chapter, the current study's research method is outlined.

Chapter Three

Method

In this study, I explored the experiences of Arab American parents of children with ASD. The purpose of this study was to understand Arab parents' experiences of having a child with ASD, and to determine their needs and concerns, in order to offer sufficient information for special education and related service providers to develop cultural awareness and the necessary skills for working with these families and their children. A qualitative interview study was used in order to investigate the experiences of Arab American parents of children with ASD, and to address the following research questions:

1. How do Arab parents make meaning of the experience of having a child with ASD?

   a. How do their cultural beliefs affect their understanding of their child's ASD?

   b. In what way(s) does their understanding of their child's ASD affect their help-seeking behaviors?

   c. How do Arab parents adapt to raising a child with ASD?

2. What are the concerns and needs of Arab parents of children with ASD?

3. What are the social support systems that assist Arab parents in raising their children with ASD?

This study was situated in the interpretive paradigm. The interpretive paradigm's primary concern is to understand the world as it is, at the level of subjective experiences of individuals. According to interpretivists, "our knowledge of reality, including the domain of human action, is a social construction by human actors" (Walsham, 2006, p. 320). Knowledge in interpretive

perspectives is constructed by individuals based on their interactions with, and the interpretations of, the world around them. Accordingly, meaning exists in complex cultural, social, and institutional milieus of individual experience (Crotty, 2003). Interpretive research assumes that individuals "create and associate their own subjective and intersubjective meanings as they interact with the world around them" (Orlikowski & Baroudi, 1991, p. 5). Thus, interpretive researchers attempt to understand the phenomena as it is from the meaning that participants assign to it.

My position as a researcher in interpretive research was to explore and understand reality as constructed by my participants. In this research vein, adopting an interpretive perspective helped me to obtain an understanding of how families' social and cultural interactions, personal beliefs, institutionalized practices, and lived experiences have shaped/constructed their perceptions and interpretations of having a child with ASD, their needs and concerns regards disability, and their involvement in the process of special education. By identifying and considering all contributing factors to these families' needs and concerns, conveying the key implications for subsequent proper services and practices to assist them and their children with ASD are made.

Research Design

A qualitative interview study was used to investigate the experiences of Arab American parents of children with ASD. A qualitative approach was chosen for several purposes. As this study aimed to understand the experiences of Arab American parents of children with ASD through an interpretive lens, a qualitative approach gave me the opportunity to understand the culture, perceptions, beliefs, and actions of my participants, and recognize or interpret the phenomena based on the meanings participants attach to it (Denzin & Lincoln, 2011; Glesne,

41

2011). Qualitative research is also suitable to study social phenomena (i.e. disability) and investigate subjects related to individual differences or issues of race, religion, gender, and class that cannot be measured and analyzed through statistical techniques (Creswell, 2013; Glesne, 2011). Finally, a qualitative approach allowed me to see the point of view from the participants' lenses, and provided me with opportunities to gain deep understanding of the investigated subject and discovered details connected to the topic at hand (Creswell, 2013; Glesne, 2011; Lichtman, 2013).

I chose to conduct in-depth interviews rather than other qualitative approaches because they provided me with the information I needed to answer the research questions, and "the interview reports can contribute substantial new knowledge to a field" (Brinkman & Kvale, 2015, p. 19). Interview techniques were needed since I am interested in exploring parents' responses to their child's diagnosis, and it is impossible to observe or replicate these past events (Merriam, 1998). The nature of the interview research provided me with insight into the lives of Arab American families of children with ASD, their everyday immediate experiences, routines, beliefs, values, goals, concerns, struggles (Brinkman & Kvale, 2015), and the services that they receive and the types of resources that available to them.

Through in-depth interviews, participants had the opportunity to share their stories with their own words, voices, language, and narrative (Lichtman, 2013). Participating in qualitative interviews can yield several benefits, including (a) self-expression through sharing one's experience and story to another; (b) enhancing self-understanding and reconstitution/self-acceptance of identity by gaining knowledge about an experience and own identity or self, and from this new knowledge, generating new recognitions and meanings; (c) relieving a sense of isolation by feeling connected with a broader community through the shared experience; and (d)

42

advocating for a community and helping others, as their participation in the research benefits other individuals and/or communities by accomplishing their needs, goals, or interests (Opsal et al., 2016; Wolgemuth et al., 2015).

In addition, as I approached this study from interpretive perspective, the interview design gave me the opportunity to gain a deeper understanding of the coherence and complexities of the participants' lives, and how their "experiences interact with powerful social and organizational forces that pervade the context in which they live" (Seidman, 2013, p. 144). Through in-depth qualitative interviews, I explored participants' stories, and asked them to provide examples and clarify their answers (Rubin & Rubin, 2011).

Sampling and Recruitment Procedure

Sampling in qualitative research aims to select participants whose responses will enable the researcher to develop a deeper understanding of the phenomena being studied (Creswell, 2013; Gall, Gall, & Borg, 2007). In this study, after receiving approval from the Institutional Review Board (IRB) Committee (see Appendix A), I used a purposeful sampling technique to recruit participants (Patton, 2015). I selected participants who would provide rich and illuminative information with respect to my inquiry. Purposeful sampling can "inform an understanding of the research problem and central phenomenon in the study" (Creswell, 2013, 156). It is designed to attain an in-depth understanding of the selected individuals (Gall et al., 2007). There are a variety of purposeful sampling strategies. Patton (2015) suggested 16 purposeful sampling strategies; each serving a different purpose. In this study, I used the snowball/chain sampling technique.

Snowball/chain sampling techniques offer an established method for identifying and accessing hidden and hard-to-reach populations (Atkinson & Flint, 2001). Given the fact that the

43

participants intended for this study represented a small racial minority and difficult group to

reach, this technique helped to access them. Therefore, at the beginning, I used snowball

sampling to locate participants. This involved asking well-situated people to recommend

participants for my study (Gall et al., 2007). This included asking Islamic schools and leaders of

the mosques. I provided them with brief information about the study and the inclusion criteria for

participation. I asked them to share my contact information with any interested and qualified

parents, instead of providing me with the parents' information, to respect confidentiality and

avoid any conflicts of interest. In addition, as part of the recruitment procedure, I distributed

flyers in the local university campus, Arabic stores and restaurants, and the mosques (see

Appendix B). However, no participant was recruited by the flyers.

After two months of recruitment efforts, only one Islamic school responded and assisted

me to access one participant, who in turn, helped me to access other participants. Snowball/chain

sampling techniques can also involve having existing study participants recruit other participants

from among their acquaintances, in which they are representatives of the purpose of the study.

Therefore, as mentioned above, the first participant, who was recommended by the Islamic

school, recruited other two participants, who met the inclusion criteria of this study, from among

her acquaintances. These two participants, in turn, recruited two more participants from among

their acquaintances. It took around four months to recruit all participants.

As mentioned above, I had initially asked that the referring persons to share my contact

information with interested parents so they could decide and contact me privately. However,

when the referring persons contacted the parents, each parent requested that their emails be given

directly to me so I could contact them. Consequently, I initially contacted each participant by

email. In this email, I introduced myself, and I provided the following information: (a) the

purpose of the study, (b) the study procedures, (c) the potential risks and benefits of participating in the study, (d) privacy and confidentiality of the data, and (e) the informed consent process. In addition, I asked each participant to take the time she needed, and to contact me if she has any question(s) or concern(s) before scheduling interview and signing the informed consent. All five participants initially agreed to participate in this study and were willing to share their phone numbers to schedule the interviews and to sign the informed consent. In the first meeting with each participant, I explained the informed consent again, and I asked if they needed more time before signing it. However, all five participants were interested to participate, and agreed to sign the informed consent immediately.

Sample size. In qualitative research, sample size is typically small (Gall et al., 2007). According to Morse (2000), several factors need to be considered in estimating the number of participants in qualitative study, including the qualitative method and study design used, the nature of the topic, the scope of the study, the quality of data, the use of shadowed data, the amount of useful information obtained from each participant, and the number of interviews per participant. A small number of participants can be extremely valuable, especially for studying hidden or hard to access populations (Baker, Edwards, & Doidge, 2012).

In this study, recruiting participants was extremely hard. As described in Chapter Two, in Arab communities, the social stigma of having a child with a disability might discourage some Arab Americans from having their children evaluated for special education and related services (Donovan, 2013; Goforth, 2011; Haboush, 2007) or sharing their experiences of having children with disabilities. Thus, as the participants intended for this study embodied a challenging group to approach, five Arab American parents were recruited. These parents were the unit of analysis in this study.

Participants

This study consisted of five Arab American parents of children with ASD from one city in the Southeast. Participants were all mothers and they were all from a Muslim religious background. I did not intend to only interview mothers and Arab-Muslims, and that was not a part of my inclusion criteria. However, all of the individuals who volunteered to participate were mothers and were Muslims. I selected participants who met the inclusion criteria of this study and would provide rich information with respect to the purpose of my inquiry. The inclusion criteria for selecting the parents were:

- Primary caregivers should be parents and identify as Arab American.

- At least one of the parents should be an immigrant (not born in the US).

- Family has at least one child who had been diagnosed with ASD.

- Family should not be a recent immigrant, and have been in the US for more than one year.

- Family has received special services related to their child's disability within the last year.

It should be noted that, to respect the participants' rights to confidentiality and to protect their privacy; I used pseudonyms throughout this document to replace all actual names of participants and their children. Additionally, to ensure that disclosed information will not link the participants' responses to their identities, I simply omitted the following identifying information: the names of therapists, teachers, schools, places of therapy, and the ages of their children's siblings. The five participants who were selected for participation are summarized below, and other important characteristics of the participants are presented generally in Table 1, to prevent linking information to the participants' identities.

Table 1. Participants Characteristics

Characteristics	Number of participants
Participants age	
30-35	2
36-40	1
41-45	2
Marital Status	
Single	0
Married	5
Educational Level	
High School	1
College Degree	2
Graduate Degree	2
Employment Status	
Employed	3
Unemployed	2
Country of Origin	
Palestine	3
Jordan	1
Egypt	1

Abeer. Abeer is a mother of six children, including 12-year-old, Arwa. Abeer and her husband were born and educated in the Arab world. Abeer moved to the US with her family over two decades ago. Then, she got married and gave birth to her children in the US. Her daughter, Arwa, was diagnosed with ASD by neurologists when she was three years old. Arwa has received special education and related services since she was diagnosed with ASD through the present day.

Salma. Salma is a mother of three children, including 13-year-old, Sara. Salma was born and educated in the US. However, her husband was born and educated in the Arab world. Salma got married and gave birth to her children in the US. Her daughter, Sara, was diagnosed with high-functioning ASD by a psychologist when she was nine years old. Salma explained that her daughter's diagnosis of ASD was delayed because her daughter went through different evaluations resulting in misdiagnoses since she was in the first grade. She was misdiagnosed with Pervasive deficit disorder (PDD) and Attention-deficit disorder (ADD) before she was finally diagnosed with high-functioning ASD. Salma also mentioned that, while she was dissatisfied, her daughter evaluated for gifted eligibility; however, she missed a question by one or two points, which prevented her from receiving gifted services. Sara is currently receiving her education in a mainstream classroom with accommodations. She also receives other therapy outside of her school setting.

Marwa. Marwa is a mother of five children, including 7-year-old, Mustafa. Marwa and her husband were born and educated in the Arab world. She got married and had her first child in their home country. Then, she and her husband moved to the US over a decade ago and completed their education in the US. Her son, Mustafa, was diagnosed with ASD by a neurologist when he was two years old. Mustafa has received special education and related services since he was diagnosed with ASD through the present day.

Basmah. Basmah is a mother of three children, including 13-year-old, Bodor. Basmah was born and educated in the US. However, her husband was born and educated in the Arab world. Basmah got married and gave birth to her children in the US. Her daughter, Bodor, was diagnosed with ASD by neurologists when she was four years old. In addition to ASD, Bodor has a diagnosis with Rett Syndrome. Bodor has received special education and related services

since she was diagnosed with ASD through the present day.

Reema. Reema is a mother of two children, including 11-year-old, Rami. Reema was born and received part of her education in the US, but also spent some of her youth in the Arab country of her ancestors. Her husband was born and educated in the Arab world. Reema got married and gave birth to her children in the US. Her son, Rami, was diagnosed with ASD by a psychologist when he was three years old. Rami has received special education and related services since he was diagnosed with ASD through the present day.

Summary of Participants

All five participating mothers identified themselves as Arab. They were all Muslims, married and had children, with one child who was diagnosed with ASD. Their ages ranged from 30 to 45 years old. They had education levels that ranged from high school to graduate degree. Three of these parents were employed, and the other two were unemployed. These parents shared their individual experiences with their children's diagnosis of ASD and special education process. Each parent had her own unique experiences in accepting and understanding her child's autism and seeking special education and related services. The next section describes the interviews with these parents and the data collection procedure.

Data Collection

The collection of data is the heart of the research project (Gall et al., 2007). In this study, interviews were the primary source of data. I used one-on-one and semi-structured interviews to solicit responses that provided meaningful information. One-on-one interviews are the most traditional form of interview, which is a face-to-face meeting and communication between two persons, in which one person extracts information from another (Merriam, 1998). Semi-structured interviews are also a common form of interview in qualitative research (Brinkman &

Kvale, 2015). It involves preparing a list of questions or topics to be covered, while staying open to change the words, forms, and sequence of the questions based on the participants' answers (Brinkman & Kvale, 2015; Rubin & Rubin, 2011). It also involves asking different probing questions based on the participants' responses to obtain additional information (Gall et al., 2007).

The interview questions were prepared in two languages, Arabic and English (see Appendix C & D); however, all interviews were conducted in English in accordance with each participant's preference. Each participant was interviewed three times. The interviews took place in different locations. Four of the parents chose to be interviewed in any public location. Thus, I suggested meeting at the university library because of two reasons: first, the library was close to all parents' homes. Second, I have a small office in the library that is private and quiet, which is a perfect place for interviews. Three of the parents agreed to meet in the library, while the fourth parent preferred to meet in a coffee shop. At the library, we sat in my office, which provided privacy, and allowed parents to speak freely. At the coffee shop, we always sat in a corner table, seeking some privacy, and the noise level was moderate in all the three interviews. The fifth parent invited me to her home for her interviews. We sat in a quiet and spacious living room. In the first interview, her daughter with autism sat with us quietly during the entire interview time, while in the second interview, she only sat for about ten minutes before she went to her room.

In the first interview with each parent, except for the interview done in the coffee shop, I brought Arabic coffee and dates, which are considered symbols of hospitality in Arab culture. In addition, at the beginning of the first interview with each parent, I spent a few minutes establishing rapport with them. I engaged in open conversation to help them get to know me. Establishing rapport between interviewer and interviewee enhances the quality of the interaction and the credibility of the research, because "People will talk more willingly about personal or

sensitive issues once they know you" (Glesne, 2011, p. 144). A few minutes later, I showed them the informed consent form, which I had described to them by email. I read it, and I walked them through each section to ensure their understanding. I asked if they had any questions or needed more time before signing it. However, all five participants were interested in participating and agreed to sign the informed consent immediately. Each parent signed two copies of the form: one for the parents to keep and one for my records.

Before beginning the actual first interviews, I asked each parent demographic questions, which served to gather background information about their family status, socioeconomic status, education level, and language abilities (see Appendix E). These questions were asked in a conversational way, not as interview questions. Then, I showed the parents the two recorders that I would use to record the interviews, and explained the reason for using the second recorder as a backup. When I confirmed with each parent that she was comfortable being recorded, I started the actual interviews. I started with questions couched ahead of time, and stayed open to add and reform them during the interview (see Appendix C). This format allowed me to follow up with the situation at hand, incorporate new insights on the topic, and respond to the stories told by participants (Brinkman & Kvale, 2015). It is also a flexible and responsive method to individual differences, and allowed me create personalized questions to deepen communication with the participant being interviewed (Patton, 2015).

In addition, open-ended questions were employed to let participants take whatever direction they chose, use their own words to share their experiences, give long, elaborate answers, and propose topics and concerns that were imperative to them (Brinkmann, 2014; Patton, 2015; Rubin & Rubin, 2011). Asking open-ended questions can diminish the imposition of pre-established answers and yield in-depth responses about the participants' perceptions,

51

feelings, experiences, and knowledge (Patton, 2015). These questions allowed participants to express their beliefs and concerns unconditionally, and allowed the conversation to stream where it desired to understand their meaning of disability.

During the interviews, I was attentive to ensuring I conducted the interviews in a way that promoted the participants' dignity. According to Hicks (2011) "Honoring peoples' dignity is the easiest and fastest way to bring out the best in them" (p. 67). This involved respectful and nonjudgmental listening, seeking understanding, and valuing the participants' experiences and stories (Hicks, 2011; Locke, Spirduso, & Silverman, 2014; Seidman, 2013). In addition, to show appreciation for their time, each parent received a gift card after completing each interview, except for two parents, who refused to take the gift cards. They mentioned that I could give them to poor people as "*Sadaqah*." The concept "*Sadaqah*" means "*charity*", which is voluntary giving in Islam.

After completing each interview, I transcribed the interview immediately, and listened to the recordings two times with the transcription in front of me to confirm the accuracy of my transcription. Afterward, I changed any identifiable information to pseudonyms, and marked the words said in Arabic between quotation marks. Additionally, I made an entry in my reflective journal after each interview. I included information about my personal thoughts and reactions, the interview setting, interaction and communication style, and noted any other significant information that I could remember. Then, when I transcribed all interviews, I emailed each parent her interview's transcripts, as part of the validity criteria to ensure credibility. I asked each participant to feel free to add and share more information, and/or omit any information that they may decide not to keep. All parent participants confirmed the accuracy of the transcriptions without omitting any information. Only one parent added more information about how Arab

52

culture might discourage some Arab parents from seeking help as early as possible.

In addition, during the interviews, one of the parents asked me to provide her with information about local parent support groups. Another parent also asked for more information regarding the process of college entrance and accommodations for her daughter. Therefore, when I emailed the parents their interview transcripts, I provided each parent with the information she asked for. After completing all the interviews, transcriptions, and confirming the accuracy of the transcriptions with the participants, I organized and managed my data, and started data analysis, which is discussed next.

Data management. As the interviews were the primary source of data in this study, I audio recorded all the interviews for later analysis with the participants' permission. Then, I transcribed the interviews. I organized the information generated from the interviews and made it accessible by labeling audio-recorded files, consent forms, and interview transcriptions files accurately and maintaining a duplicate copy of every file. I stored consent forms separately from the interview transcripts, and kept all files in a secure place. I stored all documents containing identifying information (the consent forms and the hard copy of the interview transcripts) in a secured file cabinet at all times when not in active use, in my office, with access restricted to me only. I stored all electronic data containing identifying information (the electronic copy of the interview transcripts and the digital audio record of the interviews) on my personal laptop, in password-protected files with access restricted to me only.

Data Analysis

The data in this study was obtained through in-depth semi-structured interview questions and analyzed thematically. Thematic analysis offers an accessible, flexible, and useful research tool to analyzing qualitative data (Braun & Clarke, 2006). It is an interpretive process, in which

the researcher thoroughly searches the data to identify patterns that provide an enlightening description of the phenomenon (Smith & Firth, 2011). Thematic analysis is described by Guest, MacQueen, and Namey (2012) as, "identifying and describing both implicit and explicit ideas within the data, that is, themes. Codes are then typically developed to represent the identified themes and applied or linked to raw data" (p.10).

Thematic analysis emphasizes identifying common themes within data. Themes that are important to the description of the investigated topic and are associated to research questions. Braun and Clarke (2006) summarize the advantages of thematic analysis, which include flexibility, an easy and quick method to learn and do, generating unanticipated insights, usefulness in producing qualitative analyses suited to informing policy development, usefulness in summarizing key features of a large body of data, and offering a thick description of the data set. In addition, thematic analysis can provide a wealthy, detailed, and sophisticated account of data. It can be used within different theoretical frameworks, and not necessarily associated to any pre-existing theoretical framework (Braun & Clarke, 2006).

Interpretive researchers avoid "imposing externally defined categories on a phenomenon" (Orlikowski & Baroudi, 1991, p. 14). Therefore, as I approached this study from an interpretative perspective, I used an inductive, or "bottom up," approach to analyze my data. *Inductive analysis* means to "use detailed readings of raw data to derive concepts, themes, or a model through interpretations made from the raw data by an evaluator or researcher" (Thomas, 2006, p. 238). An inductive approach means that the identified themes should be firmly associated to the data themselves (Patton, 2015). This form of thematic analysis is not theory-driven; rather, it is data-driven. With this said, inductive analysis is a process of coding the data with no intent to fit it into a pre-existing theoretical framework, coding frame, or the researcher's analytic

presumptions. The findings are directly developed from the analysis of the raw data, not from previous models or expectations (Thomas, 2006).

Numerous researchers noted that using inductive analysis is common in qualitative analysis, and less complex than using other qualitative data analysis approaches (Punch, 2014; Riessman, 1993; Thomas, 2006). The purposes of using an inductive analysis approach are to summarize raw data into a concise format, form clear connections between the research purposes and the findings obtained from the raw data, and "develop a framework of the underlying structure of experiences or processes that are evident in the raw data" (Thomas, 2006, p. 237). I chose this particular approach because it did not constrict and limit my analytic vision, as would a theoretical or deductive approach. Adopting a deductive approach involves engagement with the prior literature, which would result in focusing the analysis on certain parts of the data at the expense of other possibly critical parts (Braun & Clarke, 2006). Additionally, an inductive analysis can generate valid and reliable findings. According to Thomas (2006), the findings derived from inductive analysis can be equally evaluated by using techniques that are used with other qualitative methods (i.e. Lincoln & Guba, 1985).

For this study, I adopted the suggested thematic analysis phases outlined by Braun and Clarke (2006). Phase one started by transcribing all the interviews. The interviewer is the best person who can transcribe the interview as Ives (1995) indicates, "the ideal person to transcribe an interview is you, the interviewer" (p. 75). The process of transcription allowed me to start familiarizing myself with the data (Riessman, 1993), and provided some former knowledge of the data, which lead to the development of some initial thoughts and analytic interests (Braun & Clarke, 2006). I transcribed all interviews verbatim, which involved including full and accurate information without omitting any features of the informant's speech, such as pitch and stress.

55

According to Maxwell (1992), omitting such features of speech could threaten the validity of the research, as these might be vital to the understanding of the interview. After transcribing all the interviews, I familiarized myself with the data. This involved multiple readings and interpretations of the raw data through continuously reading back and forth between the whole data set. During reading, I jotted down ideas and potential codes.

Phase two of the analysis started when I initially generated a list of ideas about the data. I then started to identify initial codes. The coding process involved "aggregation of the text or visual data into small categories of information, seeking evidence for the code from" the data, and then labeling the code (Creswell, 2013, p. 184). I used a combination of coding techniques: "In Vivo Coding" and "Descriptive Coding" (Saldaña, 2016). *In Vivo Coding* refers to "a word or short phrase from the actual language found in the qualitative data record" and produced by the participants (Saldaña, 2016, p. 105). *Descriptive Coding* involved summarizing the basic topic of a passage of data in a word or short phrase (Saldaña, 2016).

I chose these coding techniques because they work with all qualitative studies and are appropriate to beginning qualitative researchers. In particular, In Vivo Coding is useful in honoring the voices of often marginalized groups (Saldaña, 2016). As the participants in this study represent a minority racial group, whose voice is absent in special education literature, this coding technique used their actual words and phrases to capture the meanings in their experiences (Stringer, 2014) and to honor their voices. I coded the entire data set. I performed the coding manually, without using software. I wrote notes on the printed texts (transcriptions) by using colored pens to imply possible codes. When I had all my data coded, I organized codes in computer files. Then I linked each code with data excerpts that demonstrated that code by copying excerpts of data from transcripts and pasting them under each code in the computer files.

Phase three began when I had all my data coded. This phase involved re-emphasizing the

analysis at the broader level by organizing the developed codes and the relevant coded data

excerpts into potential themes. During this process, the researcher can code individual excerpts

of data into several different themes because, at this stage, the researcher never knows what

themes might be interesting later (Braun & Clarke, 2006). Due to the flexibility of thematic

analysis, researchers can determine themes in different ways; hence, researcher judgment is

crucial to decide what a theme is. A theme is not necessarily based on quantifiable measures;

rather, it draws important ideas about the data in relation to the research questions (Braun &

Clarke, 2006).

Ryan and Bernard (2003) suggest several scrutiny and processing techniques for

identifying themes, including repetitions, indigenous typologies or categories, metaphors and

analogies, transitions, similarities and differences, linguistic connectors, missing data, theory-

related material, cutting and sorting, word lists, word co-occurrence, and metacoding. Among

these techniques, I used repetitions to identify my themes. The repetitions technique refers to the

ideas, concepts, or topics that occur repeatedly in the data texts. The more the same concept

appears in the data, the more likely it is a theme (Ryan & Bernard, 2003). This phase ended with

the identification of themes, sub-themes, and all data excerpts that coded in relation to them.

Phase four began when I identified all my themes. This phase involved reviewing and

refining the developed themes to determine if they were relevant to, and provided accurate

representation of, the data. This involved discarding themes, creating new themes, breaking

themes down into separate themes, and combining two themes into each other. This phase

included two levels. Level one involved checking the themes in relation to the coded excerpts by

reviewing all the excerpts for each theme and determining if they represented a consistent pattern

or not (Braun & Clarke, 2006). Level two involved reviewing themes in relation to the entire data set and determining if they reflected "the meanings evident in the data set as a whole" (Braun & Clarke, 2006, p. 91). This phase ended by having a clear idea of what my themes were, how they acted together, and what general story they implied about the data.

Phase five began when I developed adequate themes from my data. At this stage, I determined and wrote about the core of the story, and the aspects of the data captured by, each theme. Braun and Clarke note "It is important not to try and get a theme to do too much, or to be too diverse and complex" (2006, p. 92). Thus, I was cautious that the developed themes were simple and clearly represented the data. In addition, at this phase, I assigned clear names and definitions for each theme. Naming themes can come from different sources, such as the researcher, the participants, or literature (Merriam, 1998). Themes are not the data itself; rather they are concepts indicated by the data. Themes are abstract constructs that connect expressions in texts (Ryan & Bernard, 2003). In this study, the developed themes were derived from data and generated based on common responses that participants gave to the interview questions. At the end of this phase, it is important to confirm that themes do not have too much overlap. Moreover, since not all themes are equally important, I decided what the salient themes were, how the themes related to each other, and how they related to the research questions (Braun & Clarke, 2006).

The final phase, or phase six, of thematic analysis was writing up the report. This phase began when I had a final and satisfactory set of themes. At this phase, I wrote the final analysis and report. I considered the audience for whom the study is targeted (Merriam, 1998). I provided a detailed analysis for each theme, supported by excerpts from the data to validate the prevalence of each theme. In this analysis, I provided interpretation and examination of the data and went

beyond the description. In addition, I was eager to strike a good balance between the reprehensive excerpts and the analytic narrative, consistency between the analysis and the data, and ensuring the excerpts exemplified the analytic claims. Overall, I was intent that my analysis "tells a convincing and well-organized story about the data and topic", and provides answers to the research questions (Braun & Clarke, 2006, p. 96).

Lastly, it is important to check the validity of the final list of the developed themes and the interpretation of the data. Some scholars consider researcher judgments as one way to check theme validity as he/she makes the judgments clear and explicit (Ryan & Bernard, 2003). In certain cases, some scholars recommend that the study participants review, comment, and confirm the accuracy of themes/analysis (Lincoln & Guba 1985; Patton 2015). Others refer to the collective judgments of the scientific or research community as a strategy to check the validity of the analysis (Bernard, 2011; Patton, 2015). In this study, I engaged in peer debriefing after analyzing my data to check the validity of the final list of the developed themes. Detailed information in this technique is discussed next in validity criteria section.

Validity Criteria

Regardless of the research method, all researchers seek to produce valid and reliable research findings and knowledge. In qualitative research, to ensure validity, the researcher should conduct the study in an ethical manner (Merriam, 1998). Maxwell defined validity as, "The correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account" (2013, p. 122). In this study, credibility, transferability, and confirmability (Lincoln & Guba, 1985) were established as validity criteria to ensure the rigor of my research.

Credibility refers to the extent to which the findings of a study are authoritative, believable, and "accurately represented what the participants think, feel, and do and the process

59

that influence their thoughts, feelings, and actions" (Lodico, Spaulding, & Voegtle, 2010, p. 169). Credibility in qualitative research can be established by using several strategies, including data triangulation, methodology triangulation, investigator triangulation, theory triangulation, disconfirming evidence, researcher reflexivity, member checks, collaborative work, peer debriefing or scrutiny, examination of previous research findings, and prolonged field engagement (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005; Creswell, 2013; Gall et al., 2007; Merriam, 1998; Miles, Huberman, & Saldaña, 2014; Lincoln & Guba, 1985; Patton, 2015; Shenton, 2004). In this study, credibility is accomplished by establishing the following techniques:

- Member checks: this involves having the participants review and confirm the accuracy or inaccuracy of the interview transcriptions. Prior to the analysis and interpretations of the data, I emailed each participant her interview transcriptions and asked them to review, comment, and confirm the accuracy of transcriptions. All participants confirmed the accuracy of transcriptions without any changes. Only one parent added more information about how Arab culture might discourage some Arab parents from seeking help as early as possible.
- Peer debriefing: this involves having colleagues, peers, professionals, or someone familiar with the phenomena being studied review the research project, comment, and provide feedback. In this study, after finalizing the coding process and identifying major themes, I engaged in peer debriefing with my major professor. This included reviewing and evaluating the accuracy of the findings, interpretations, and conclusions, and determining whether or not they were supported by the data.

- Researcher's reflexivity: this involves researchers self-disclosing their biases, assumptions, values, and theoretical orientations that influenced the research process. I kept a researcher reflective journal while conducting this study, where I clarified how my expectations, beliefs, and experiences come into play in the research process. Excerpts from my reflective journal are provided later, in Chapter Five.

Further, although the purpose of qualitative research is to develop a deep understanding of the phenomena under the study, rather than generalize the findings to different contexts, transferability is considered one common validity criteria in qualitative research (Lincoln & Guba, 1985). *Transferability* refers to the extent to which the findings of a study can be applicable or transferrable to other contexts or settings (Ravitch, & Carl, 2016). Providing thick and detailed descriptions of the study, typical or model category comparison, and using multisite designs can enhance the transferability of qualitative research (Brantlinger et al., 2005; Creswell, 2013; Merriam, 1998; Miles et al., 2014; Lincoln & Guba, 1985; Patton, 2015; Shenton, 2004). In this study, I provided a rich, thick, and detailed description of this study to allow the readers to understand, evaluate, and compare the phenomena in this study with those that they investigate in their research. This involved providing sufficient and thick detailed account of field experience, a detailed description of the phenomenon being studied and the implications of the study, and reporting appropriate quotes and field note descriptions.

Finally, complete objectivity is nonsensical in much qualitative research, as the researcher is considered the research instrument, and the researcher's biases are expected (Patton, 2015). The issue of researcher bias in qualitative research is still debated in methodology texts, whether or not that the researcher influence needs to be controlled, or if it can be accounted for (Ortlipp, 2008). Interpretivists considered it impossible to eliminate researcher bias; rather, it

61

is the researcher's responsibility to explicitly clarify their assumptions and the relationships in which research was conducted (Kloos et al., 2012). Miles et al. (2014) consider researcher recognition of his/her own predispositions as vital criterion for confirmability.

Confirmability in qualitative research can be established by developing an audit trail, a researcher reflective journal, a confirmability audit or external audit, and triangulation (Brantlinger et al., 2005; Creswell, 2013; Merriam, 1998; Miles et al., 2014; Lincoln & Guba, 1985; Patton, 2015; Shenton, 2004). Since I approached this study from an interpretative perspective, I clarified my role within the construct of research knowledge to ensure confirmability. I tried to identify the perceptions that may influence my interpretations of the data, and declare what has been highlighted, downplayed, and overlooked in the research. This is "not in order to suspend subjectivity, but to use the researcher's [my] personal interpretive framework consciously as the basis for developing new understandings" (Levy, 2003, 94).

Ethical Considerations

Ethical challenges arise in qualitative research, especially with the human subjects. It is even more critical with the use of technology, which has disadvantages as well as benefits (Glesne, 2011). Ethical dilemmas can emerge at every step of the research process. Acting ethically as a practical researcher involves some kind of struggle, as it challenging to identify all situations that may involve an ethical concern (Seidman, 2013). According to Merriam (1998), in qualitative research, ethical issues are most likely to arise during data collection and dissemination of findings. Several qualitative researchers attempt to develop ethical standards, codes, or guidelines. While researchers might be informed by ethical guidelines, eventually, the researcher's own integrity and conscience enlightens the decision (Merriam, 1998). All researchers have a responsibility to acknowledge the potential harm to participants and education

profession that results from producing inaccurate knowledge out of ethical misconduct (Gall et al., 2007).

In this study, I adopted Creswell's (2013) ethical guide to outline and organize my ethical considerations throughout the research process. This started prior to conducting the study, by reading the IRB guide of my university and consulting ethical standards with my major professor. Then, I sought university approval by submitting my proposal for the IRB (Creswell, 2013). After obtaining the IRB approval, I started conducting the study. At the beginning of the study, I obtained an informed consent from each participant. Informed consent is one of the research ethical priorities. It preserves the rights of both parties. Informed consent confirms the participants' willingness to participate in the research study. Participation in this study was voluntary. The informed consent form included sufficient information about the research process, to ensure the participants' full understanding of the topic and what they were involved in. This included providing information on the purpose of the study, how the data would be used, the procedure used to ensure the participants' privacy and protect their anonymity, and that participation was voluntary and they had the right to withdraw from the study at any time (Creswell, 2013; Gall et al., 2007; Locke et al., 2014).

I went over the informed consent form with my participants to ensure their understanding and that they took it seriously (Seidman, 2013). I also included my contact information to allow participants to ask questions in regards to the study. In addition, scholars suggested that informed consent forms in cross-cultural research should be written simply, and in the participants' first language if preferred (Liamputtong, 2008). Therefore, the informed consent form was written in two languages, Arabic and English (see Appendix F & G). I used the English version in

accordance with each participant's preference. When participants signed the form, I provided

them with a copy and kept a second copy with me.

According to Merriam (1998), interviewing brings with it benefits and risks to the

participants. Since interviews were the primary source of data in this study, during the data

collection I considered the following: (a) conducting the interview in the preferred language of

each participant; hence, I prepared the interview questions in two languages, Arabic and English

(see Appendix C & D); (b) examining culture, religion, and privacy when forming the questions

and choosing the terminologies; (c) asking questions explicitly and in a culturally appropriate

manner and avoided asking culturally sensitive questions (Liamputtong, 2008); (d) asking

participants for permission to explore sensitive topics (Seidman, 2013); (e) considering the

interviewee right to reject the response to any question (Merriam, 1998); (f) selecting an

appropriate location, time, and length that fit both parties' schedules (Glesne, 2011); (g)

obtaining the participants' permission to audio record their interviews by signing the consent

form; and (h) keeping all recorded interviews on my personal laptop, in password-protected files

with access restricted to me only.

In addition, I conducted the interviews in a way that preserved the participants' dignity.

According to Hicks (2011) "Honoring peoples' dignity is the easiest and fastest way to bring out

the best in them" (p. 67). This involved respectful and nonjudgmental listening, seeking

understanding, and valuing the participants' experiences and stories (Hicks, 2011; Locke et al.,

2014; Seidman, 2013). Moreover, as the researchers benefit from their work with participants, it

is morally appropriate to ask themselves what they are giving back to the participants? In this

study, at the end of the each interview, I provided each participant with a gift card to show

appreciation (Creswell, 2013). Further, since English is my second language, when transcribing

the interviews, I considered the accuracy of transcription by listening carefully and several times to my recorded interviews to transcribe full and accurate information. I also had each participant check and confirm the accuracy of the transcripts. I was planning to have other scholars, who speak both languages (Arabic and English), review the accuracy of my translation if the interview was conducted in Arabic. However, all interviews were conducted in English in accordance with each participant's preference.

Finally, analyzing data and reporting findings may present ethical concerns. Therefore, I respected the participants' rights to confidentiality and protected their privacy by ensuring anonymity, preventing linking participant responses to their identities, avoiding collecting or disseminating data without the participants' knowledge, and ensuring that disclosed information would not harm the dignity, privacy, or safety of the participants. Additionally, I reported multiple perspectives and contrary findings, reported honestly (i.e. no plagiarism, falsifying data, evidence, or findings), and used appropriate language for the research audience (Creswell, 2013; Gall et al., 2007; Locke et al., 2014; Merriam, 1998).

Chapter Four

Findings

In this study, five Arab American parents of children with ASD were recruited. Through in-depth, semi-structured interviews, these parents were able to share their individual experiences with their children's diagnosis of ASD and special education processes. The findings of this qualitative interview study are presented in this chapter after analyzing the data obtained from the interviews. Data analysis revealed that responses clustered around particular themes. These themes were generated based on common responses that parents gave to the interview questions. After finalizing the coding process and peer debriefing the identified themes, six major themes, some with sub-themes emerged from the data. These themes and their connected sub-themes are described and outlined in this chapter and supported by excerpts from the interview transcripts.

Theme One: Parents' Journeys Toward the Acceptance of the Diagnosis of ASD

An essential part of this study aimed to explore how Arab American parents of children with ASD understand their child's diagnosis of ASD, and how their understanding affected their reactions and help-seeking behaviors. Parents were asked to describe and reflect on their initial concerns about their child's development and their initial experience and reaction when receiving the ASD diagnosis. Parents' responses revealed several critical experiences. All parents passed through a gradual process, starting from the day they began to feel concerned about their child's development until the day they accepted their child's diagnosis of ASD. I arranged these

experiences into the following sub-themes: period of uncertainty, ASD diagnosis, now what?, understanding, and acceptance.

Period of uncertainty. This period is called uncertainty because parents did not know what the reason was behind their child's atypical development, and they did not gain any support to allay their concerns, whether from other family members or doctors. Thus, parents were floating in a sea of mystery and contradiction. They did not know who to believe! Themselves? Or others around them? Prior to the autism diagnosis, all parents went through a confusion stage, where they noticed something atypical about their child's development. Some parents noticed these differences from the very beginning, while other parents experienced a period of typical development followed by regression or changes in their child's development. All parents described their initial concerns using phrases like: "something not normal," "something not right," "something wrong," and "she/he was delayed." Some parents made frequent comparisons between their typically developing children and their child who was later diagnosed with ASD. They noted differences, which supported their initial concerns. All parents were certainly aware of changes and differences in their child's development. Parents described the initial signs and symptoms they noticed as poor eye contact, communication difficulties, delayed in language development, not responding to their names being called, non-compliance, delays in gross and fine motor skills, poor emotional regulation, and reduced interest in people and social interactions.

For parents whose children experienced a period of typical development followed by regression, the change in their child's development was extremely difficult to understand and it affected them mentally and emotionally.

Marwa: I feel like every time you question yourself what happened to you? What

67

happened you were completely fine, you were talking, you were eating, you were happy

and out of nowhere he starts to get attached to one toy, which is the cars, and he does not

play properly. He start banging, he start screaming, and start flapping. I am like this is not

my son.

Abeer: I was looking at her, this is not the girl that used to be, she is totally changed, the

way that she was plying with things…. she was smart she was talking with us and that

was a big shocked to me.

Some parents recalled noticing a regression and shift in their child's development,

including poor eye contact, reduced interest in social interactions, and regression in language

acquisition.

Abeer: "she used to talk, she used to play, socialize interacting with us, and she stopped doing all

these things."

Marwa: He was doing absolutely fine. He was having few words, one sentence out of two

words. He was very alert to everything, but out of nowhere he stopped talking, and he

stopped responding to his name, and he stopped following orders. Even the very simple

orders, he was not responding. He did not understand. He was not even looking at me.

At this stage, mothers were not encouraged by their husbands and other extended family

members to seek help regarding their concerns about their child's development. Family members

did not support the idea that there was something unusual, and they attributed the delay in

development to the child's young age. In some cases, they connected the child's delay in

communication and speech to other family members who had speech issues in their childhood.

Salma: "my sisters and my mom, my husband sometimes said no she is fine, there is nothing

wrong, she still little."

Basmah: They shun me away, be quiet, nothing is wrong with your daughter, she is good, she is a baby, she is just crying. She will talk, we all have delayed speech. The typical Arab response, my grandmother did not talk till she was five. Your aunt was the slowest one in our family, she did not talk till she was four. Wait, wait, wait. That's all the response. Nothing is wrong, we do not have that in our family. This never happened before.

Reema: My mom thought that I was crazy. No, he is just so smart, and he is still smart, then he is just a genius. And you are boring, he does not want to talk to you because you are boring. All this crazy stuff.

Continuously, parents heard the phrase, "she/he is fine," from doctors when they initially spoke to them regarding their concerns, which made parents more confused about their child's situation. Parents attributed the delay in correct diagnosis and, thus, the delay in providing appropriate interventions and services to help their children to the doctors' reaction of ignorance to their concerns.

Marwa: "I was noticing that he was not responding to his name, he does not responding to anyone talking to him. I went to the doctor, and she told me, he is fine."

Basmah: "Nobody encouraged me. Even her own pediatrician. She does not seem like nothing is wrong. And she was running around his office and he was like, no, she does not have anything, just a little hyper."

Salma: I kept asking something is not there. I did not like how her doctor dismissed her very quickly and just kept saying, you are over-analyzing, you are over-analyzing. To me as a pediatrician he made me feel that he always knew more than me.

ASD diagnosis, now what? The identification and diagnosis of ASD can cause a significant emotional response in parents. Each parent of a child with autism undergoes a unique journey. Although receiving the ASD diagnosis is an important event, allowing parents to initiate intervention services and support for their child, it is also a life-changing event that results in strong emotional reactions and poses unique challenges within the family. In this study, parents were asked to describe their initial experience and reaction upon receiving the diagnosis of ASD. For all parents, the diagnosis of ASD was totally surprising news. Parents reported feeling and experiencing a variety of emotions and reactions to their child's diagnosis of ASD including depression, sadness, shock, guilt, and relief. For some parents, the word "autism" was completely new, while other parents had limited information. Thus, all parents learned about their children's autism and the special education process simultaneously.

All parent participants in this study were unfamiliar with the evaluation and special education process. Some parents were also completely unaware of autism. They did not know that it existed, and they never heard about it.

Abeer: "I never heard of it…. I was surprised, what autism is? I do not know what autism word."

> Marwa: She told me have you ever heard about autism? That was my first time to hear about autism. What is this? I know that he is delayed, but what is autism? I did not even know what it means in Arabic.

Other parents possessed limited information about autism before their child's diagnosis. Even with a degree of education, the information they held about autism was narrow, somewhat inaccurate, or almost non-existent.

> Salma: I thought like the idea of autism that we have is very stereotype, you see, you google the idea of autism, or we learned about autism, even when I was doing my

70

education degree, it was always about kids who are non-verbal, who are very severe, not potty trained.

Reema: I thought autism was negative, and people used to use the word retard a lot. And if you look up the definition of retard, it means when something stops working. So I thought that it was going to be lifelong.... you know, it is a lifelong struggle, but I thought it was going to be a negative and a downhill battle.

Basmah: It was not very big in our community. We did not know too much about it…. Even with my degree in psychology. Nobody ever mentioned it. Even with my degree in early childhood education, a separate degree, nobody ever mentioned it.

The lack of parents' knowledge about autism contributed to their struggle with the understanding and acceptance of their children's diagnosis. All parents described their initial emotional and intellectual reactions to their children's diagnosis of ASD. Some parents reported feelings of depression, sickness, and sadness.

Abeer: "My life totally changed. I had severe depression, I was very sick, and I was not like the same what I used to be, what I used to do, I became very sick."

Basmah: "I cried a lot. I was emotional. I was really sad."

Reema: Sadness, grief. I was grieving what I had expected him to be. Disbelief. I kept saying, he will grow out of it, he will get better. It will go away; maybe this is not really what it is, even though I knew it was. I was like, well, maybe, maybe not.

Some parents reported feelings of guilt about misunderstanding their children behaviors before the diagnosis. Other parents blamed themselves for their child's autism. Having too many children and being busy with other children in the family were factors that contributed to their feelings of guilt and self-blame.

71

Abeer: They made me feel guilty they said because, I have six children I had them all in

five years, because it was C-section, they told that it could be multiple C-sections....

Because I was busy with other kids…. So I felt guilty, because I thought I was the one

who cause this to her.

Marwa: At the beginning, I used to cry and cry day and night, day and night…. I was so

angry at myself. I used to blame myself for what happened? What did I eat when I was

pregnant with him so he can be like that? …. Then after you got busy with the three

oldest kids with the studying and the homework and school and activity.

Salma: "But when I heard this is the diagnosis, in my heart I was like oh my God is not that she

is want to, she did not do it purposely. It just the guilt I felt."

Only one parent described her initial reaction to her child's diagnosis of ASD as a

"relief." She felt a sense of relief because she finally realized what her child's specific concern

was, so she could help and support her child better.

Salma: "My heart had very sense of relief. I felt like now that I know what it is, I can now zone

it and help her better."

Once a child receives an ASD diagnosis, one of the most difficult stages in parents' lives

is facing the ambiguity of the diagnosis. For many parents, and due to the lack of overall

awareness about autism, parents struggled with wanting a clearer understanding and answers to

many questions about autism and how autism will affect their child. Parents frequently

mentioned that their lack of knowledge about autism, combined with vague information provided

at the time of diagnosis, made them feel uncertainty about what the diagnosis meant, uncertainty

about the causes, and an overall feeling of unpreparedness about how to move forward.

Basmah: "The first thing everybody always says is we do not know what caused this…. We are

not sure what caused this. It may or may not get better but that is what it is."

Abeer: What is the cure? Finding the cure, how to help her? Was any body ever gets cured of autism? Nobody was giving the answer, nobody even the doctors; they said there is no cure…. It was like a mysterious disease, nobody knows what caused it; nobody knows how to cure it…. And that was the really frustrating thing. This is way I got sick, because how? Because you know in our culture we believe every disease has a cure. So they telling me something against my religion, against my belief.

Finally, some parents referred to the social stigma associated with any diagnosis of disability in Arab culture can cause a parent to take a stance of denial or keep the diagnosis secret from others.

Reema: I struggled with that a lot [with the stigma]. I did not want anyone to know that my son had autism. I did not want anyone to think that there was anything wrong with him, because I was just taught that this is not normal, and this is not something that people discuss in our culture. So I did not actually tell anybody outside of my immediate family until he was 8 years old.

Salma: My mom goes to me, this is all from Allah [God], but just keep it to yourself. That's what she said to me. I looked at her and I was like, mom, why do I need to keep it to myself. She was like, nobody needs to know that she has something going on.

Basmah: At first it was denial. It is almost like stages of grief. They are going in denial at first. And then now they are accepting but they are still stuck in that accepting phase. They are not moving on. They are not moving on to let's support her.

Understanding. When parents reach the stage of understanding and start confronting their initial feelings to the diagnosis of ASD, they are able to better help their child. As the parent

73

understands more about the diagnosis, the benefit for the child increases, as understanding often leads to early intervention. In this study, parents were asked questions about their understanding of autism and how it had changed from before and after the diagnosis. Parents were also asked to reflect on useful techniques and sources that assisted them to understand the diagnosis of autism. Parents' responses reflected their journey towards becoming informed, illustrating that their uncertainty lessened when they received more information. Parents shared that they developed a better understanding and connection with their children through interacting with experienced service providers, searching and reading on the subject, and connecting with other families who have gone through similar experiences. Their desire to help and support their child fueled an internal drive to educate themselves and find answers. In doing so, they are fulfilling their parental role to find any means possible to help their child, which they know is an effort that will last their child's entire life. This is done to ensure that they and their family can be happier and find fulfillment in their lives.

The ambiguity surrounding an autism diagnosis causes parents to seek the answers to questions about the autism diagnosis, the possible causes of the disorder, and available treatment and intervention options, in addition to what their child's future will hold. Some parents begin to seek out this information as soon as the diagnosis is given. When doctors or other service providers fell short of an explanation, parents sought out explanations to relieve their uncertainty about the causes for the differences in their child's behavior and quality of life.

Abeer: I figured it out that sadness and depression will do not do anything to help my child…. the lack of information was the most challenging thing, which was I did not know what to do, and I need some one to explain to me what was autism, so I started reading, we started asking people with children with autism…. I was seeking information

from people with the same condition same situation, and other sources.

Marwa: Honestly no one explained it to me. When I heard the word autism that's when I started going to the library and get books and educate myself about it…. I felt like I am in a race with time. I am not going to waste my time taking vacation. We are going to stay here, I am going to put him in a program that helps kids with autism.

Parents described the sources they sought out to find information about ASD. Parents usually worked with a multidisciplinary team of service providers, who they credited with giving them useful information about ASD, and supplying them with techniques they could use at home with their child. Parents also searched for information on the Internet, through reading books, and talking to other families with related experiences.

Basmah: " I was reading and researching and reading and researching. Mostly fellow autistic parents and children, I read research papers a lot too, and research studies and research with medicine."

Salma: It is like my own research I do online, and any books that can I have that I looked to."

Marwa: All my sources were the books. I used to read a lot…. I got advice from them [service providers]. I used to attend the therapy sessions with him. They have camera access so I used to watch him. I used to learn and do what they were doing. That was my sources, the cameras, attending the therapy sessions with him and the books.

Reema: The Internet of course. I connected a lot with... when they connected me with outside services. I was a member of... and then now I am a member of the one here at the... I read a lot of books about autism, I have probably read every single one.

Acceptance. All parent participants described the process toward accepting their child's ASD diagnosis, which was a stage that allowed them to more successfully provide support and

care for their special needs child. For most parents, the acceptance stage took place gradually. They described the acceptance stage as viewing and accepting the symptoms that are unique to an autism diagnosis, which included behaviors that their child exhibited that were atypical and accepting that autism is a condition their child would live with their entire life. Another part of the acceptance stage was understanding that their role as a parent was changing, and they would have to adapt to their child's set of needs to enhance their family life.

> Marwa: This is a lifetime things. We have to accept it…. I think it is, in addition to that, at least we have our son at home with us. He is not in a hospital…. That's what I told my husband because he told me, my son is fine. Your son, he is fine, but he is different. Accept it. He is fine, he will be fine. He is different. He needs a lot of work, he needs efforts, he needs directions all the time.

> Basmah: More recently because we are at a point that we have overcome it, we do not care anymore. If we want to go out to eat, we are gonna go out to eat and we are just gonna have to deal with it.

Abeer: "just a God thing. We have to be strong for our children, and we have to strengthen our belief that our children will get better."

Parents also pointed out that one of the first aids that helped them accept their child's autism was a belief that their child's autism is the will of God. Parents cited from the Quran that God chose them because they are qualified and capable of caring for a child with special needs. Parents believed that having a child with autism is a test from God, and they must pass this test. Some parents felt having and caring for a child with autism is their path to heaven after life.

> Marwa: the first thing that helped me was the acceptance of the destiny. The acceptance of what is going on. Just accept it and deal with it. It is the faith. Dealing with it as if it is

76

a test from God and from Allah [God] and we have to accept it…. I mean it is Ebtla'a

[Trials]. Seriously it is a test from God. When you decide okay you are going to study

hard for this test and you have to pass it you will do it…. I have to accept it, maybe by

the end in the after life God will not gonna judge him. He is gonna go to heaven right

away and he is gonna take me with him.

Salma: So I want to say that I feel like Allah [God] put me in special position and I am

hoping that I am completing this task in the right way…. I felt happy to know that there

was something there and that God is testing me, because he only tests those who can

handle things. That's how in our religion we see things in the Islamic religion.

Abeer: "We have to have deep believe in Allah [God] to guide us to the right path…. it God

things, we are a Muslim family…. and it is a God things we have to accept it Alhamdulillah

[thanks to God]."

Of the acceptance stages, some parents felt it was a blessing to have a child with autism,

as well. Some parents shared stories about things in their lives that got better because God

rewarded them for their care of a child with autism.

Marwa: "Now I am realizing there is nothing wrong, he is just different. For me I think I am

blessed to have him. I know I am blessed to have him."

Abeer: she is the blessing of the house. We kicked out the house because they raise up the

rent, and we have 24 hours evacuating note. So my husband call a lawyer, and went to the

judge and he said I have a child with autism. Seriously that was the only problem how we

are gonna find a house with 24 hours. He said like I have a child with autism and

changing routine in her life all the sudden you know how that affect child with autism?

And the judge was so mean and he said: it is your problem you deal with it and you have

to leave the house in 24 hours. So my husband went to the mosque and he was so sad. He told the priest I am having a problem with my house, we have to leave the house within 24 hours, I do not know what to do, and I am thinking about my daughter. He was like do not worry I know a friend he have houses and he can give you a house. He is like ok do not worry I will give you a key just for your daughter and your family, no contract, no nothing, no deposit, is that like Arwa blessing Sobhan Allah [Glory to God]. Just because of her every thing went easy, we loved the house, and we moved into the house within hours Alhamdulillah [thanks to God].

Finally, all parents not only reached the stage of acceptance, but also had the desire to educate other people about autism, especially in Arab community. They exposed their children's autism, they took their children everywhere, and they were willing to answer any question regarding their children's autism.

Abeer: I talked about it a lot [autism], because when I see people I explain her situation and I like to talk about it, I do not like to keep it for myself. I have to explain to people what is going on with my daughter.

Salma: I was not a person who kept it a secret. I was tell myself if God gave me a child in this way, I need to use this to help educate people. Because we have a lot of people who are in denial and sometimes when you give your personal story, it might help them to open up and realize that they need to test their child…. we have to teach not just ourselves and intermediate family but to extended. Do not hide it. Because if we hid it no one will understand that child.

Basmah: Arab friends was never understanding, more like staring, constantly asking questions, which was uncomfortable at first, but then I thought about it, we are gonna

stay uncomfortable if we do not answer their questions. Maybe that's raising awareness, answering their questions and bringing her out more often. Now I take her to Eid [Islamic holiday] in public, I do not care. You want to ask me? Ask me.

Theme Two: Beliefs About the Cause of Autism

As part of this study aims to explore how Arab culture affects parents' understanding of their children's autism, parents were asked what they believe is the cause of their children's autism. As discussed in the previous sub-theme "autism diagnosis, now what?" parents were unfamiliar with autism and the special education process. This lack of knowledge led parents to develop a variety of explanations that they believed might be the cause of autism. Some beliefs were specifically culturally based, while others were universal and not related to a particular culture. In addition, some parents held more than one belief on the cause of their children's autism.

One of the beliefs that was based on Arab culture is "*Ein*" or "*evil eye*." In Arab culture, receiving the evil eye will cause harm or misfortune. Some parents believed that their children's autism could be result of envy and "*Ein*."

>Abeer: maybe because I have too many kids people were always like envy me, like they jealous, so when I notice that what happened with her, I said like maybe because people talk a lot about us, and they were jealous look what happened…. it something has to do a lot with culture and in our religion, it could be Ein [evil eye], because as I told you I have them all in short time, now they all in the same age, some people they used to come and tell me we did not congrats you with that child and know you have another one, oh come on too many kids, and that was too much.

Reema: this is gonna sound like a typical Arab woman, my son was very, very cute

when he was a baby. People used to tell me how cute he was, and I would obsess over

him, and say how cute he was, and how perfect he was. And how I did not want the

world to ruin him, and how I was never gonna let him go to school so that people would

not ruin him.

While some parents held the belief that "*Ein*" could be the cause of their children's

autism, other parents mentioned that they do not believe that "*Ein*" could be the cause. One

parent discussed how culture can affect one's understanding of the causes of autism. She shared

her experience with her relatives when she went to visit in the Arab world. They tried to

convince her that "*Ein*" could be the cause of her child's autism. Additionally, they

misinterpreted her child's behaviors that resulted from autism and thought that her child was

possessed.

Basmah: I know a lot of people who told me it could be that Ein [evil eye]. I was just

thinking, I am very spiritual; I do not believe that at all. When I went to my country, the

first time when I took her there, she was about two and a half. You know how many,

what do you call it? When they go read Quran on her, because they think she is

possessed? I swear. I went to two different sheikhs [religious leader] to do Ruqya

[incantation] because they thought she was possessed, because they have never seen

anything like this in their life. Somebody, a small child, three years old, squirms, crying,

ripping everything in her sight and not complying. They said, she is possessed, and they

made me suffer.

The parents mentioned above reflected beliefs that were based on culture. Other beliefs of

the cause of autism shared by parents were general and can be found in different cultures. For

instance, some parents believed that vaccinations could be the cause of their child's autism. They argued that their child's development changed after receiving the vaccines. One parent specifically insisted that the MMR vaccine was the cause of her child's autism.

Abeer: it could be the vaccination that they save and preserved in mercury. Because we switch, all my children used to go to the same pediatrician, except for her we moved to a different county and it was like the clinic for every body, it was not special doctor. So I thought yes maybe that caused it.

Marwa: I believe it is the vaccine because and even his doctor, I used to take him to a doctor, an autism doctor. I told him everything, I showed him the videos of my son and he told me everything start change after the vaccine. MMR.

Only one parent held the belief that her child's autism could be caused by a genetic factor. This belief took root when her husband's nephew developed similar characteristics of her child with autism.

Salma: I honestly think it is a genetic.… genetic makeup for her…. The only reason I feel like it could be a genetic situation is my husband has a brother overseas and when they explain their son situation I heard a lot of parallels.

Other parents mentioned that environmental factors could have caused their children's autism, as well as many other children.

Basmah: could it be that just with the turn of the century and all the pesticides in food and the pollution in the environment and the world how it's changing. I feel like that's causing a lot of ADHD and autism in the world.

Reema: Environmental stressors. I believe that over the last, I do not know, 30 to 50 years, our food supply has become very disgusting, and our air supply has become

81

disgusting. The stuff that we bring into our homes, the plastic containers, and the plates, and the cups.... Everything has changed so much, that it is actually changed our DNA. And I think that's why, I do not think every case is that way, but I think that's why we have an increased number.

Theme Three: Concerns

Parenting a child with autism can be very challenging and demanding task. Parents have to find ways to cope with additional stressors, such as grief over their child's diagnosis, worrying about what the future will hold for their child, and obtaining appropriate services that will help their child in their development. One of the critical purposes of this study was to identify the concerns of Arab American parents in regards to their children with autism. Parents were asked several questions related to the challenges they encounter and the concerns they have about their children with autism. Parents' responses revealed a variety of concerns; some of which were culture-specific concerns. These concerns included their child's future, allocating time and attention across family members, and social stigmas for both being Muslims in the US and the stigma related to their child's disorder.

Future. All parent participants expressed concerns about their children's future and what the future would hold for them. Sadness and anxiety were among the emotional struggles that parents identified, particularly when contemplating their child's future. Parents' concerns were related to variety of areas, including future care for their children, cultural and religious identities, marriage, and education. Parents expressed concern about providing adequate caregiving for their children in the future at a time that they would not be able to due to sickness, age, or death. They wondered who would take care of their children, as autism causes life-long dependence on others and ongoing supervision. Additionally, children with special needs in Arab

82

culture depend on their parents, and the idea of institutionalization and social services for

individuals with disabilities is not widely accepted. Thus, parents feel apprehension about their

ability to depend on other family members to take over for them as a responsible and caring

caretaker.

Basmah: "What gonna happen if anything happens to me? What's gonna happen to her? If

something happens to me who is gonna take care of her?"

Abeer: "I always tell them if I am gone or your dad is gone who will take care of her….Who else

there for her?"

Reema: "His future. I am worried about where he is gonna end up. I do worry about his care."

Marwa: "I have concerns that I may die anytime, who's going to take care of him?"

All parents discussed how they instilled Arab culture and Islamic religion identities in

their children, including their children with autism. Thus, living in a country that is vastly

different, culturally and religiously, raised the concern about preserving Islamic values and

culture identity. Parents perceived that their children with autism's thoughts and beliefs are

subject to change more easily than their typical siblings. Some parents expressed their concerns

clearly in how their children with autism could maintain their culture and religious identities, as

well as practice religion in the future when they grow up.

Marwa: "I have concerns that is he going to be able to practice religion?"

Salma: I do not want whatever is going to be provided to her, where she loses our culture

and the religion. Because sometimes it starts to play a role. I do not want that to be the

situation because at home we instill it…. It is hard for her because things that are

considered I guess abstract. Like when you talk about heaven and hell…. it was pretty

83

scary to me because in my mind I am like, if she grows up, is she going to start double

thinking Islam? It was getting to that level. It really worried me at times.

Some parents discussed their concerns regards their children's future with regards to

marriage. Specifically, one parent was concerned about whether their child would ever marry,

and the other parent's main concern was who would marry her child and if her child's partner

would be understanding.

Marwa: "I have concerns that.... Is he going to be able to love? Is he going to be able to get

married?"

Salma: "The future definitely worries me. I keep telling my husband, we should not limit it to

who she marries. As long as he is Muslim and he practices. She needs somebody who can

understand her."

One parent expressed her concerns about her child's future in terms of education. She

spoke about her child's desire to complete her post-secondary education, but she was concerned

about the college entry process and available accommodations for her child.

Salma : my worry is also what about when she enters college…. and she has to take her

SATs and I know she needs the extra time and the accommodations. I am hoping they are

not gonna give us the run around. I need to know, does she need to get retested by then or

will they accept what she has, does that already count? Because I definitely do not want

her to be lost in anything.

Allocating time and attention across family members. All parent participants in this

study had other children living with them. Parents expressed that they felt a significant amount of

stress with having to care for more than one child and determining how to allocate their time and

energy across all family members. Parents discussed how typically developed children in the

family feel the impact of having a sibling with autism. They expressed jealousy and insecurity as they began to observe their parents dedicating more time and attention to their sibling with autism. Comparisons between the amount of time the typical children received from their parents as opposed to their sibling with autism translated to feeling like their parents loved or cared for them less. Parents also felt guilt about spending less time with their typical children.

> Salma: my oldest child I feel really affected by her diagnosis of autism. Where I want to say even until now it is not as bad, she can get a little sick, and she makes it a really big situation, she wants the attention. She always felt, and she onetime broke down and starts crying, Sara is always has the attention, you always paying attention to her, you always helping her with her assignment, you always doing this with her, she is like my little brother, you are always helping him, you are making sure because he is the baby…. so she broke down to me, you always doing that for them, but you not care about me.

> Reema: I do see that he gets less than other kids his age [the typically developing son].... if he wants to go to Chuck E. Cheese's, we cannot just go to Chuck E. Cheese's. It is a whole ordeal. I have to make sure that I have another adult with me. I have to make sure that we have enough time.... We cannot just do things easily. So that is where he suffers age [the typically developing son].

> Marwa: My kids, the other kids. At a certain time I was giving a lot of attention to him and some of them were getting why don't we go out? Why do not we have fun? Why do not you go and visit…? I am like guys we have to stay because he needs help. They are like why are you giving him a lot of attention? They did not get it.

> Basmah: I am always giving her so much time. And then here is my son [the typically developing son], mom, mom, look what I did at school today. Wait, mom I have to finish.

And then he will go away and he will not talk to me. Then the eight year old because I

am so busy with her, he takes advantage of the IPad, all day. Get off the IPad, do your

homework. I need help [the typically developing son said]. It is very challenging when it

comes to the boys.

Social stigma. This sub-theme is totally culturally based. As mentioned above, parents

expressed their concerns regarding social stigma for both being Muslims in US and the stigma

related to their children's autism. Some parents discussed social concerns of being Muslims and

wearing the "*Hijab*," a headscarf worn by Muslim women. They revealed that being

"*Mohjabah*," wearing the headscarf, draws extra attention and undesirable reactions from others

when their children with autism displayed challenging behaviors in public places. Parents shared

stories that portrayed how they have been harshly discriminated from others who expressed a

belief that Muslims do not know how to appropriately raise their children.

Basmah: "because I wear the scarf. I also feel like in conclusion my experience draws extra

attention as if you do not already have attention with the child."

Salma: Filter does not exist in her vocabulary. We can be anywhere and she just says

what she wants…. I know that she does not mean what she says but when we are out in

public and she goes off. Certain things that she says sound kind of scary. When we got

home I am going to pound your head in the wall. She will something along those lines….

we definitely do not have abuse at home but then on top of the whole child abuse and

then you are Arab, it is like you looked at double. They wait for you to mess up. They

wait for you to say something.

Some parents discussed their concerns regarding their daughters' "*Hijabs*." One of them

expressed that she is hesitant to place her daughter in a public school where there are better

86

services because her daughter wears a "*Hijab*," and this might cause her daughter discomfort in school. The other parent expressed her desire to let her daughter wear her "*Hijab*," but she was worried about how her daughter's social image in school might be affected.

Salma: Do I put her back in public school and get the full services that she needs or do I leave her where she is and just play the yo-yo game? It is hard. Putting her in public school, because she does wear hijab.

Abeer: I have always wanted to put hijab on Arwa to protect her. It is a shield from nasty stares and intentions, and as her mother I want to protect her from those things given she is so beautiful. One of the most major variables holding me back is her image at school. She would not be able to understand the questions she would be asked by her peers, let alone answer them. Wearing the hijab calls for understanding why you do so and defending what it stands for. She cannot fully do any of those things, so putting her in that type of position, especially at school, is scary for me.

In addition, all parents expressed several concerns regarding the social stigma associated with disabilities in Arab societies in particular. Parents indicated that many in Arab communities perceived individuals with any type of disability as "mentally retarded or crazy," which is a harmful social stigma. Some parents also mentioned that in Arab culture, males with disabilities are less stigmatized than females with disabilities.

Abeer: "people needs to know about that, and they need to understand is not something like they crazy or anything."

Marwa: When my son was diagnosed with autism I decided not to go back to my country for so many reasons…. I know that we do not have the culture that look at those kids as they are very innocent, hopeless kids and they are actually very, very smart. I did not

want to have someone looking at my son as he is mentally retarded.

Salma: Culturally speaking, she is gonna be looked at.... I will be honest with you, if it was a boy it would have been okay. They would have stated, he is just angry, he gets a little angry. They can reword it and it is not a problem.

Parents discussed their concerns regarding the reactions of others in Arab communities, as well. They indicated that having a child with special needs in Arab culture caused others to have compassion and empathy of the family that is not necessarily welcome.

Abeer: "some people felt sorry and sympathy and you know all these. I did not like that, I do not need anybody's sympathy."

Basmah: "Like being Arab and everything and having a daughter like this and nobody else does around us…. I do not want anybody feeling sorry for me."

Marwa: "When my son was diagnosed with autism I decided not to go back to my country…. I did not want to have someone looking at my son…. I am so sorry for you."

Reema: "I had expected people to… if I said something, whisper behind my back, and say, oh, my God, that's the one ... the son of hers. I was very worried about it [the compassion and empathy from other], extremely."

One parent explained how social stigma in Arab culture also reflects that if a child is diagnosed with any disability, they will not have any future. Another parent described having a child with a disability in Arab culture as a "taboo."

Salma: "Arab culture in particular is very much in denial, and it is because mainly due to the fact that they feel like if they are diagnosed with it, their future is done."

Basmah: "In conclusion as an Arab mom with autism, I think it is definitely harder because it is still taboo, very much."

88

Theme Four: Needs

Part of this study aims to identify the needs of Arab American parents to better provide them with services for their children with autism. Parents were asked several questions related to their needs regarding their children with autism. Parents' responses focused on an understanding and consciousness of their child's experiences in relation to their diagnosis, as well as a desire to obtain more information and services to assist their child with improving their abilities and skills. They also reflected on society's general lack of awareness concerning autism and expressed a desire for others to learn more about the disorder. Parents also expressed a desire for support and for others to recognize and be sensitive to their well being as a parent. Three sub-themes emerged from this main theme including need for more information, need for improvement in services and therapies, and need for acceptance and support.

Need for more Information. All parents expressed the need for more information about autism. Parents used their past experiences with their children's initial diagnosis as examples to describe the kind of information they needed. In reflecting back to the "ASD diagnosis, now what?" sub-theme, parents shared an expectation for professionals to provide more information about the diagnosis. While some parents had a vague understanding of their child's diagnosis, they expressed a desire to have a deeper, well-rounded understanding in an effort to better provide for their child's needs.

Abeer: "nothing, I never heard of it [autism]…. the lack of information was the most challenging thing, which was I did not know what to do, and I need someone to explain to me what was autism."

Basmah: "I was very disappointed with how they relayed the information. I was very disappointed with the lack of resources they offered me at the time of giving me the information. It was just disappointing."

Parents also shared the importance of getting more information about local support organizations, agencies, and any other free local support systems that are available for them and their family. Parents expressed their desire to connect with other families with autism to exchange their experiences and knowledge.

Salma: "I found it really hard and very limited [social support] and all of it you need insurance."

Abeer: there is no local support here…. well, it is something that not a school, and something not therapy, like a place where they can get children with autism getting together and let them involve and play to gather, and families helping families, like watching our kids playing and you know sharing experiences and point of views…. we do not know families with autism, so we need someone to get us connect together, so we know each other.

Basmah: Having a support group for just Arab. Imagine because we all can relate to one another culturally, maybe it will help us to open up more about, because like I said it is so tender. A lot of people do not even want to say, you know.

Need for improvement in services and therapies. All parents in this study had experiences with special education and related services including specially designed instruction in a special education classroom, accommodations in the mainstream classroom, speech-language pathology services, and physical and occupational therapies. Generally, parents who used these services had positive experiences, and were satisfied with their children's progress and improvement. They also valued when their child received individualized learning plans and

hands-on assistance in school, as well as how those services will positively impact their children's future. However, parents expressed that there were some aspects of special education services that need improvement. Some parents also desired more specialized services and more time in services so that they would be more effective.

Across all interviews, parents expressed a need for further continuing education for professionals to hone their training and add to their expertise on how to treat children with autism. Especially, parents noticed that pediatricians were not as well-informed with up-to-date information on autism, particularly since pediatricians are often the first professional that parents contact in regards to delays in their child's development.

> Abeer: They do not know any things, it is like they do not go to conference, and they do not get knowledge, and what is latest in autism, they do not read…. So I am surprised why these doctors not get more information they do not get all these things…. So I need someone that will tell me what the latest in autism cure, is there anything new.
>
> Basmah: The first thing everybody always says is we do not know what caused this…. It may or may not get better but that's what it is. It is kind of like leaving you hanging like what is that? What am I supposed to do? Is there medicine? Can she get better? You are left with questioning everything.

Parents also felt that pediatricians should improve their education about autism to adequately listen to parents' concerns about their children's development and to take those concerns seriously rather than dismissing them because parent concerns should not be underestimated. A pediatrician's ignorance can increase a parent's confusion about their child's development, cause a delay in diagnosis, and cause delays in receiving appropriate early intervention services.

91

Salma: I did not like how her doctor dismissed her very quickly and just kept saying, you are over-analyzing, you are over-analyzing. To me as a pediatrician he made me feel that he always knew more than me. And I used to tell him, I was like, I am not trying to overstep your boundaries, but as a parent I am not ignorant…. doctors cannot be so pushy about, it is their way. Because parents have a gut feeling. We have that gut feeling and I think more doctors need to be aware of that gut feeling.

Parents also desired more appropriately matched services and treatment for their child's skills and abilities, to include proper class placement, so the child can receive an education tailored to their needs. Parents concerned that their children being placed in classes that were generalized for children with autism as opposed to being placed in a classroom tailored more to their children learning levels. By placing their children into classrooms that are more appropriate to the child's ability, parents felt that their children would be challenged to learn more. In some cases, parents supported placing their child in specialized schools for special needs children, in an attempt to provide what they felt was best for their child.

Basmah: I feel like healthcare providers really need to look at, like my daughter is developing scoliosis. Not every child with autism has that. My daughter has flat feet, she is getting blisters, not every child has that. I feel like my child has more physical problems as well. They are just looking at autism like, in general. I wish there was a more individualized approach.

Salma: They did the full testing and they said socially she is not an issue, she is gifted. I was like we want more than just gifted. Socially she is on the autism spectrum. I go to her, she is on the autism spectrum. She was like; I honestly did not see it. Then I told myself, that's okay. I go to her like, let's keep going with the giftedness. I figured maybe

if we can get into the gifted program, but they are like, we have a small situation. She

does not have a school number.... I keep contacting the school to see, did you guys get

her a number? Until now, they say no, not yet, no, not yet. So I am still waiting on that

perspective, which is really hard on her.

Abeer: I gave her medication and I really regretted because she did not really need it,

why you giving her medicine for? Because she autistic and usually all the kids that come

to my clinic they have this medicine, well, she is different.

Parents also expressed a need for additional therapy, as well as more time in therapy.

They believe that their child's involvement in specialized therapies will contribute more

improvements in their child's development.

Basmah: Because behavior therapy covers such a wide range, but it covers almost

everything that I want, but at the same time it only touches each thing. To be able to go

back to speech and occupational therapy I think would beneficial, because then you get

more of each thing, not just a touch.

Salma: I still think she could receive some therapy sessions with time management,

organization. Even a psychologist to talk to her because now that she understands what is

autism, to talk to her, to be able to get exactly what she is feeling, because even

sometimes I can pull, pull, pull. She had a bad day, she will never tell me what happened.

She will just feel really, it is hard for her to express her feelings. It is really hard for her.

That's what I wish she could definitely receive.

In addition, insurance issues proved to be a roadblock. Parents have had to deprive their

children of services and therapies they need due to issues with health insurance, leading some

parents to seek services on their own and out of their pocket. In some cases, service providers

stopped providing services when they did not observe any improvement and they needed to

discharge them to make room for new patients.

Salma: "I take her to occupational therapy and they did the consultation and insurance denied

it…. Insurance is very difficult. Government insurance with therapy is very difficult. I feel like

that was the issue we had."

Reema: "But the only problem that I have is that, now with different insurance, I only get a

certain amount of hours."

> Basmah: We stopped speech, because in blatant terms. If you want to be harsh. They
>
> think she is never gonna talk, so they stopped speech basically. Basically your daughter is
>
> never gonna talk, she is been in speech for five years. It's not improving, so you are out.
>
> Occupational therapy. We stopped that too…. they discharged me because I was there for
>
> a long time…. If there is a long waiting list and you have already had your chance for
>
> two years with us, then we are gonna clear you out to make room for new patients.

> One parent expressed her desire to have a camera in childcare centers and special

education classrooms. She explained that some of these kids are nonverbal or have

communication disorder, so they cannot communicate their needs, express their feelings, or

describe what, if any, harsh treatment they might receive. She shared her experience with an

abuse incident that happened to her child with autism and how this incident affects her child to

the present day.

> Abeer: So I just want to suggest why they do not put cameras. Because kids they do not
>
> talk.... The things why that I am saying everything I am telling you this experience
>
> because they need cameras, they needs awareness, these kids do not talk. They should
>
> have camera in each class.

Need for acceptance and support. Parents who experienced insensitivity from others attributed this behavior to an overall lack of public awareness and understanding of autism in general, as well as not understanding the challenges that parents of children with autism face in their new role as a caregiver of a child with special needs. An overall lack of awareness and education about autism led to others reacting to their children differently, such as making hurtful comments, judging, or making assumptions about their child without indeed knowing, which affects the child and the parent. The child's odd behaviors and unique needs also present challenges in regards to engaging with their communities. Finally, parents stressed the importance of their desire for their child to be accepted, included, and receive equal amount of love and respect that other children enjoy. Some parents described negative experiences with others in mainstream; interactions they would like to see end.

Abeer: people needs to know about that, and they need to understand is not something like they crazy or anything, they going through a disorder and it is not something contagious. Like you have to teach, am talking about other people, they have to teach their kids how to deal with children with special needs and how to be nice to them.

Marwa: the way the people used to look at him. I used to hate when someone tell me, your son is so quiet, because I know he is quiet because he lost his words. When he used to get angry, he did not say anything, so he used to scream or bang his head on the floor or on the wall. When people ask me, why is he behaving like that? And the sympathy look that I see in people's eyes. In our culture, they do not accept this behavior and they always look at it like my son is mentally retarded, but I know that he is not. I remember I told my mom, if anyone come and talk to me about his behavior or his case or his diagnosis out of ignorance, I am not going to talk to them. They have to read about my

95

son is diagnosis first and then come and ask me questions. I would be so happy to answer them.

Basmah: as an Arab-American, just basically being accepted in the community, taking her out in the community, having the Arab community accept her more. Having a support group for just Arab. Imagine because we all can relate to one another culturally, maybe it will help us to open up more about, because like I said it is so tender. A lot of people do not even want to say, you know.

Theme Five: Coping Techniques

When parents achieved the acceptance stage of their child's diagnosis of autism, they began looking for ways to help them and other family members cope effectively with their child's autism. Parents shared numerous techniques that assisted them to adjust, cope, and overcome challenges that are associated with parenting a child with autism. Parents described several techniques that not only helped them as parents, but also assisted other family members to understand, adjust, and support the child with autism in the family. These techniques included accepting the child's diagnosis as the will of God, spirituality, family and extended family unity and support, patience, and participation in support groups.

All parents who attributed their beliefs of their child's autism as the will of God credited this as one of the first aids that helped them to deal and cope with their child's autism. Parents cited from the Quran that God chose them because they are qualified and capable of caring for a child with special needs. Parents also believed they received strength from God to bear and overcome the challenges they were facing, and that their spirituality and faith equipped them with the tools they needed to adapt to their situation, accept their child's diagnosis, and retain hope for their and their child's future.

Marwa: the first thing that helped me was the acceptance of the destiny. The acceptance

of what's going on. Just accept it and deal with it. It is the faith. Dealing with it as if it is a

test from God and from Allah [God] and we have to accept it. We have to practice. That

was the first thing that made me calm down inside.

Salma: "So I want to say that I feel like Allah [God] but me in special position and I am hoping

that I am completing this task in the right way."

Abeer: "We have to have deep believe in Allah [God] to guide us to the right path…. it God

things we are a Muslim family…. and it is a God things we have to accept it Alhamdulillah

[thanks to God]."

Reema: "I went towards the way of God, I became more spiritual, and I taught myself to accept

that everything happens for a reason, which I am very lucky."

Spirituality was one of the coping techniques that all the parents identified that they often

turned to as a method to cope and deal with the challenges and difficulties they encountered in

addressing and handling their child's needs. Parents turned to prayers and reading the Quran for

guidance and support, and felt that their situation had deepen their spirituality.

Salma: I will make wudu [ritual ablution] and I start to pray and I ask for the best. I ask

for shifa'a [healing]…. It is very helpful. I do feel like it has brought me closer to God,

because any time, like I said, any time I am falling away and I get frustrated. I say this is

from Allah [God] because we have to accept it.

Basmah: "Definitely my faith. Reading a lot of Quran. Being spiritual."

Abeer: "from my culture just praying ….we pray for them and it is a God things we have to

accept it Alhamdulillah [thanks to God]."

Reema: "praying. And just connecting from my heart, not just to words, and not just movements,

but actually from my heart connecting to religion."

Parents described how having a close-knit family and a strong sense of unity helped them to cope with their child's diagnosis and assist them in caring of their child with autism. Talking, explaining to, and training other typically developed children in the family helped parents to cope and assisted them in caring of a child with autism, as well. Parents also credited extended family for their support and acceptance of their child with autism.

Salma: my parents, my friends, my family, very supportive. They even, they are always telling me, what Allah [God] wills is what Allah [God] will give you. You will always hear the positive. It is definitely what keeps me going.

Marwa: They accept him, they love him. They look at him, as he is an angel. I have the support from my family. My kids, the other kids.... I told them, listen guys, you have to know that we are blessed with a super hero baby.

Abeer: They love her so much. We trained them, I keep explaining to them about her situation, I used to take them to her school just to let them see the other kids in her situation how they look like and how they dealing with them.

Patience is a quality that parents' felt was of high value, particularly during periods of high stress. They frequently referenced the necessity of patience and stressed that patience was an important virtue to practice as they care for their child with autism.

Marwa: "That I have to accept what is going on. Then after that, the patience. You learn how to be patient. Very, very patient."

Abeer: "We have to have patient, we keep prying…. and hoping and being patient."

Basmah: "patient definitely gave everybody in the family patience…. everybody in the family is gonna be more patient, more understanding."

One parent discussed the positive effect that support groups had in her family life. She acknowledged that participating in support groups gave her family the opportunity to share their experiences and concerns with other parents who would be empathic and understanding of their situation and provide them with emotional support. Attending support groups also provided them with access to new information, techniques, and strategies, shared by other parents who had similar experiences that they could utilize with their child. Moreover, participating in support groups not only assisted parents, it also helped their typical children to interact with other siblings, who were going through the same situation, to deal with the change in their family dynamic due to having a sibling with autism.

> Basmah: Taking them to the support groups with me to meet other families and other children their age with the same thing, dealing with the same thing. So they know they are not alone, there is other boys your age who have siblings like this…. Same thing [to husband], seeing other dads, so he does not feel less. It was very being a man and having a child like this, and he was ashamed because he was born there. He does not know. I think seeing other men and relating really helped him.

Theme Six: Unanticipated Positive Effects

The last theme that emerged from this study was the unanticipated positive effects that parents and other family members gained in their lives that resulted from their experiences with their children with autism. Parents were asked if they had any unexpected positive effects in their lives provided by their experiences with their children with autism. The most prevalent positive effect was that autism helped them to change their overall perspective in terms of thinking and how they viewed life, particularly with other people. They also saw a change in how they and other family members treated others with disabilities in terms of respect, empathy, and a better

99

sense of understanding.

> Salma: it made me more aware…. I have to see from different perspectives…. Even
> towards my students. I always told myself if my child needs this extra help, whither the
> student is autistic or not, they still need that extra help, and they need that extra love.
> Abeer: they care of any child with disability, even their friends now they have the same
> thing, and if any body who makes fun with any child with disability and that affects their
> friends as well. They made a good influence.

Basmah: "I think my kids were provided with an experience that nobody else got. How to be more accepting maybe…. have more empathy for the world around them."

Reema: "because when you are affected with something so life changing, you look at the world differently, and I think he was able to give everybody that lens to look through."

Parents also indicated that this experience positively affected their own, and other family members' personal growth and family connections. Parents shared that they and other family members became more patient, more sympathetic, and more loving of others. Parents felt they became more resilient and better equipped to deal with life's challenges. They also found they felt a stronger bond with their child diagnosed with autism, and found that they had an increased ability to enjoy their child for who they are as opposed to who they wanted their child to be.

> Marwa: It made me stronger, patient, more loving, more caring, believer…. positive
> effects, I guess more love, more focusing on the family, and get more connected just to
> help him…. brings us as family to get more connected and spend more time with each
> other.

Basmah: How to be more loving and patient definitely gave everybody in the family patience…. I guess it was expected that if you have a child with special needs everybody in the family is gonna be more patient, more understanding, more loving, more caring.

Parents also expressed that one of the positive effects that they never expected at all was how their children with autism brought a lot of joy, happiness, and fun into their lives. Basmah: "Unexpected things, we laugh a lot. I did not think that would happen…. I did not think that she would bring us that much joy at the same time as being, there is a lot of positive." Abeer: "So she is blessing, she the joy of the family like having a little child, she brings happiness, we laughed, we enjoyed her being with us."

Parents discussed how having a child with autism had positive effects in terms of their relationships with their extended family. Members of the extended family become more caring and supportive, both emotionally and financially, and gave excuses for not fulfilling some family obligations. Salma: "the way my family, whether it is my mom, my aunts, my cousins, they are very kind. The kindness that she now receives from everybody is very understanding."

Basmah: My family treats me better than my siblings…. my dad will give me a little more money let's say because I have to spend so much on my daughter. I know it sounds bad, but one of the unexpected positive things is the extra help or family attention I get. We get a little more. Like my cousins will cut me slack if I do not go to a wedding. It is probably because of her daughter she did not come. I get a lot of excuses.

Reema: I see with my parents, and my in-laws, and all my cousins, and my sister-in-law, and brothers-in-law, and my nieces, and my nephews, everyone has so much love in their heart, so much more love. And so much more tolerance for him.

101

Finally, parents also shared that their experiences with their child's autism brought them closer to God, and their spirituality was deepened because of their situation, and they perceived this as a positive effect.

Marwa: "Believe it or not that made me closer to Allah [God]."

Salma: "I do feel like it has brought me closer to God."

Summary

The purpose of this study was to explore the experiences of Arab American parents of children with ASD. A qualitative interview approach was used to explore Arab American parents' experiences of caring for children with ASD, their cultural beliefs and understandings of their children's ASD, and their concerns and needs regarding their children. After analyzing the data obtained from the interviews, six major themes, some with sub-themes, emerged from the data (1) parents' journeys toward the acceptance of the diagnosis of ASD, (2) beliefs about the cause of autism, (3) concerns, (4) needs, (5) coping techniques, and (6) unanticipated positive effects.

In this chapter, the findings of these qualitative interviews' exploration of the experiences of Arab American parents of children with ASD were detailed. In the next chapter, these findings are reviewed in relation to the current study research questions, situated within the current relevant literature, and discussed in relation to the conceptual framework explained earlier in Chapter Two. Also discussed in the next chapter are researcher reflexivity, implications of the findings for the field of special education, and recommendations for future research.

Chapter Five

Discussion

In this chapter, the findings of this study are reviewed in relation to the current study research questions, situated within the current relevant literature, and discussed in relation to the conceptual framework that was discussed in Chapter Two. In addition, researcher reflexivity, implications of the findings for the field of special education, and recommendations for future research are discussed later in this chapter.

Review of Current Study Findings in Relation to the Research Questions

This qualitative interview study explored the experiences of Arab American parents of children with ASD. The intent of this study was to understand Arab American parents' experiences of caring for children with autism, their cultural beliefs and understanding of their children's autism, and their concerns and needs regarding their children. As detailed in Chapter Four, six major themes regarding the experiences of Arab American parents of children with autism emerged from the data analysis, including (1) parents' journeys toward the acceptance of the diagnosis of ASD, (2) beliefs about the cause of autism, (3) concerns, (4) needs, (5) coping techniques, and (6) unanticipated positive effects.

In this section, these findings are reviewed in relation to the current study research questions. The intent of this review is to connect these findings to each research question to illustrate how the research questions were satisfactorily addressed through this qualitative interview study. Further, detailed discussions of these findings are presented later in this chapter.

First Research Question: How do Arab American parents make meaning of the experience of having a child with ASD?

      a.   How do their cultural beliefs affect their understanding of their child's ASD?

      b.   In what way(s) does their understanding of their child's ASD affect their help-seeking behaviors?

      c.   How do Arab parents adapt to raising a child with ASD?

The first research question, in all of its parts, aimed to explore Arab American parents' experiences of caring for children with autism in general. It focused on how they understand their children's autism, how their understanding affects their approaches to seek help, and how they adapted to raising their children with autism. It also has an emphasis on the influence of culture in their overall experiences. During interviews, parents were asked to describe and reflect on their initial experience and reaction when receiving the autism diagnosis, their beliefs toward autism, their help-seeking methods and coping techniques, and their overall experiences as Arab American parents of children with autism. Parents' responses clearly revealed their unique experience as an Arab. The influence of Arab culture and Islamic values was explicit. This manifested in their child rearing practices, their beliefs toward disability, and their accepting and coping techniques.

Parents specifically discussed the influence of Arab culture on their beliefs toward disability. For example, some parents shared the belief that *"Ein"* or *"evil eye"* could be the cause of their children autism. Additionally, parents discussed the role of the extended family in assisting them with caring for their children with autism, as well as supporting them emotionally and financially. The strong familial bonds represent a central aspect in Arab culture. The extended families provide care and support to the young and people with disabilities amongst

themselves rather than seeking outside services from governmental or nongovernmental organizations, as is common for Euro-American families (Ajami et al., 2016; Sharifzadeh, 2011).

Further, parents reflected on the influence of Islamic religion on their child rearing practices. They discussed how they instilled Islamic values in their children, including their children with autism. For example, parents were keen to send their children to the mosque after school or on the weekends to learn Arabic, Islamic studies, and reading the Quran. For some parents, the ability to maintain Islamic values and practice religion was a major concern regarding their children with autism. Parents also discussed the influence of religious beliefs on their interpretations of disability and their accepting and coping techniques. Parents pointed out that one of the first aids that helped them accept their child's autism was a belief that their child's autism is the will of God. Parents cited from the Quran that God chose them because they are qualified and capable of caring for a child with special needs. Parents believed that having a child with autism is a test from God, and they must pass this test. Some parents felt that having and caring for a child with autism is their path to heaven after life.

These findings satisfactorily addressed the first research question as they clearly revealed parents' unique experiences as an Arab and showed the influence of Arab culture and Islamic values in their overall experiences of raising their children with autism. These findings were detailed and supported by excerpts from the participants' interview transcripts in Chapter Four. Further discussion of these findings is illustrated later in this chapter.

Second Research Question: What are the concerns and needs of Arab American parents of children with ASD?

One of the critical purposes of this study was to identify the concerns and needs of Arab American parents in regards to their children with autism. Parents were asked several questions

related to the challenges they encounter and the concerns they have about their children with autism. Additionally, parents were asked questions related to their needs regarding their children with autism. Parents' responses revealed a variety of concerns; some of which were culture-specific concerns. These concerns included their child's future, allocating time and attention across family members, and social stigmas for both being Muslims in the US and the stigma related to their child's diagnosis. Parents also expressed a variety of needs, which included a desire to obtain more information and services to assist in improving their child's abilities and skills, and a desire for others to learn more about the disorder and to recognize and be sensitive to their well-being as a parent.

These findings clearly addressed the second research question (what are the concerns and needs of Arab parents of children with ASD?). A detailed description of these findings, supported by excerpts from the participants' interview transcripts, was outlined in Chapter Four (Theme Three: Concerns and Theme Four: Needs). Further discussion of these findings is presented later in this chapter.

Third Research Question: What are the social support systems that assist Arab American parents in raising their children with ASD?

In this study, parents were asked several questions related to the available social support systems that assist them and their children with autism. Parents explicitly described the social support systems that helped them and their family in coping, adapting, and raising a child with autism. In most cases, parents identified extended family members as a major social support system that assisted them in overcoming challenges that are associated with parenting a child with autism. Parents credited extended family members for becoming more caring and supportive, both emotionally and financially, and for their acceptance of their child with autism.

They described how having a close-knit family and a strong sense of unity helped them to cope with their child's diagnosis and assist them in caring for their child with autism.

In one case, the parent identified support groups as a social support system. She explained the positive effect that parent support groups had in her family life. She acknowledged that participating in support groups gave her family the opportunity to share their experiences and concerns with other parents who would be empathic and understanding of their situation and provide them with emotional support. Attending support groups also provided them with access to new information, techniques, and strategies, shared by other parents who had similar experiences, that they could utilize with their child. Moreover, participating in support groups not only assisted parents, it also helped their typical children to interact with other siblings who were going through the same situation, helping them to cope with the change in their family dynamic due to having a sibling with autism.

These findings addressed the third research question (What are the social support systems that assist Arab parents in raising their children with ASD?). These findings were detailed and supported by excerpts from the participants' interview transcripts in Chapter Four (Theme Five: Coping Techniques). Further discussion of these findings is illustrated later in this chapter.

Synthesis of Current Study Findings and Previous Research on Related Topics

As discussed in Chapter Two, research including cases of Arab Americans or immigrant Arabs with disabilities in the US is limited. Arab Americans with disabilities are a neglected sub-minority of arguably the most stereotyped and marginalized minority in the US (Al Khatib, 2017; Campbell-Wilson, 2012). Whether in literature related to ethnic minorities with disabilities or in literature pertinent to Arab Americans, individuals with disabilities from Arab ancestry have generally been overlooked (Al Khatib, 2017). Al Khatib (2017), in his recent review of

literature, reported that there are only three empirical studies regarding disability among Arab American children. These studies explored the experiences of Arab American parents of children with disabilities regarding daily routine and adaptation (Kuaider, 2005), home/school communication (Abadeh, 2006), and special education process (Donovan, 2013). However, no previous research has been published on the experiences of Arab American parents of children with ASD in particular. The current study is the first of its kind. Therefore, it is difficult to situate the current study findings within the existing literature. Yet, it is critical to link the findings to the existing published research.

This section synthesizes the current study findings that were described in Chapter Four with the existing relevant research. The discussion centered on the following topics: knowledge of autism and interaction with professionals and implications of Arab culture on families' experiences. The discussion related to these topics help to clarify how the current study findings contribute to the body of published research. They most significantly contribute to literature on Arab culture and disabilities and research on Arab American parents of children with disabilities.

Knowledge of Autism and Interaction with Professionals

Based on existing literature, a parent's journey with autism usually starts when they notice that there is something different or unusual about their child's development (Guinchat et al., 2012; Saint-Georges et al., 2010). Findings of this study indicate a similar finding in which parents reported that their initial concerns began when they observed something abnormal about their children's behaviors and development. Parents described these initial concerns using phrases like "something not normal," "something not right," or "something wrong." Parents in this study also described the initial signs they noticed about their child development as poor eye contact, communication difficulties, delay in language development, not responding to their

names being called, non-compliance, and reduced interest in people and social interactions. These descriptions are consistent with previous literature indicating that these symptoms are the early signs of autism that parents most often observed (Barbaro & Dissanayake, 2009; Guinchat et al., 2012; Matson & Sipes, 2010; Saint-Georges et al., 2010).

Research showed that many parents relied primarily on the caretaking experiences they had with their own typically developing children, which created a natural benchmark for parents to identify delays and differences in development in their child who was later diagnosed with ASD through comparison to their typically developing children (Flores, 2012). Findings of this study indicate a similar finding in which some parents made frequent comparisons between their typically developing children and their child who was later diagnosed with autism. They noted differences, which supported their initial concerns. For these parents, the comparisons with their typically developing children served as a first guide that assisted them to recognize their children's delays in development.

Given that family is considered a primary source of support for parents in Arab culture, other family members are often the first individuals that parents speak to about their concerns regarding their children's development. Usually, mothers are the first-hand observers of their child's development (Gardiner & Iarocci, 2012). In this study, mothers were the first to notice and express concern about the development of their children. However, when they spoke about their concerns to their husbands, they were not encouraged to seek help regarding their concerns. Husbands did not support the idea that there was something unusual. These findings are consistent with research conducted with Arab American parents of children with disabilities. Donovan (2013) indicated that some mother participants in her study described their experiences with their husbands' rejection to the idea that their children had a disability; even after the

official diagnosis, they continued to keep their children's disabilities a secret from others. This is despite the fact that some of these husbands had professional medical training. Moreover, in this study, when parents expressed their concerns to other members of the extended family, they did not gain any support to allay their concerns, and they were faced with rejection and denial. In some cases, family members attributed the delay in development to the child's young age or they connected the child's delay in communication and speech to other family members who had speech issues in their childhood. This is similar to the findings from Myers, Mackintosh, & Goin-Kochel (2009), in which parents expressed that their extended family did not believe and doubted the child's diagnosis and continued to live in constant denial.

For most parents, the search for an explanation started with their child's pediatrician. The pediatrician was identified as the first professional that the parents spoke to regarding their initial concerns (Dillenburger, McKerr, Jordan, & Keenan, 2016; Flores, 2012; Rhoades, Scarpa & Salley, 2007). In this study, parents turned to their children's pediatricians with their initial concerns about their children's development. However, parents' early symptom recognition did not always necessary lead to early diagnosis by doctors. Continuously, parents heard the phrase, "she/he is fine," from doctors when they initially spoke to them regarding their concerns, and their concerns were dismissed without obtaining satisfactory answers and explanations to their questions and concerns. This is similar to studies finding by Dillenburger et al. (2016); Flores (2012); Graungaard & Skov (2007); and Rhoades et al. (2007), where parents reported that pediatricians overlooked early and subtle signs, and dismissed them early with no further assessment of their children.

Studies show that early diagnosis could lead to early intervention, which is crucial and associated with improved outcomes (Atun-Einy & Ben-Sasson, 2018; Dillenburger et al., 2016;

Landa, 2008; Stadnick et al., 2017). Parents in this study attributed the delay in correct diagnosis to the doctors' reaction of ignorance to their concerns, which resulted in a delay in providing appropriate interventions and services to help their children. This made parents more confused about their child's situation, and caused them to feel extremely dissatisfied with their children's pediatricians, as they believed that early intervention would have had a positive effect on their child. In general, parents in this study expected professionals to demonstrate sufficient knowledge about autism and to prove their expertise and competence. However, parents reported that professionals did not provide them with information they were searching for and did not take their inquiries and concerns seriously. This, in turn, led parents to switch professionals, as they felt disappointment, dissatisfaction, and unwillingness to continue working with them. Similar to the findings from Renty and Royers (2006) and Graungaard and Skov (2007), conflict and dissatisfaction are likely to appear when professionals do not meet families' expectations and needs and do not respond to their concerns.

As a result, parents in this study expressed a need for further continuing education for professionals to enhance their training and add to their expertise on how to treat children with autism. In particular, parents noticed that pediatricians were not as well-informed with up-to-date information on autism, particularly since pediatricians are often the first professional that parents contact in regards to delays in their child's development. The lack of allied health professionals' autism-specific training, both basic and advanced, has been documented in research, which impacted their overall knowledge of autism's early symptoms, resulting in a delay in the diagnosis (Atun-Einy & Ben-Sasson, 2018; Dillenburger et al., 2016; Stadnick et al., 2017).

Mothers, in particular, tended to consider themselves the experts of their children's development. Thus, they assumed an essential role in participation in their children's care and

treatment and a desire from professionals to respect their concerns, thinking, and decisions about their children, whether or not professionals agreed with them (Gardiner & Iarocci, 2012; Graungaard & Skov, 2007). This is consistent with findings from this study, in which mothers felt that professionals should adequately listen to their concerns about their children's development and to take those concerns seriously rather than dismissing them because mothers' concerns should not be underestimated.

When parents finally had their children's diagnosis of autism, the struggle to understand the ambiguity and complexity of autism began (Flores, 2012; Renty & Royers, 2006; Rhoades et al., 2007). All parent participants in this study were unfamiliar with the evaluation and special education process. Some parents were also completely unaware of autism and its existence. Other parents possessed limited information about autism before their child's diagnosis. However, the information they held about autism was narrow and somewhat inaccurate. It is noticeable that parents in this study, who were born and educated in the US, reported having prior knowledge about autism (although minimal) more than parents who were born and educated in the Arab world. Similar to the findings from Donovan (2013), Arab American parents who were born in the Arab world reported having no prior knowledge about autism compared to other parents who were born in the US. This lack of prior knowledge about the disability could be correlated to the social stigma associated with disability in the Arab world, which makes it rare to meet an individual with a disability in public, as family members with a disability might be kept hidden from the public (Al-Kandari & Al-Qashan, 2010; Al Thani, 2007; Crabtree, 2007).

Again, once a child receives an autism diagnosis, one of the most difficult stages in the parents' life is facing the ambiguity of the diagnosis. For many parents, due to the lack of overall

112

awareness about autism, there was a desire for a clearer understanding and answers to many questions about autism and how autism would affect their child. In this study, parents frequently mentioned that their lack of knowledge about autism, combined with vague information provided at the time of diagnosis, made them feel uncertain about what the diagnosis meant, uncertainty about the causes, and an overall feeling of unpreparedness about how to move forward. Parents' need for more information and a clearer understanding about autism was a common need expressed by parents of children with autism in other studies (Dillenburger et al., 2016; Flores, 2012; Rhoades et al., 2007).

In addition, the ambiguity surrounding an autism diagnosis causes parents to seek out sources to answer their questions about the autism diagnosis, the possible causes of the disorder, and available treatment and intervention options. Research found that parents of children with autism obtain information about their child's autism diagnosis from sources other than healthcare professionals, including media, videos, magazines, books, and the Internet (Flores, 2012; Lutz, Patterson, & Klein, 2012; Rhoades et al., 2007). In this study, parents' narratives reflected their journey toward becoming informed, illustrating that their uncertainty lessened when they received more information. Parents described the sources they sought out to find information about autism. For some parents, this began as soon as the diagnosis was given, when doctors or other service providers fell short of an explanation. Parents shared that they developed a better understanding and connection with their children through interacting with experienced service providers, searching and reading on the subject on the Internet and in books, and connecting with other families who have gone through similar experiences.

When parents gained sufficient information and reached the stage of understanding their child's diagnosis of autism, they were able to better help their child. As the parent learned and

understood more about the diagnosis, the benefit for the child increased, as understanding often leads to early intervention and parents advocating for their child to receive better services (Hess, Molina, & Kozleski, 2006). In this study, all parents had experiences with special education and related services including specially designed instruction in a special education classroom, accommodations in the mainstream classroom, speech-language pathology services, and physical and occupational therapies. Generally, parents who used these services had positive experiences, and were satisfied with their children's progress and improvement. However, parents expressed that there were some aspects of special education services that needed improvement. Some parents also desired more specialized services and more time in services so that they would be more effective.

One of the contributing factors to parents' desires for additional services is the lack of insurance coverage (Lin et al, 2012; Myers et al., 2009). In this study, insurance issues proved to be a barrier. Parents had to deprive their children of services and therapies they needed due to issues with health insurance, leading some parents to seek services on their own and out of their pocket. In some cases, service providers stopped providing services when they did not observe any improvement in the child, and they needed to discharge them to make room for new patients. These findings are consistent with previous research that indicated that families who have difficulties accessing health care due to a lack of health insurance receive less types of services, face additional barriers, and experience greater difficulties in locating support and informational resources (Hidalgo et al., 2015; Irvin et al., 2012; Lin et al, 2012).

Additionally, parents in this study desired more appropriately matched services and treatment for their child's skills and abilities, to include proper class placement, so the child could receive an education tailored to their needs. Parents were concerned that their children

114

were being placed in classes and receiving services that were generalized for children with autism, as opposed to being placed in a classroom tailored more to their children's learning levels. This is similar to findings of several studies that discussed the dissatisfaction of parents of children with autism regarding the inadequacy of their children's Individualized Education Program (IEP) content and inappropriate services, programs, and placement they received (Hess et al., 2006; White, 2014; Williams, Atkins, & Soles, 2009).

An extension of the parents' desire for more information and services, parents also shared the importance of getting more information about local support organizations, agencies, and any other free local support systems that were available for them and their family. Parents expressed their desire to connect with other families with autism to exchange their experiences and knowledge. Research found that parents who participate in support groups gained more knowledge from interacting with other parents facing similar challenges, experienced less child-related stress, reported using more adaptive coping strategies, reduced feelings of social isolation, and felt empowered to support their child (Banach, Iudice, Conway, & Couse, 2010; Clifford & Minnes, 2013). However, families in this study did not attend support groups, except for one family. This was because either they were not aware of this kind of social support service or because of the lack of information about such support groups in their area. Moreover, it could be possible that parents are not attending these groups because they feel they are different and that non-Arab parents would not understand them, as some parents referenced to the need for support group for Arab parents in particular. This finding is consistent with findings from research conducted with Arab American parents of children with disabilities (Kuaider, 2005), in which the researcher found that Arab families avoid attending, or showed disinterest in, parent support groups, either because they found no benefit in them or because they felt they were

different and that non-Arabs do not understand them.

One of the reasons that parents expressed a desire to participate in parent support group is because they acknowledged that participating in such groups would give them the opportunity to share their experiences and concerns with other parents who would be empathetic and understanding of their situation and provide them with emotional support. In addition, an understanding of their situation usually cannot be found from the public. Some parents in this study experienced insensitivity from others in public. They attributed the insensitivity to an overall lack of public awareness and understanding of autism in general, as well as not understanding the challenges that parents of children with autism face in their new role as a caregiver of a child with special needs. They felt this led others to react to their children differently, such as making hurtful comments, judging, or making assumptions about their child without indeed knowing, which affects the child and the parents. Such undesirable reactions and misunderstanding from the public have been expressed by other parents of children with disabilities in different studies (Myers et al., 2009; Lutz et al., 2012). Thus, parents in this study most stressed the importance of their desire for their child to be accepted, included, and receiving an equal amount of love and respect that other children enjoy.

The Implications of Arab Culture on Families' Experiences

Understanding the role of culture in family interactions and child rearing practices is essential when working with families and students from different cultural backgrounds. Although Arabs are a heterogeneous group and have a diverse cultural heritage that includes different religions, nationalities, education levels, Arabic dialects, and social classes (El-Khadiri, 2009), certain cultural commonalities in the Arab culture can be underlined, including family structure, child rearing practices, and conceptualization of disabilities.

Family structure. Arab culture is characterized by hierarchical and interrelated family relationships, and emphasizes interdependence rather than individualism (Dedoussis, 2004; Dwairy et al., 2006). Traditionally, the Arab family structure is extended rather than nuclear. Strong family ties represent a central aspect in Arab culture, and the extended family is the most important institution (Britto & Amer, 2007; Cainkar & Read, 2014; Sharifzadeh, 2011). The familial bonds of the typical Arab family play an important role in society (Ajami et al., 2016; Sharifzadeh, 2011). The extended families provide care and support to the young and people with disabilities amongst themselves rather than seeking outside services (Ajami et al., 2016; Sharifzadeh, 2011).

This was evident in all cases in this study. Although families from this study are not in their country of origin, the extended family still played a significant role in providing a network of support to the mother, and helped to alleviate the need to tend to every moment of childcare by herself. Mother participants identified extended family members as a major social support system that assisted them in overcoming challenges that are associated with parenting a child with autism. They credited extended family members for becoming more caring and supportive, both emotionally and financially, and for their acceptance of their child with autism. They described how having a close-knit family helped them to cope with their child's diagnosis and assist them in caring of their child with autism. One mother explicitly expressed that she is lucky to be a part of culture that promotes an extended family structure compared to someone without extended family, describing how their help lessens the burden and anxiety of caring for a child with special needs.

In addition, patriarchy is dominant in Arab culture. Fathers seldom engage in caregiving procedures and see themselves as responsible for providing the family with material needs and

expenses, but not engaging in day-to-day caregiving (Ajrouch et al., 2016; Sharifzadeh, 2011).

Mothers are typically responsible for all aspects of household management, such as cleaning and

cooking, as well as providing the majority of the day-to-day caregiving for children (Ajrouch et

al., 2016; Ajami et al., 2016). This was evident in the composition of the participants in this

study (five mothers), which may be a reflection of these responsibilities, as mentioned above, I

did not intend to only interview mothers. Mother participants also reported that they were

responsible for the daily care of their children, as well as being involved in their children's

education and interventions more than fathers were.

The fact that mothers have the responsibility to provide the majority of the day-to-day

caregiving for children causes them a significant amount of stress. Mothers in this study

expressed difficulty with having to care for more than one child and determining how to allocate

their time and energy across all family members. They also discussed how typically developed

children in the family felt the impact of having a sibling with autism. Their typically developing

children expressed jealousy and insecurity as they began to observe their parents dedicating more

time and attention to their sibling with autism. Comparisons between the amount of time the

typical children received from their parents as opposed to their sibling with autism translated to

feeling like their parents loved or cared for them less. Parents also felt guilt about spending less

time with their typical children. Such concerns were expressed by mothers of children with

disabilities in different studies (Gardiner & Iarocci, 2012; Flores, 2012; Lutz et al., 2012; Myers

et al., 2009).

Child rearing practices. In Arab societies, Arab families view interdependence and

sharing as significant; consequently, they promote them as socialization goals for children. Child

socialization fosters a collective identity, in which an individual's socioeconomic status is

greatly associated with the family's status, and an individual's decisions are made taking all family members into consideration (Ajrouch et al., 2016; Goforth, 2011). Individuality may be viewed as selfish and as a rejection of the family. Mutual commitments, interdependence, and reciprocity relationships are endorsed in Arab culture (Al Khateeb et al., 2014).

The emphasis on interdependence was mirrored in some mothers' responses. They did not refer to it as a broad cultural value. Rather, their stories reflected how they foster interdependence/collective child rearing style, particularly with their typically developed children. Mothers described how they endorse strong bonds between their typically developing children and the sibling with autism, and how they often had conversations with their typically developing children, urging them to take care of, and play with, the sibling with autism. In doing so, these parents confirmed how they reinforced interdependent values to their children for the advantage of the whole family. This finding appears to be typical of Arab families, as stated earlier; Arab families involve collectively insuring the well-being of all family members.

In addition, as discussed in Chapter Two, one of the main differences in the child rearing practices between Arab families and Euro-American families is the nature of parent-child attachment "independence vs. nurturance." In Arab families, there is an emphasis on attachment and parent-child bonding. Separation between mother and child is minimized, and in general, children are dependent on their parents for longer than most Euro-American children. Therefore, there is less parental concern about developing independence skills and self-help skills (i.e. early toilet training, self-feeding, self-dressing), which are taught early for children in American culture (Gregg, 2005; Sharifzadeh, 2011). This is even more obvious in cases of children with disabilities. Holding low expectations of children with disabilities and their capability to be independent is documented in different literature. Additionally, children with special needs in

Arab culture depend on their parents, and the idea of institutionalization and social services for individuals with disabilities is not widely accepted (Soliman, 2013). This caused mothers in this study to express concern about providing adequate caregiving for their children in the future at a time that they would not be able to due to sickness, age, or death. They wondered who would take care of their children, as autism causes life-long dependence on others and ongoing supervision. Such concerns were also discussed in different literature pertaining to families of children with disabilities (Gardiner & Iarocci, 2012; Graungaard & Skov, 2007; Flores, 2012; Myers et al., 2009).

Conceptualization of disabilities. The discussion of disability in Arab culture is challenging due to the fact that literature on this subject is minimal (Gharaibeh, 2009), as well as the cultural and religious differences characterizing Arab societies, making the interpretations of disabilities varied (Al- Krenawi & Graham, 2011). This was demonstrated in this study where participants expressed multiple beliefs about the causes of the disability, different reactions to the identification, several concerns, and a variety of coping approaches.

Beliefs on etiology. Parent participants in this study expressed a variety of beliefs and explanations for the causes of autism. Some beliefs were specifically culturally based, while others were universal and not related to a particular culture. Some parents also held more than one belief about the cause of their children's autism. As discussed above, parents were unfamiliar with autism and the special education process. This lack of knowledge could be a contributing factor that led parents to develop a variety of interpretations about the cause of autism.

In this study, some parents believed that their children's autism could be result of *"Ein"* or *"evil eye."* In Arab culture, receiving the evil eye will cause harm or misfortune to the

individual. Another parent discussed how culture could affect one's understanding of the causes of autism. She shared her experience with her relatives when she went to visit in the Arab world, how they misinterpreted her child's behaviors that resulted from autism, and their belief that her child was possessed. Such explanations were found in literature discussing disabilities in Arab culture that was described in Chapter Two (Al-Krenawi & Graham, 2011; Crabtree, 2007; Dwairy, 2006).

In addition, in the Arab world, disabilities can be explained as a plan from God. In this study, some parents felt that having a child with disability is a test from God, which they must go through. Parents also believed that having a child with a disability is the will of God, and that if they care for their child appropriately, God will reward them. Other parents believed that God chose them because they are qualified and capable of caring for a child with special needs. These findings were also demonstrated in previous research with Arab and Muslim families of children with disabilities that was discussed in Chapter Two (Crabtree, 2007; Donavon, 2013; Kuaider, 2005; Mirza et al., 2009; Jegatheesan et al., 2010).

Other beliefs shared by parents in this study were universal and can be found in different cultures. Some parents believed that vaccinations could be the cause of their child's autism. They argued that their child's development changed after receiving the vaccines. Other parents discussed environmental factors that could have caused their children's autism. One parent held the belief that her child's autism could be caused by a genetic factor. Such explanations were widely discussed in research investigating the etiology of autism (i.e. Ravindran & Myers, 2012; Rutter, 2000; Volkmar, Westphal, Gupta, &Wiesner, 2008). Moreover, in literature exploring the perceptions of parents of children with autism, such interpretations of autism were recognized. For example, Flores (2012) explored the psychoeducational needs and concerns that were unique

to immigrant Mexican parents of a child with autism. The findings of her study aligned with the findings of the current study, where parents shared a variety of explanations that they believed were possible causes of autism, including vaccinations, genetics, and environmental factors.

Reactions to the identification. In the family context, as it exists in other cultures, Arab parents experience a series of responses and feelings upon their child's diagnosis of disability, such as shock, disbelief, guilt, anger, shame, and stress (Al Khateeb et al., 2014; Donovan, 2013). However, shame and guilt are the most common reactions when a child with a disability is born in an Arab family, which mostly results in overprotection and isolation (Donovan, 2013; Kuaider, 2005; Sharifzadeh, 2011). In this study, parents reported feeling and experiencing a variety of emotions and reactions to their child's diagnosis of autism, including depression, sadness, shock, guilt, shame, and relief. Guilt was common among mother participants, while feeling ashamed was associated with some fathers, which aligned with previous literature discussing disabilities in Arab culture (Crabtree, 2007; Haboush, 2007; Sharifzadeh, 2011).

Parental reaction of denial has been found to be a common response to the initial process of identification of disabilities (Flores, 2012; Graungaard & Skov, 2006; Myers et al., 2009). In this study, some mothers referred to the social stigma associated with any diagnosis of disability in Arab culture, can cause some parents to take a stance of denial or keep the diagnosis secret from others. These mothers described their experiences with their husbands and other members of their extended family and how they initially denied that their children had autism. Members of their extended family also strongly suggested keeping the diagnosis secret from others, particularly those from the Arab community. This finding is consistent with previous research findings conducted with Arab parents of children with disabilities. Crabtree (2007) and Donovan (2013) found that several parents experienced emotional reactions, including denial and

difficulty accepting their children's disabilities, which was more common among fathers.

Again, the lack of knowledge and ambiguity surrounding autism made many parents uncertain about the causes and turned to their own experiences to interpret the causes of autism in their child. In this study, some parents reported feelings of guilt and blaming themselves for their child's autism. One mother described how she frequently was trying to recall her memories from the time of her pregnancy, and asked herself if she did or ate something wrong, causing autism for her child. Another mother blamed herself for having multiple C-sections, which she felt may have caused her child's autism. Moreover, having too many children and being busy with other children in the family were factors that contributed to parents' feelings of guilt and self-blame. Such reactions to the identifications of disability are also found among Arab mothers of children with disabilities in different literature (Crabtree, 2007; Haboush, 2007; Kuaider, 2005; Sharifzadeh, 2011).

Stigma. Although there is a lack of published literature on disabilities in the Arab world, the stigma associated with disabilities in the Arab culture has been well documented (Al-Kandari & Al-Qashan, 2010; Al Thani, 2006; Crabtree, 2007; Wehbi & Lakkis, 2010). In Arab societies, stigmas and social attitudes toward disabilities vary and depend on the kind and severity of disability. Visual impairments, blindness, and deafness are less stigmatizing than other disabilities (Bazna & Hatab, 2005; Gharaibeh, 2009; Lawson, 2015; Sharifzadeh, 2011). Disabilities with no obvious physical signs (i.e. mild mental disabilities, learning disabilities) mostly result in a near typical life under strong protection of the family. Severe mental disabilities and mental illnesses are more stigmatized than physical and sensory disabilities (Ahmead et al., 2010; Al Thani, 2007; Gharaibeh, 2009; Sharifzadeh, 2011).

In this study, all parents expressed several concerns regarding the social stigma

123

associated with individuals with disabilities in Arab communities in particular. Parents indicated that many in Arab communities perceived individuals with any type of disability as "mentally retarded or crazy," which is a harmful social stigma. Parents' concerns regarding mental ability stigma in particular could be correlated with the strong negative stereotypes associated with mental disabilities or mental illnesses in Arab culture, which often results in isolation of a family (Ahmead et al., 2010; Al Thani, 2007; Gharaibeh, 2009; Sharifzadeh, 2011).

Literature also indicated that having a child with a disability might arouse compassion for the individual and empathy for the family in Arab culture (Bazna & Hatab, 2005; Gharaibeh, 2009; Lawson, 2015; Sharifzadeh, 2011). Parents in this study discussed their concerns regarding the reactions of others in Arab communities. They indicated that having a child with special needs in Arab culture caused others to have compassion and empathy of the family that is not necessarily welcome. They shared stories of different reactions from members of the Arab community, including feelings of empathy, mercy, crying, and praying for the child with special needs and his or her family. Such reactions were not desirable by the parents.

Additionally, in Arab societies, females with any disability are more likely to be stigmatized and institutionalized than males with a disability (Gharaibeh, 2009; Sharifzadeh, 2011). In this study, one parent made reference to the cultural perspectives of the difference between male and female with disability. She mentioned that in Arab culture, males with disabilities are less stigmatized than females with disabilities. She clearly stated that if her daughter with autism were a boy, there would be no issues related to social stigma, as Arab society would reword and justify any misbehavior that resulted from autism as a little anger.

As discussed earlier, marriage and having children in Arab culture is imperative (Gregg, 2005; Inhorn, 2012). This cultural more is so ingrained that an adult who is not married is

considered outside the social norm (Inhorn, 2012). However, in terms of individuals with disability, research shows that there are negative implications of disabilities on the marriage prospects for individuals with disabilities and other members in the family (Al-Kandari & Al-Qashan, 2010; Crabtree, 2007; Turmusani, 2003). Moreover, females with disabilities are considered unmarriageable and incapable of fulfilling the primary role of marriage and childbearing (Al Thani, 2007; Wehbi & Lakkis, 2010). In this study, some parents discussed their concerns regards their children's future in regards to marriage. Specifically, one parent was concerned about whether their child would ever marry, and the other parent's main concern was who would marry her daughter and if her daughter's partner would be understanding. This concern is also confirmed with a study conducted with Arab American parents of children with disabilities. Donovan (2013) indicated that parents in her study expressed concerns related to the difficulties their children with disabilities and their siblings would likely confront when seeking a marriage partner in the future.

In several Arab countries, childbearing issues tend to be blamed on mothers, in which mothers are usually considered responsible for the birth of a child with disability (Sharifzadeh, 2011). In this study, one parent described how people around her, including the doctor who diagnosed her child with autism, blamed her for causing her child's autism. This caused her a great sense of guilt and depression, which resulted in her isolation from people for some time. Such social stigma is proven by research in Arab countries (Crabtree, 2007).

Coping and adapting. Religion and spirituality has been found to be a contributing factor to parents' acceptance of their children with disabilities (Al-Krenawi & Graham, 2011; Flores, 2012; Jegatheesan et al., 2010; Kuaider, 2005; Lutz et al., 2012; Rogers-Adkinson et al., 2003). Prayer was identified as a resource and a coping strategy by many parents of children with

disabilities (Coulthard & Fitzgerald, 1999; O'Hanlon, 2013). Some parents used spirituality as a way to understand the purpose behind their child's autism (Flores, 2012; Mirza et al., 2009). The findings of previous research aligned with the findings of the current study. All parents in this study who attributed their beliefs of their child's autism as the will of God credited this as one of the first aids that helped them to deal and cope with their child's autism. Parents cited from the Quran that God chose them because they are qualified and capable of caring for a child with special needs. Parents also believed they received strength from God to bear and overcome the challenges they were facing, and that their spirituality and faith equipped them with the tools they needed to adapt to their situation, accept their child's diagnosis, and retain hope for their and their child's future. Additionally, spirituality was one of the coping techniques that all the parents identified that they often turned to as a method to cope and deal with the challenges and difficulties they encountered in addressing and handling their child's needs. Parents turned to prayer and the Quran for guidance and support.

In addition to religion and spirituality, research has shown the importance that the extended family serves in the lives of Arab families (Ajami et al., 2016; Cainkar & Read, 2014; Sharifzadeh, 2011). As discussed above, the role of the extended family in assisting parents to overcome challenges associated with parenting a child with autism was evident in all cases in this study. Parent participants acknowledged extended family members as a key support that provided them with a network of support to cope and adapt to their new role as parents of a child with autism.

Positive gains. In this study, parents expressed finding positive aspects of having a child with autism in the family. Parents described different positive effects that they and other family members gained in their lives that resulted from their experiences with their children with

autism, including a change in their overall perspective in terms of thinking and how they viewed life, particularly how they treat others with disabilities in terms of respect, empathy, and a better sense of understanding. Parents shared that they and other family members became more patient, more sympathetic, more loving of others, more resilient, and better equipped to deal with life's challenges. Similar findings have been indicated by parents of children with disabilities in different studies (Flores, 2012; Kuaider, 2005; Myers at al., 2009).

Finally, parents also shared that their experiences with their child's autism brought them closer to God, and their spirituality was deepened because of their situation; they perceived this as a positive effect. Some parents felt it was a blessing to have a child with autism, as well. Some parents shared stories about things in their lives that got better because God rewarded them for their care of a child with autism. This finding is consistent with previous research findings by (Flores, 2012; Gardiner & Iarocci, 2012; Kuaider, 2005; Myers at al., 2009), in which parents felt it was a blessing from God to raise a child with a disability and expressed that having a child with a disability strengthened their religious beliefs and increased their spirituality.

Discussion of Current Study Findings in Relation to the Conceptual Framework

As detailed in Chapter Two, the synthesis of literature regarding multicultural perspectives and disability revealed a number of linked concepts that influence families' perspectives of having a child with a disability and their decisions regarding their children's education. In this study, these concepts presented as a conceptual framework that provided me with a basis and direction for pursuing a productive review of literature, analyzing and interpreting the findings of this inquiry, and a broader understanding of the phenomenon being studied (Imenda, 2014). These concepts represent factors that predict or explain how parents differently raise their children, view disability, respond to their children's diagnosis, access

127

health care, and are involved in their children's education and intervention. These concepts include religious beliefs, education level, socio-economic status, acculturation, and English language proficiency. In this section, the influence of each concept is discussed in relation to the current study findings.

Religious Beliefs

The influence of religion on beliefs regarding disability is widespread and global. In research on children with disabilities, the perception that religious beliefs can play a significant role in the interpretation, explanation, responses, and acceptance of disability is consistently recognized (Jegatheesan et al., 2010). In this study, all participants were Muslim, and the profound influence of Islamic values was explicit. This was demonstrated in their child rearing practices, their beliefs toward disability, and their accepting and coping techniques. Parents discussed how they instilled Islamic values in their children, including their children with autism. For example, parents were keen to send their children to the mosque after school or on the weekends to learn Arabic, Islamic studies, and reading the Quran. For some parents, the ability to maintain Islamic values and practice religion was a major concern regarding their children with autism.

In addition, parents explicitly discussed the influence of religious beliefs on their interpretations of disability, and their accepting and coping techniques. Parents pointed out that one of the first aids that helped them accept their child's autism was a belief that their child's autism is the will of God. Parents cited from the Quran that God chose them because they are qualified and capable of caring for a child with special needs. Parents believed that having a child with autism is a test from God, and they must pass this test. Some parents felt having and caring for a child with autism is their path to heaven after life. These findings also confirmed the

128

findings of previously discussed literature conducted with Muslim parents of children with disabilities (Jegatheesan et al., 2010; Mirza et al., 2009). Hence, in this study, parents' religious beliefs proved to be a contributing factor to their interpretation, responses and acceptance of their children's autism.

Education Level

The parents' educational level has a great influence on their perception and acceptance of disability, their help-seeking behaviors, and their expectations and involvement in their children with disabilities intervention and education. Studies have shown that higher levels of parental education were associated with earlier diagnosis, greater satisfaction with the diagnostic process, more involvement in child intervention and education, and overall satisfaction with professionals and services (Deslandes & Bertrand, 2005; Garland et al., 2013; Fishman & Nickerson, 2015; Jones & Gansle 2010; Halsey, 2005; Hidalgo et al., 2015). Parents with higher education are more able to locate support and informational resources, more likely to be informed and aware about best practices, services, and intervention, as well as better prepared for challenges and barriers to their children's education (Hidalgo et al., 2015). In addition, the parents' education level predicts how much participation in school is observed. Research on parents of children with disabilities indicate that parents with a higher level of education are more likely to participate and involve themselves in school activities than parents with lower levels of education (Deslandes & Bertrand, 2005; Fishman & Nickerson, 2015; Jones & Gansle 2010; Halsey, 2005).

In general, research suggests that highly educated parents form more reasonable expectations about their children's performance and educational outcomes (Alexander et al., 1994; Halle et al., 1997), have more abilities to foster children's adjustment and produce a

cognitively motivating home environment (Davis-Kean, 2005; Wang et al., 2016), are more

motivated to seek help for their children (Garland et al., 2013), showed lower levels of anger,

and cope with barriers and stress efficiently (Parkes et al., 2015; Shokoohi-Yekta et al., 2011),

compared to parents with a lower education level.

This study consisted of parents who had an education level that ranged from high school

to graduate degree. However, these differences in parents' educational levels did not necessarily

present a difference in their abilities to understand their children's diagnosis, locate support and

informational resources, seek help for their children, cope with barriers and stress efficiently, and

involve themselves in their children's education and interventions. All parents were equally able

to understand and accept their children's autism, and were able to seek help and be involved in

their children's education regardless of their education level. Thus, based on the findings of this

study, the parents' educational level does not necessarily contribute to their perception,

expectations, and involvement with their children with disability's intervention and education.

However, the only difference that I noticed and would like to point out is that parents who were

born and educated in the US reported having more prior knowledge about autism (although

minimal) than parents who were born and educated in the Arab world. Therefore, the place of

education could be a contributing factor to their prior knowledge about autism in particular.

Socioeconomic Status (SES)

The discussion of families' socioeconomic status (SES) in this section is intended to be

interpreted as the family's income. A family's income affects their ability to access health care,

which directly impacts their children's early diagnosis and identification, planning of

intervention, technology utilization, and specialized training and support services provided to

their children with disabilities (Ennis-Cole et al., 2013; Gibson, 2007; Lin et al., 2012). In this

study, most parents consistently reported limited access to therapies due to issues with health insurance. Insurance issues proved to be an obstacle. Parents had to deprive their children of services and therapies they needed as their health insurance did not cover these therapies, and parents, at the same time, cannot afford these expenses. These findings are consistent with previous research that indicated families who have difficulties accessing health care due to a lack of health insurance receive less types of services, face additional barriers, and experience greater difficulty in locating support and informational resources (Hidalgo et al., 2015; Irvin et al., 2012; Lin et al, 2012).

On the other hand, families in this study who have a higher income were more able to start early intervention, access a variety of services and did not have to limit their child's therapies to the only one approved by their health insurance. These findings are consistent with previous findings showing that families with a higher income are more likely to report being satisfied with the special education process, are more likely to receive more types of services, and face fewer barriers to accessing services than families with lower incomes (Goin-Kochel et al., 2006; Hidalgo et al., 2015; Irvin et al., 2012; Moh & Magiati, 2012). Accordingly, in this study, parent income proved to be a contributing factor to the overall ability to access health care and necessary services for their children with autism.

Acculturation

Acculturation is defined as "a complex process of psychological and cultural change resulting from the contact of two different cultures, with one group of people being dominant and the other forced to modify or adapt some of their original cultural patterns and to absorb some of the dominant culture's in order to accommodate to a new environment" (Rodriguez, 2010, p. 83). Acculturation is a complex and multidimensional process that involves several domains,

131

including identity, behaviors, attitudes, values, and cultural beliefs (Matsudaira, 2006; Sun et al., 2016; Yoon et al., 2011). The multidimensional process of acculturation indicates that individuals adopt both cultures and do not necessarily give up one or the other (Pak, 2006). Literature showed that the degree of acculturation with mainstream culture changed families' perception, motivation, and behaviors from similar cultural and linguistic backgrounds. This includes changes in their child rearing practices, perceptions of disability, help-seeking attitudes and behavior, and involvement in their child's intervention (Al Khateeb et al., 2014; Dinh & Nguyen, 2006; Guerrero, & Leung, 2008; Sklar et al., 2016; Venza, 2002).

This study consisted of parents who have been in the US for different periods of time. Some parents were born, raised, and educated in the US, while others were born, raised, and educated in the Arab world. However, these differences did not appear to affect their degree of acculturation. In other words, all parents, no matter where they were born and raised, shared similar beliefs toward disabilities, child rearing practices, concerns, and needs, in which most related to their culture. For example, all parents shared the belief that having a child with disability is the will of God, a test from God, and that God chose them and will reward them for caring for a child with special needs. Some parents shared the belief that *"Ein"* or *"evil eye"* could be the cause of their children's autism. These findings are consistent with previous research findings conducted with Muslim parents, and Arab parents of children with special needs living in the Arab world (Al- Krenawi & Graham, 2011; Jegatheesan et al., 2010; Mirza et al., 2009). This also could be interpreted by the profound influence of the Islamic religion and Arab culture on these families. Therefore, the degree of acculturation to mainstream culture does not appear to be a contributing factor to Arab American parents' beliefs toward disability, child rearing practices, concerns, and needs that are identified in this study.

English Language Proficiency

Scholars found that immigrant families' English language ability affected their ability to understand their children's disabilities and to communicate, advocate, and access appropriate services for their children with disabilities (Al-Hassan & Gardner III, 2002; Al Khateeb et al., 2014; Hornby & Lafaele, 2011; Sentell et al., 2007). Parents with poor English language skills face more barriers and difficulties that limit their ability to access resources and needed services, communicate effectively with professionals, and obtain clear information on intervention and treatment (Hornby & Lafaele, 2011; Mui et al., 2007; Sentell et al., 2007). Limited English proficiency has been shown to be a barrier to most parents' involvement at school and subsequent withdrawal from participating in school activities (Geenen et al., 2001; Hornby & Lafaele, 2011; Lai & Ishiyama, 2004; Tumey & Kao, 2009).

In this study, all parent participants speak English fluently; their language was not a barrier in any way relating to their children's education or interventions. No single parent reported miscommunication or barriers to access services or information due to language difficulty. Parents were able to communicate effectively with professionals working with their children, were able to access different sources of information, and were fully involved in their children's education and interventions. Thus, the parents' English language proficiency could be a contributing factor to their overall successful communication and participation in all aspects related to their children's education and services.

Researcher's Reflexivity

In qualitative studies, researchers are considered a "human instrument" as they collect, analyze, and interpret data. The researcher's background, biases, beliefs, perspectives, and experiences could influence every step of the research process. Researchers cannot separate

themselves from collection, analysis, and interpretation of data (Holloway & Biley, 2011). Accordingly, different researchers could approach the same study from different perspectives. This might lead to the development of different understandings of the same study. Thus, qualitative researchers are advised to talk about their presumptions, experiences, decisions, and actions throughout the research process (Mruck & Breuer, 2003). Several scholars believe that it is crucial and precious to concisely report in manuscripts how researchers' presumptions, values, position, and beliefs may have influenced the research process (Amankwaa, 2016). Developing a reflective journal can provide a context in which researchers' assumptions, values, and perspectives can be revealed (Amankwaa, 2016) and allows researchers to begin to acknowledge themselves as co-generators of the knowledge presented in their investigations (Holloway & Biley, 2011).

My interest in this area is longstanding. Both my undergraduate and graduate studies were in special education, specifically in autism studies, in addition to my experience as a special education teacher in my country in the Arab world. This is also further bolstered by my experience as an Arab parent who is currently living in the US. Thus, these combined experiences prompted my interest in the experiences of Arab American parents of children with autism. To me, further deepening my understanding in this area has been substantial to conducting this imperative research, as was my desire to contribute to the field of special education. In this study, I kept a reflective journal where I made an entry after each interview. I included information about my personal thoughts, expectations and reactions, the interview settings, interaction and communication style, and noted any other significant information that I could remember.

My search for my dissertation's literature review, my previous experience working with Arab families with children with special needs, and being an Arab myself, who grew up in Arab culture, all shaped my expectations going into this study. Accordingly, prior to conducting the interviews, I was anticipating some of the responses to the interview questions that I received. This included the parents' initial reactions to the diagnosis of autism and feelings of guilt, shame, and denial; the parents' concerns of social stigma associated with disabilities in Arab communities; the importance of extended family and the extended family's essential role in supporting and assisting parents to cope and raise a child with autism; and the influence of religion on parents' beliefs toward disability. Generally, these expectations were confirmed in the parents' interviews that were conducted for this study. However, in this study, I was surprised at how Arab parents openly and comfortably shared their unique experiences, as disability is a very sensitive topic in Arab culture. I was also surprised by their negative experiences with their child's pediatricians in the initial stage.

Further, in this study, I was anticipating the process of recruitment to be difficult. Thus, a small number of participants was expected. Accordingly, I planned to recruit participants by different ways (flyers, asking leaders of mosques, asking Islamic schools, asking the existing study participants to recruit other participants from among their acquaintances), so the process would be more sufficient and efficient. However, what I did not anticipate was the recruitment period. It took around five months to recruit all participants. I was expecting two months to be sufficient for requirement. In looking back, I would plan for a longer recruitment period to lessen stress during this phase of the study.

Overall, my experience while conducting this study was very rewarding. I deeply appreciate how parents displayed courage in sharing their personal experiences, especially to a

person who was a stranger to them. I also appreciated their desire to increase awareness and help other families in similar situations through their participation in this study and sharing their experiences. Their commitment to their family and their daily sacrifices for their children proved that parents remain the foremost experts on their children. In my opinion, parents always play the most significant role, regardless of the number of professionals who are involved in caring for a child with autism. Thus, it is imperative for professionals to acknowledge the parents' essential role and to support them in this overwhelming, ambiguous, and complex process. It is also abundantly clear that it is important for parents and professionals to collaborate when it comes to providing quality care for children with autism.

Implications of Findings for the Field of Special Education

The findings of this study present imperative implications for the needs and concerns of Arab American parents of children with special needs, particularly regarding their communication and interactions with special education and service providers. These recommendations are designed to promote cultural competence and professional understanding of the Arab American population. Special education and related service providers can benefit from the following recommendations to increase professional knowledge of the values and needs of the Arab American families, enhance the collaboration process, build trust and sustain respectful relationships, and design and provide more appropriate educational plans and services for the child and family. In this section, recommendations are formed based on the findings of this study as well as on the current related literature. The recommendations relate to communication and interactions, perspectives and beliefs of disabilities, and arranging support for Arab American families.

Communication and Interactions with Arab American Families

Given that Arab American service providers represent a small number of total service providers, it is highly possible that non-Arabs will be interfacing with Arab American families with different cultural values, beliefs, and perspectives from those of the mainstream US culture. Hence, it is imperative to address this cultural gap between Arab American families and service providers. The following clarification about communication and interaction features that characterize the differences of Arab culture from dominant US culture is intended to provide support for special education and related service providers to increase cultural awareness and necessary skills when interacting with Arab American families and their children.

Communication style. Within the Arab culture, preference for informal and in-person forms of communication are recognized. Therefore, when reaching out to parents, a personal and informal approach should be used, rather than formal and assertive communication. Additionally, most Arab Americans tend to be less direct, and they do not clearly emphasize and express what they want others to know. They instead rely greatly on subtle messages, such as the use of facial expression and body language (Al Khatib, 2017). Thus, special education and related service providers should be aware of Arab American families' differing communication styles to produce more effective interactions and avoid misunderstandings that might result in conflict between them.

Proximity. Proximity and touching is different in Arab culture. Arabs tend to maintain a distance between speaker and listener, unless they are very familiar with each other. Close distance between strangers is uncomfortable. Thus, the close conversational distance between parents and service providers might be unacceptable. Additionally, initiating a handshake, especially between unacquainted males and females, might be unacceptable unless the individual

extends their hand to you first. Hugging and backslapping, for example, are not acceptable, especially between unacquainted males and females.

Eye contact. Professionals working with Arab American families should be aware of the level of eye contact in Arab culture. For example, prolonged eye contact, or making eye contact with someone in authority, may be interpreted as disrespectful. Eye contact between unacquainted males and females maybe considered shameful. Therefore, it is important to not interpret lack of eye contact as disinterest or disrespect.

Gender sensitivity. Gender differences in Arab culture are obvious. Relationships and communication between males and females in Arab societies, especially Muslims, are restricted. Accordingly, being the opposite gender may pose some difficulties when interacting with Arab families. For example, a female parent would find it embarrassing and difficult to discuss private subjects related to women (i.e. pregnancy or childbirth) with male doctors or service providers. Therefore, it is necessary for special education and related service providers to maintain specific gender boundaries, such as avoiding discussing sensitive topics with opposite gender, avoiding initiating a handshake or hugging, maintaining minimal eye contact, and considering an appropriate physical distance between the parent and the service provider.

Knowledge of Arab Cultural Perspectives and Beliefs on Disabilities

Understanding the role of culture in family perspectives, beliefs, and interactions is essential when working with families and children from different cultural backgrounds. Given the importance of Arab culture and Islamic values to parent participants in this study, it is important for special education and related service providers to become familiar with Arab cultural values and perspectives toward disabilities. It is also critical to understand each family's unique experiences and backgrounds, as Arabs are a heterogeneous group and have a diverse

cultural heritage that includes different religions, nationalities, education levels, Arabic dialects, and social classes (El-Khadiri, 2009). There are no specific guidelines that can sufficiently describe all aspects of the Arab culture to accurately understand them and their needs. Therefore, it is important for professionals working with Arab American families to seek out information about the Arab world's history, religions, politics, and the different socio-economic levels of Arab countries. Getting to know each family well also can be the best way to understand the family's unique experiences and background and provide them with more adequate services. This could be, if appropriate, through informal phone calls or home visits, where professionals can express an interest in the family's background to better understand and learn more about their particular perspectives and experiences.

Parental reactions to the identification. The identification and diagnosis of disability can cause a significant emotional response in parents. During the initial stage of identification, and due to cultural stigmas attached to disabilities in Arab culture, some Arab Americans parents may respond with strong emotion and refuse any discussion or reference to disabilities. For these parents, especially fathers, the struggle with accepting their children's identification with disabilities and placement in special education settings is greater (Crabtree, 2007; Haboush, 2007), as they perceive this placement might cause lower self-esteem among their children (Al Khateeb et al., 2015). Therefore, it is particularly important during the initial stage to work extensively with Arab American families. To thoughtfully cross this stage, professionals need to disclose disability with sensitivity, and avoid using terminology related to disabilities, especially terms related to intellectual and mental abilities. Rather, they should emphasize the child's strengths and his/her unique learning needs compared to other children.

In addition, there could be a variety of different reactions to the identification in one family. One parent might be reassured and accept the situation, while the other might respond with denial, rejection, or anger. If this situation arises, professionals need to talk to each parent differently, and attempt to recognize their concerns and understand their perspectives. Doing this would allow professionals to sustain relationships with both parents without creating a divisive situation. In case only one parent is involved and participates in meetings, professionals need to ask how the other parent could be reached if the professionals should be in touch with him or her.

Further, while being from a Muslim religious background was not part of the inclusion criteria for this study, all of the individuals who volunteered to participate were Muslim. Since religion and spirituality have been found to be critical factors in the beliefs, acceptance, adaptation, and daily routine of Arab American Muslim families, professionals need to be attentive to the influences of these factors on the perspectives and reactions of Arab American Muslim families of children with special needs. For example, some parents may turn to spirituality and prayers and rely on them for their child's situation to recover more than on interventions and therapies, which is something that might cause an opposing view from professionals. Therefore, professionals should acknowledge the significant role of religion and spiritualty in the lives of Arab American Muslim families and express a respect for and awareness of the family's religion and beliefs. In doing so, professionals would gain more family trust, which would improve the relationship between them, and would result in more family involvement and a more fruitful collaboration process.

Confidentiality. Given the social stigma attached to disability in the Arab culture, Arab American parents may show greater concerns regarding privacy and confidentiality. During

communication and interaction, special education and related service providers should respect and understand parents' concerns, and should frequently overemphasize that all personal information about the child and family will be kept confidential. Parents should also be informed of why particular information is obtained, who will be able to access their private information, and how it will be used.

Sensitivity of social and religious status. Arabs and Muslim Americans are vulnerable to discrimination, negative distortions, and even hate crimes more than other ethnic group in the US (Cainkar, 2009; Khan & Ecklund, 2012). During the interviews conducted for this study, and given that all participants were Muslims, I sensed that the participants felt they were disadvantaged and discriminated against because of their religion and culture. Such feelings can hamper the trust relationship. Thus, special education and related service providers should be sensitive and conscious of this issue and assist families in feeling more comfortable to lessen possible suspicion, especially in the initial interfaces.

Help Arranging Support

In this study, parents expressed the greatest need for more information about the autism diagnosis, the causes of autism, and how autism will affect their child. For many parents, and due to the lack of overall awareness and knowledge about autism combined with vague information provided at the time of diagnosis, parents struggled with wanting a clearer understanding and answers to many questions about autism, which made them feel uncertainty about the diagnosis of autism, and an overall feeling of unpreparedness about how to move forward. Therefore, it is important for professionals working with Arab families to provide parents with this critical information in a clear and jargon-free manner to foster better understanding. In some cases, diagnostic information should be provided in the parents' native language.

Moreover, service providers should inquire about available community resources and support to Arab American families, and assist them in locating and utilizing theses resources. Parents also should be asked what types of support and resources they would prefer and could utilize, such as parent support groups, parent education workshops, web sites, literature, community organizations, and mental health counseling. Doing so will lessen possible feelings of stress and anxiety and assist parents to better prepare for forthcoming care of their child with special needs. Additionally, due to the complexity and long-term prognosis of autism, it is important for any service providers who have contact with the family to frequently check in with parents concerning their child's development and their personal well-being and stress levels. If parents are able to manage their stress and well-being, they are more able to meet their child's daily needs as a caregiver.

In addition, in this study, it has been found that families do not attend parent support groups, either because they are not aware of this kind of social support system or because of the lack of information about such support groups in their area. Moreover, it could be possible that parents are not attending these groups because of issues existing within the structure of these groups, or because they feel they are different and that non-Arab parents would not understand them, as some parents referenced to the need of support group for Arab parents. This should be addressed by service providers who want to provide social support for Arab families of children with disabilities. Such issues could be addressed by providing parents with information about the available parent support groups in their area, modifying existing services, or establishing a support group for Arab parents of children with disabilities. If such issues are addressed, families may find the support they need in these groups, especially for immigrant families who may have lost their social support when leaving their home countries.

Further, one of the areas parents felt could see a significant amount of improvement is continuing education for professionals to better recognize and diagnose autism, especially for pediatricians, as they are often the first professional the family seeks when they notice a difference in their child's behavior and development. Even when parents recognized symptoms early, pediatricians did not acknowledge that there was an issue, and dismissed the parents' concerns. These children ended up receiving an autism diagnosis several months to years later, which resulted in them not having access to early intervention or timely referrals, which are services that can make a drastic difference in producing a better outcome for children living with autism. Parent experiences indicate a need for physicians to receive more education and training on the identification, diagnosis, and management of autism to better help their patients and families in terms of recognizing the early symptoms and providing accurate information to parents about what to expect so the parent can be informed of how to improve their child's well-being.

Recommendations for Future Research

The primary aim of this study was to explore Arab American parents' experiences of caring for a child with autism. This study is the first of its kind. No previous research, qualitative or quantitative, has focused on the experiences of Arab American parents of children with autism. Thus, this research merely begins to explore this significant topic; further research is needed. Future explorations would allow special education and service providers to increase their cultural competence, which in turn, would improve the outcomes for Arab American families and their children with disabilities.

In this study, all participants lived in the same city in the Southeast US, and were recruited through acquaintances. Therefore, participants' experiences could have been different if

143

they lived in different regions. It is also possible that participants generally share the same experiences, perspectives, and values regardless of location of residence. Thus, future research is recommended to access a wider array of participants in different geographical regions in the US, as this could potentially yield different findings or could illustrate that experiences, perspectives, and values are comparatively steady.

Future research that also could enhance our understanding of the experiences of Arab American parents of children with autism could explore the perspectives and experiences of service providers who work with these families. Observational research that investigates the interactions between Arab American parents and service providers could also explain the dynamics involved in those interactions. Future research could also compare or explore the differences between the experiences and interactions of Arab American parents of children with autism and mainstream American parents with service providers.

Further, given that autism is a lifetime disorder, the burden of raising and caring for a child with autism can affect the family as a whole. Thus, further research that investigates the perspectives and experiences of fathers and typically developing siblings of individuals with autism is important. Given the fact that the majority of participants in research related to Arab parents of children with special needs are mothers, including participants in this study, it is suggested that future research should address the lack of male participation, particularly fathers in the Arab community. Future research could make a greater effort to recruit several sets of Arab parents of children with autism. This may allow researchers to gain a richer perspective from fathers' experiences that are absent in the current literature.

It is also suggested that future research should explore the experience of siblings of individuals with autism, their responsibilities and functions within the family, and their

understanding of their sibling's diagnosis. Siblings play an important role within the family, and are affected by their sibling's autism diagnosis, as well. Parents in this study expressed concerns about how their typically developing children have been impacted and will continue to be impacted by autism. It will be important for research to explore the perspectives of typically developing siblings and how autism has impacted their lives. It is also important to identify mechanisms and strategies that would assist typically developing siblings to adapt and adjust to living with a sibling with autism. These important research aspects need to be explored from the perspective of Arab families, given the fact that there is no previous research focused on typically developing siblings of individuals with autism within the Arab community context.

Conclusion

In this last chapter, the findings of this qualitative interview research are reviewed in relation to the current study research questions and discussed in the context of relevant literature and in relation to the conceptual framework. This study is the first study exploring this topic. The findings offered insight into Arab American parents' unique experiences of caring for a child with ASD, and provided detailed discussion on the aspects related to Arab cultural beliefs with the autism diagnostic process. Future research is strongly recommended to continue exploration of Arab American parents' experiences with their children with ASD, and their communication and interactions with special education professionals and related services. Thus, relevant recommendations have been provided for future research. In addition, implications of the findings for the field of special education were discussed in this chapter.

References

Abadeh, H. (2006). *Perceptions of Arab American parents with children with special needs regarding home–school communications* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database. (UMI No. 3244125).

Abel, E. L. (2003). *Arab genetic disorders: A layman's guide*. Jefferson, NC: McFarland & Company Publisher.

Adeeb, P., & Smith, P. (1995). The Arab Americans. In C. A. Grant (Ed.), *Educating for diversity: An anthology of multicultural voices* (pp. 191-207). Boston, MA: Allyn & Bacon Publisher.

Ahmad, S., & Reid, D. W. (2008). Relationship satisfaction among South Asian Canadians: The role of 'complementary-equality' and listening to understand. *Interpersona, 2*(2), 131-150.

Ahmead, M. K., Rahhal, A. A., & Baker, J. A. (2010). The attitudes of mental health professionals towards patients with mental illness in an inpatient setting in Palestine. *International Journal of Mental Health Nursing, 19*(5), 356-362.

Ajami, J., Rasmi, S., & Abudabbeh, N. (2016). Marriage and family: Traditions and practices throughout the family life cycle. In M. M. Amer & G. H. Awad (Eds.), *Handbook of Arab American psychology* (pp. 103-116). New York, NY: Routledge Publisher.

Ajrouch, K. J., Hakim-Larson, J., & Fakih, R. R. (2016). Youth development: An ecological approach to identity. In M. M. Amer & G. H. Awad (Eds.), *Handbook of Arab American psychology* (pp. 91-102). New York, NY: Routledge Publisher.

Albrecht, S. F., Skiba, R. J., Losen, D. J., Chung, C. C, & Middelberg, L. (2011). Federal policy
on disproportionality in special education: Is it moving us forward? *Journal of Disability
Policy Studies, 23*(1), 14-25.

Al-Busaidi, Z. Q. (2010). A qualitative study on the attitudes and beliefs towards help seeking
for emotional distress in Omani women and Omani general practitioners: Implications for
post-graduate training. *Oman Medical Journal, 25*(3), 190-198.

Alexander, K. L., Entwisle, D. R., & Bedinger, S. D. (1994). When expectations work: Race and
socioeconomic differences in school performance. *Social Psychology Quarterly, 57*(4),
283-299.

Al-Hassan, S., & Gardner III, R. (2002). Involving immigrant parents of students with
disabilities in the educational process. *Teaching Exceptional Children*, *34*(5), 52-58.

Al-Kandari, H. Y., & Al-Qashan, H. (2010). Maternal self-efficacy of mothers of children with
intellectual developmental disabilities, Downe syndrome, and autism in Kuwait. *Child
and Adolescent Social Work Journal, 27*(1), 31-39.

Al Khateeb, J. M., Al Hadidi, M. S., & Al Khatib, A. J. (2014). Arab Americans with disabilities
and their families: A culturally appropriate approach for counselors. *Journal of
Multicultural Counseling and Development*, *42*(4), 232-247.

Al Khateeb, J. M., Al Hadidi, M. S., & Al Khatib, A. J. (2015). Addressing the unique needs of
Arab American children with disabilities. *Journal of Child and Family Studies*, *24*(8),
2432-2440.

Al Khatib, J. M. (2017). *Arab American children with disabilities: Considerations for teachers
and service providers.* New York, NY: Routledge Publisher.

Al-Krenawi, A., & Graham, J. R. (2011). Mental health help-seeking among Arab university

    students in Israel, differentiated by religion. *Mental Health, Religion and Culture, 14*(2),

    157-167.

Al-Krenawi, A., & Jackson, S. O. (2014). Arab American marriage: Culture, tradition, religion,

    and the social worker. *Journal of Human Behavior in the Social Environment, 24*(2), 115-

    137.

Al-Omari, J. (2008). *Understanding the Arab culture: A practical cross-cultural guide to*

    working in the Arab world. London, UK: Hachette UK Publisher.

Al Thani, H. A. (2007). Disability in the Arab region: Current situation and prospects. *Journal*

    for Disability and International Development, 3(1), 4-9.

Amankwaa, L. (2016). Creating protocols for trustworthiness in qualitative research. *Journal of*

    Cultural Diversity, 23(3), 121-127.

Amer, M. M., & Kayyali, R .A. (2016). Religion and religiosity: Christian and Muslim faiths,

    diverse practices, and psychological correlates. In M. M. Amer & G. H. Awad (Eds.),

    Handbook of Arab American psychology (pp. 48-62). New York, NY: Routledge

    Publisher.

Arab American Institute. (2010). *Demographics.* Retrieved from

    http://www.aaiusa.org/demographics

Arab American Institute. (2010). *Detailed state profiles.* Retrieved from

    http://www.aaiusa.org/state-profiles-detailed

Arab American Institute. (2014). *Who are Arab Americans?* Retrieved from

    http://www.aaiusa.org/who-are-arab-americans

Artiles, A. J., Kozleski, E. B., Trent, S. C., Osher, D., & Ortiz, A. (2010). Justifying and explaining disproportionality, 1968–2008: A critique of underlying views of culture. *Exceptional Children*, *76*(3), 279-299.

Atkinson, R., & Flint, J. (2001). Accessing hidden and hard-to-reach populations: Snowball research strategies. *Social Research Update*, *33*(1), 1-4.

Atun-Einy, O., & Ben-Sasson, A. (2018). Pediatric allied healthcare professionals' knowledge and self-efficacy regarding ASD. *Research in Autism Spectrum Disorders, 47*(1), 1-13.

Awad, G. H., & Amayreh, W. M. (2016). Discrimination: Heightened prejudice post 9/11 and psychological outcomes. In M. M. Amer & G. H. Awad (Eds.), *Handbook of Arab American psychology* (pp. 63-75). New York, NY: Routledge Publisher.

Baker, S. E., Edwards, R., & Doidge, M. (2012). How many qualitative interviews is enough?: Expert voices and early career reflections on sampling and cases in qualitative research. *National Centre for Research Methods Review Paper.* Retrieved from http://eprints.ncrm.ac.uk/2273/

Banach, M., Iudice, J., Conway, L., & Couse, L. J. (2010). Family support and empowerment: Post autism diagnosis support group for parents. *Social Work with Groups, 33*(1), 69-83.

Barbaro, J., & Dissanayake, C. (2009). Autism spectrum disorders in infancy and toddlerhood: A review of the evidence on early signs, early identification tools, and early diagnosis. *Journal of Developmental & Behavioral Pediatrics, 30*(5), 447-459.

Bazna, M. S., & Hatab, T. A. (2005). Disability in the Qur'an: The Islamic alternative to defining, viewing, and relating to disability. *Journal of Religion, Disability and Health*, *9*(1), 5-27.

149

Beitin, B. K., & Aprahamian, M. (2014). Family values and traditions. In S. C. Nassar-McMillan, K. J. Ajrouch, & J. Hakim-Larson (Eds.), *Biopsychosocial perspectives on Arab Americans: Culture, development, and health* (pp. 67-88). New York, NY: Springer.

Bernard, H. R. (2011). *Research methods in anthropology: Qualitative and quantitative approaches* (5th ed.). Lanham, MD: AltaMira Press.

Bishop, S. L., Richler, J., Cain, A. C., & Lord, C. (2007). Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *American Journal on Mental Retardation*, *112*(6), 450-461.

Bleakley, H., & Chin, A. (2004). Language skills and earnings: Evidence from childhood immigrants. *Review of Economics and Statistics*, *86*(2), 481-496.

Bornstein, M. H., & Cote, L. R. (2004). Mothers' parenting cognitions in cultures of origin, acculturating cultures, and cultures of destination. *Child Development, 75*(1), 221-235.

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children*, *71*(2), 195-207.

Brinkmann, S. (2014). *Qualitative Interviewing*. New York, NY: Oxford University Press.

Brinkmann, S., & Kvale, S. (2015). *Interviews: Learning the craft of qualitative research interviewing* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Britto, P. R., & Amer, M. M. (2007). An exploration of cultural identity patterns and the family context among Arab Muslim young adults in America. *Applied Development Science, 11*(3), 137-150.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.

Brown, H., Guskin, E., & Mitchell, A. (2012). Bringing news to a diverse community. Pew

    Research Center, Washington, D.C. Retrieved from

    http://www.journalism.org/analysis_report/arabamerican_media

Cainkar, L. (2006). The social construction of difference and the Arab American experience.

    Journal of American Ethnic History, 25(2/3), 243-278.

Cainkar, L. A. (2009). *Homeland insecurity: The Arab American and Muslim American*

    experience after 9/11. New York, NY: Russell Sage Foundation.

Cainkar, L., & Read, J. N. G. (2014). Arab Americans and gender. In S. C. Nassar-McMillan, K.

    J. Ajrouch, & J. Hakim-Larson (Eds.), *Biopsychosocial perspectives on Arab Americans:*

    Culture, development, and health (pp. 89-105). New York, NY: Springer.

Camacho-Thompson, D. E., Gillen-O'Neel, C., Gonzales, N. A., & Fuligni, A. J. (2016).

    Financial strain, major family life events, and parental academic involvement during

    adolescence. *Journal of Youth and Adolescence, 45(*6), 1065–1074.

Campbell-Wilson, F. (2012). Middle East and Arab American cultures. In D. E. Battle (Ed.),

    Communication disorders in multicultural and international populations (pp. 61-75). St.

    Louis, MO: Mosby Publishing.

Centers for Disease Control and Prevention. (2016). *New data on autism: Five important facts to*

    know. Retrieved from http://www.cdc.gov/features/new-autism-data/index.html

Chapman, A. R., & Bennett Cattaneo, L. (2013). American Muslim marital quality: A

    preliminary investigation. *Journal of Muslim Mental Health, 7*(2), 1-24.

Clifford, T., & Minnes, P. (2013). Who participates in support groups for parents of children

    with autism spectrum disorders? The role of beliefs and coping style. *Journal of Autism*

    and Developmental Disorders, 43(1), 179-187.

Coulthard, P., & Fitzgerald, M. (1999). In God we trust? Organized religion and personal beliefs

    as resources and coping strategies, and their implications for health in parents with a

    child on the autistic spectrum. *Mental Health, Religion, and Culture*, *2*(1), 19-33.

Crabtree, S. A. (2007). Family responses to the social inclusion of children with developmental

    disabilities in the United Arab Emirates. *Disability and Society, 22*(1), 49-62.

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five*

    approaches. Los Angeles, CA: Sage Publications.

Crotty, M. (2003). *The foundations of social research: Meaning and perspective in the research*

    process. Thousand Oaks, CA: Sage Publications.

Davis-Kean, P. E. (2005). The influence of parent education and family income on child

    achievement: The indirect role of parental expectations and the home environment.

    Journal of Family Psychology, 19(2), 294-304.

Dallo, F. J., Al Snih, S., & Ajrouch, K. J. (2009). Prevalence of disability among US- and

    foreign-born Arab Americans: Results from the 2000 US Census. *Gerontology, 55*(2),

    153-161.

Davis, R., & Gordon, J. (Eds.). (2010). *Social work and the law in Scotland*. London, UK:

    Palgrave Macmillan Publisher.

Dedoussis, E. (2004). A cross-cultural comparison of organizational culture: Evidence from

    universities in the Arab world and Japan. *Cross Cultural Management: An International*

    Journal, 11(1), 15-34.

Denzin, N. K., & Lincoln, Y. S. (2011). *The SAGE handbook of qualitative research*. Thousand

    Oaks, CA: Sage Publications.

Deslandes, R., & Bertrand, R. (2005). Motivation of parent involvement in secondary-level

    schooling. *The Journal of Educational Research*, *98*(3), 164-175.

Dillenburger, K., McKerr, L., Jordan, J. A., & Keenan, M. (2016). Staff training in autism: The

    one-eyed wo/man. *International Journal of Environmental Research and Public Health,*

    13(7), 716-733.

Dinh, K. T., & Nguyen, H. H. (2006). The effects of acculturative variables on Asian American

    parent-child relationships. *Journal of Social and Personal Relationships, 23*(3), 407- 426.

Donovan, E. A. (2013). *Arab American parents' experiences of special education and disability:*

    A phenomenological exploration (Doctoral dissertation). Retrieved from ProQuest

    Dissertations and Theses database. (UMI No. 3618900).

Dwairy, M., Achoui, M., Abouserie, R., & Farah, A. (2006). Adolescent-family connectedness

    among Arabs: A second cross-regional research study. *Journal of Cross-Cultural*

    Psychology, 37(3), 248-261.

Dwairy, M., Achoui, M., Abouserie, R., Farah, A., Sakhleh, A. A., Fayad, M., & Khan, H. K.

    (2006). Parenting styles in Arab societies: A first cross-regional research study. *Journal*

    of Cross-Cultural Psychology, *37*(3), 230-247.

Dwairy, M. (2006). *Counseling and psychotherapy with Arabs and Muslims: A culturally*

    sensitive approach. New York, NY: Teachers College Press.

El-Khadiri, D. M. (2009). *Factors affecting Arab Americans' psychological health: Culture,*

    religion, acculturation, and experiences of discrimination (Doctoral dissertation).

    Retrieved from ProQuest Dissertations and Theses database. (UMI No. 3388991).

Elsaman, R. S., & Arafa, M. A. (2012). The rights of the elderly in the Arab Middle East: Islamic

    theory versus Arabic practice. *Marquette Elder's Adviser, 14*(1), 1-53.

Ennis-Cole, D., Durodoye, B. A., & Harris, H. L. (2013). The impact of culture on autism diagnosis and treatment: Considerations for counselors and other professionals. *The Family Journal*, *21*(3), 279-287.

Erin, J. N., Rudin, D., & Njoroge, M. (1991). Religious beliefs of parents of children with visual impairments. *Journal of Visual Impairment and Blindness, 85*(4), 157-162.

Farver, J. A. M., & Lee-Shin, Y. (2000). Acculturation and Korean- American children's social and play behavior. *Social Development, 9*(3), 316–336.

Fishman, C. E., & Nickerson, A. B. (2015). Motivations for involvement: A preliminary investigation of parents of students with disabilities. *Journal of Child and Family Studies*, *24*(2), 523-535.

Flores, L. Z. (2012). *Psychoeducational needs and concerns of immigrant Mexican parents of a child with autism.* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database. (UMI No. 3539987).

Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, *33*(4), 365-382.

Gabel, S. (2004). South Asian Indian cultural orientations toward mental retardation. *Mental Retardation, 42(1)*, 12-25.

Gall, M. D., Gall, J. P., & Borg, W.R. (2007). *Educational research: An introduction* (8th ed.). Boston, MA: Allyn & Bacon Publisher.

Gardiner, E., & Iarocci, G. (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities, 33*(1), 2177-2192.

154

Garland, A. F., Brookman-Frazee, L., & Gray, E. (2013). The role of parent characteristics in

    community-based medication treatment for children with disruptive behavior

    problems. *Community Mental Health Journal*, *49*(5), 507-514.

Geenen, S., Powers, L. E., & Lopez-Vasquez, A. (2001). Multicultural aspects of parent

    involvement in transition planning. *Exceptional Children*, *67*(2), 265-282.

Gharaibeh, N. (2009). Disability in Arab societies. In C. A. Marshall, E. Kendall, M. E. Banks,

    & R. M. S. Gover (Eds.), *Disabilities: Insights from across fields and around the world*

    (pp. 63-80). Westport, CT: Praeger Publishers.

Gibson, D. D. (2007). Racial disparities in the age of diagnosis of autism spectrum disorder:

    Examining factors that may contribute to delayed diagnosis in African-American

    children. *Praxis, 7*(1), 34-38.

Glesne, C. (2011). *Becoming qualitative researchers: An introduction* (4th ed.)*.* White Plains,

    NY: Prentice Hall.

Goforth, A. N. (2011). Multicultural Affairs: Considerations for school psychologists working

    with Arab American children and families. *NASP Communique, 39*(6), 1-3.

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to

    make an autism spectrum diagnosis? *Autism*, *10*(5), 439-451.

Graungaard, A. H., & Skov, L. (2007). Why do we need a diagnosis? A qualitative study of

    parents' experiences, coping and needs, when the newborn child is severely disabled*.*

    Child: Care, Health and Development, 33(3), 296-307.

Gregg, G. S. (2005). *The Middle East: A cultural psychology.* New York, NY: Oxford University

    Press.

Guerrero, C., & Leung, B. (2008). Communication matters: Communicating effectively with culturally and linguistically diverse (CLD) families. *NASP Communique, 36*(8), 1-3.

Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis*. Los Angeles, CA: Sage Publications.

Guinchat, V., Chamak, B., Bonniau, B., Bodeau, N., Perisse, D., Cohen, D., & Danion, A. (2012). Very early signs of autism reported by parents include many concerns not specific to autism criteria. *Research in Autism Spectrum Disorders, 6*(2), 589-601.

Haboush, K. L. (2007). Working with Arab American families: Culturally competent practice for school psychologists. *Psychology in the Schools, 44*(2), 183-198.

Hess, R. S., Molina, A. M., & Kozleski, E. B. (2006). Until somebody hears me: Parent voice and advocacy in special educational decision making. *British Journal of Special Education, 33*(3), 148-157.

Halle, T. G., Kurtz-Costes, B., & Mahoney, J. L. (1997). Family influences on school achievement in low-income, African American children. *Journal of Educational Psychology, 89*(3), 527–537.

Halsey, P. A. (2005). Parent involvement in junior high schools: A failure to communicate. *American Secondary Education, 34*(1), 57-69.

Hanson, M. J. (2014). Families with Anglo-European roots. In E. W. Lynch & M. J. Hanson (Eds.), *Developing cross-cultural competence: A guide for working with young children and their families* (pp. 80-109). Baltimore, MD: Paul H. Brookes Publishing.

Harb, C. (2016). The Arab region: Cultures, values, and identities. In M. M. Amer & G. H. Awad (Eds.), *Handbook of Arab American psychology* (pp. 3-18). New York, NY: Routledge Publisher.

Harrell, P. E., & Forney, W. S. (2011). Ready or not, here we come: Retaining Hispanic and

    first-generation students in postsecondary education. *Community College Journal of*

    Research and Practice, 27(2), 147-156.

Hassan, S. D. (2002). Arabs, race and the post September 11 national security state. *Middle East*

    Report, 32(3), 16-21.

Hicks, D. (2011). *Dignity: The essential role it plays in resolving conflict*. New Haven, CT: Yale

    University Press.

Hidalgo, N. J., McIntyre, L. L., & McWhirter, E. H. (2015). Sociodemographic differences in

    parental satisfaction with an autism spectrum disorder diagnosis. *Journal of Intellectual*

    and Developmental Disability, *40*(2), 147-155.

Holloway, I., & Biley, F. C. (2011). Being a qualitative researcher. *Qualitative Health Research,*

    21(7), 968-975.

Hornby, G., & Lafaele, R. (2011). Barriers to parental involvement in education: An explanatory

    model. *Educational Review*, *63*(1), 37-52.

Imenda, S. (2014). Is there a conceptual difference between theoretical and conceptual

    frameworks. *Journal of Social Sciences*, *38*(2), 185-195.

Inhorn, M. C. (2012). *The new Arab man: Emergent masculinities, technologies, and Islam in the*

    Middle East. Princeton, NJ: Princeton University Press.

Irvin, D. W., McBee, M., Boyd, B. A., Hume, K., & Odom, S. L. (2012). Child and family

    factors associated with the use of services for preschoolers with autism spectrum

    disorder. *Research in Autism Spectrum Disorders*, *6*(1), 565-572.

Ives, E. D. (1995). *The tape-recorded interview: A manual for field workers in folklore and oral*

    history. Knoxville, TN: University of Tennessee Press.

Jegatheesan, B., Miller, P. J., & Fowler, S. A. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. *Focus on Autism and Other Developmental Disabilities, 25*(2) 98-109 .

Jones, B. A., & Gansle, K. A. (2010). The effects of a mini-conference, socioeconomic status, and parent education on perceived and actual parent participation in individual education program meetings. *Research in the Schools*, *17*(2), 23-38.

Kayyali, R. A. (2006). *The Arab Americans*. Westport, CT: Greenwood Press.

Khan, M., & Ecklund, K. (2013). Attitudes toward Muslim Americans post-9/11. *Stigma*, *7*(1), 1-16.

Kloos, B., Hill, J., Thomas, E., Wandersman, A., Elias, M. J., & Dalton, J. H. (2012). *Community psychology: Linking individuals and communities*. Belmont, VA: Wadsworth Cengage Learning.

Kuaider, S. M. (2005). *Ecocultural study of Arab American families of children with disabilities* (Master's thesis). Retrieved from ProQuest Dissertations and Theses database. (UMI No. 1431856).

Lai, Y., & Ishiyama, F. I. (2004). Involvement of immigrant Chinese Canadian mothers of children with disabilities. *Exceptional Children*, *71*(1), 97-108.

Lalvani, P., & Polvere, L. (2013). Historical perspectives on studying families of children with disabilities: A case for critical research. *Disability Studies Quarterly*, *33*(3), 1-20.

Landa, R. J. (2008). Diagnosis of autism spectrum disorders in the first 3 years of life. *Nature Clinical Practice Neurology, 4*(3), 138-147.

Lawson, H. h. (2015). Religious beliefs of parents of children with visual impairments. *Journal of Visual Impairment and Blindness*, *109*(5), 419-422.

Leon, A. L. (2014). Immigration and stress: The relationship between parents' acculturative

stress and young children's anxiety symptoms. *Inquiries Journal, 6*(3), 1-5.

Levy, P. (2003). A methodological framework for practice-based research in networked

learning. *Instructional Science*, *31*(1-2), 87-109.

Liamputtong, P. (Ed.). (2008). *Doing cross-cultural research: Ethical and methodological*

perspectives. Dordrecht, Netherlands: Springer Netherlands.

Lin, S. C., Stella, M. Y., & Harwood, R. L. (2012). Autism spectrum disorders and

developmental disabilities in children from immigrant families in the United States.

Pediatrics, *130*(2), 191-197.

Lichtman, M. (2013). *Qualitative research for the social sciences*. Thousand Oaks, CA: Sage

Publications.

Lincoln, Y. S., & E. G. Guba. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.

Locke, L. F., Spirduso, W. W., & Silverman, S. J. (2014). *Proposals that work: A guide for*

planning dissertations and grant proposals. Thousand Oaks, CA: Sage Publications.

Lodico, M. G., Spaulding, D. T., & Voegtle, K. H. (2010). *Methods in educational research:*

From theory to practice (2nd ed.). San Francisco, CA: John Wiley & Sons, Inc.

Lorenzo-Blanco, E. I., Meca, A., Unger, J. B., Romero, A., Gonzales-Backen, M., Piña-Watson,

B., ... Villamar, J. A. (2016). Latino parent acculturation stress: Longitudinal effects on

family functioning and youth emotional and behavioral health. *Journal of Family*

Psychology, *30*(8), 966-976.

Lutz, H. R., Patterson, B. J., & Klein, J. (2012). Coping with autism: A journey toward

adaptation. *Journal of Pediatric Nursing, 27*(3), 206-213.

Matson, J. L., & Sipes, M. (2010). Methods of early diagnosis and tracking for autism and

pervasive developmental disorder not otherwise specified (PDDNOS). *Journal of

Developmental and Physical Disabilities, 22*(4), 343-358.

Matsudaira, T. (2006). Measures of psychological acculturation: A review. *Transcultural

Psychiatry, 43*(3)*, 462-487.

Maxwell, J. A. (1992). Understanding and validity in qualitative research. *Harvard Educational

Review, 62*(3), 279-301.

Maxwell, J. A. (2013). *Qualitative research design: An interactive approach* (2nd ed.). Thousand

Oaks, CA: Sage Publications.

Merriam, S. B. (1998). *Qualitative research and case study applications in education: Revised

and expanded from case study research in education*. San Francisco, CA: Jossey-Bass

Publishers.

Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative data analysis: A methods

sourcebook* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Mirza, I., Tareen, A., Davidson, L. L., & Rahman, A. (2009). Community management of

intellectual disabilities in Pakistan: A mixed methods study. *Journal of Intellectual

Disability Research*, *53*(6), 559-570.

Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during

the process of diagnosis of children with autism spectrum disorders. *Research in Autism

Spectrum Disorders*, *6*(1), 293-303.

Morse, J. M. (2000). Determining sample size. *Qualitative Health Research*, *10*(1), 3-5.

Mruck, K., & Breuer, F. (2003). Subjectivity and reflexivity in qualitative research. *Forum:

Qualitative Social Research, 4*(2), 1-13.

Mudge, S., & Higgins, D. J. (2011). College access programming: Removing higher education

    barriers for underrepresented student populations. *International Journal of Learning*,

    17(11), 123-139.

Mui, A. C., Kang, S. Y., Kang, D., & Domanski, M. D. (2007). English language proficiency and

    health-related quality of life among Chinese and Korean immigrant elders. *Health and*

    Social Work, *32*(2), 119-127.

Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest

    heart ache:" Parents' own words on how having a child in the autism spectrum has

    affected their lives and their families' lives. *Research in Autism Spectrum Disorders,*

    3(3), 670-684.

National Center for Education Statistics (2016). *Children and youth with disabilities.* Retrieved

    from http://nces.ed.gov/programs/coe/indicator_cgg.asp

National Center for Education Statistics (2016). *Racial/ethnic enrollment in public schools.*

    Retrieved from http://nces.ed.gov/programs/coe/indicator_cge.asp

Newman, I., Ridenour, C. S., Newman, C., & DeMarco Jr, G. M. P. (2003). A typology of

    research purposes and its relationship to mixed methods. In A. Tashakkori & C. Teddlie

    (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 167-188).

    Thousand Oaks, CA: Sage Publications.

Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011).

    The post-high school outcomes of young adults with disabilities up to 8 years after high

    school: A report from the National Longitudinal Transition Study-2 (NLTS2). NCSER

    2011-3005. *National Center for Special Education Research*. Retrieved from

    https://ies.ed.gov/ncser/pubs/20113005/pdf/20113005.pdf

Nydell, M. (2012). *Understanding Arabs: A contemporary guide to Arab society*. Boston, MA: Nicholas Brealey Publishing.

Oberg, K. (2006). Cultural shock: Adjustment to new cultural environments. *Curare, 29*(2), 142-146.

O'Hanlon, E. E. (2013). Religion and disability: The experiences of families of children with special needs. *Journal of Religion, Disability and Health*, *17*(1), 42-61.

Opsal, T., Wolgemuth, J., Cross, J., Kaanta, T., Dickmann, E., Colomer, S., & Erdil-Moody, Z. (2016). "There are no known benefits...": Considering the risk/benefit ratio of qualitative research. *Qualitative Health Research, 26*(8), 1137-1150.

Orlikowski, W. J., & Baroudi, J. J. (1991). Studying information technology in organizations: Research approaches and assumptions. *Information Systems Research*, *2*(1), 1-28.

Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report*, *13*(4), 695-705.

Pak, J. H. C. (2006). *Korean American women: Stories of acculturation and changing selves*. New York, NY: Routledge.

Park, J. H. (1999). The earnings of immigrants in the United States: The effect of English-speaking ability. *American Journal of Economics and Sociology, 58*(1), 43-56.

Parkes, A., Sweeting, H., & Wight, D. (2015). Parenting stress and parent support among mothers with high and low education. *Journal of Family Psychology, 29*(6), 907–918.

Patton, M. Q. (2015). *Qualitative evaluation and research methods*: *Integrating theory and practice* (4th ed.). Thousand Oaks, CA: Sage Publications.

Perna, L. W., & Thomas, S. L. (2008). Theoretical perspectives on student success: Understanding the contributions of the disciplines. *ASHE/ERIC Higher Education Report, 34*(1), 1-87.

Peterman, A. C. (2016). *Factors influencing college readiness: Supports and barriers experienced by academically resilient first-generation Hispanic males* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database. (UMI No. 10044704).

Punch, K. F. (2014). *Introduction to social research: Quantitative and qualitative approaches* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies, 21*(2), 311-319.

Ravitch, S. M., & Carl, N. M. (2016). *Qualitative research: Bridging the conceptual, theoretical, and methodological.* Thousand Oaks, CA: Sage Publications.

Reichard, A., & Turnbull, H. R. (2004). Perspectives of physicians, families, and case managers concerning access to health care by individuals with developmental disabilities. *Mental Retardation, 42*(3), 181-194.

Reilly, A. L. (2011). The aftermath of a revolution—victims or heroes? *International Journal of Therapy and Rehabilitation, 18*(10), 540-541.

Riessman, C. K. (1993). *Narrative analysis.* Newbury Park, CA: Sage Publication.

Renty, J. & Roeyers, H. (2006). Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents. *Child: Care, Health and Development, 32*(3), 371-385.

Rhoades, R. A., Scarpa, A., & Salley, B. (2007). The importance of physician knowledge of

    autism spectrum disorder: Results of a parent survey. *BMC Pediatrics, 7*(1), 37-47.

Rodriguez, J. (2010). *Our lady of Guadalupe: Faith and empowerment among Mexican-*

    American women. Austin, TX: University of Texas Press.

Rogers-Adkinson, D. L., Ochoa, T. A., & Delgado, B. (2003). Developing cross-cultural

    competence serving families of children with significant developmental needs. *Focus on*

    Autism and Other Developmental Disabilities, *18*(1), 4-8.

Rubin, H. J., & Rubin, I. S. (2011). *Qualitative interviewing: The art of hearing data*. Thousand

    Oaks, CA: Sage Publications.

Rutter, M. (2000). Genetic studies of autism: From the 1970s into the millennium. *Journal of*

    Abnormal Child Psychology, 28(1), 3-14.

Ryan, G. W., & Bernard, H. R. (2003). Techniques to identify themes. *Field Methods*, *15*(1), 85-

    109.

Saint-Georges, C., Cassel, R. S., Cohen, D., Chetouani, M., Laznik, M. C., Maestro, S., &

    Muratori, F. (2010). What studies of family home movies can teach us about autistic

    infants: A literature review. *Research in Autism Spectrum Disorders, 4* (3), 355-366.

Saldaña, J. (2016). *The coding manual for qualitative researchers.* Thousand Oaks, CA: Sage

    Publications.

Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education*

    and the social sciences. New York, NY: Teachers College press.

Sentell, T., Shumway, M., & Snowden, L. (2007). Access to mental health treatment by English

    language proficiency and race/ethnicity. *Journal of General Internal Medicine*, *22*(2),

    289-293.

Seung, H. (2013). Cultural considerations in serving children with ASD and their families: Asian American perspective. *SIG 1 Perspectives on Language Learning and Education*, *20*(1), 14-19.

Shaheen, J. G. (2003). Reel bad Arabs: How Hollywood vilifies a people. *The Annals of the American Academy of Political and Social Science*, *588*(1), 171-193.

Shaked, M. (2005). The social trajectory of illness: Autism in the ultraorthodox community in Israel. *Social Science and Medicine*, *61*(10), 2190–2200.

Sharifzadeh, V. (2011). Families with Middle Eastern roots. In E. W. Lynch & M. J. Hanson (Eds.), *Developing cross-cultural competence: A guide for working with young children and their families* (pp. 392-436). Baltimore, MD: Paul H. Brookes Publishing.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63-75.

Shin, J. Y. (2002). Social support for families of children with mental retardation: Comparison between Korea and the United States. *Mental Retardation, 40*(2), 103-118.

Shokoohi-Yekta, M., Zamani, N., & Ahmadi, A. (2011). Anger in mothers of children with disabilities: Effects of occupation and level of education. *Procedia Social and Behavioral Sciences*, *15*(1), 712-716.

Skiba, R. (2013). CCBD'S position summary on federal policy on disproportionality in special education. *Behavioral Disorders*, *38*(2), 108-120.

Sklar, Q. T., Pak, J. H., & Eltiti, S. (2016). Parent–child closeness and acculturation in predicting racial preference in mate selection among Asian Americans. *Asian American Journal of Psychology*, *7*(4), 265-273.

Smith, J., & Firth, J. (2011). Qualitative data analysis: The framework approach. *Nurse Researcher*, *18*(2), 52-62.

Soliman, H. H. (Ed.). (2013). *Social work in the Middle East*. New York, NY: Routledge Publisher.

Sorkhabi, N. (2010). Sources of parent-adolescent conflict: Content and form of parenting. *Social Behavior and Personality*, *38*(6), 761-782.

Stadnick, N., Chlebowski, C., Baker-Ericzén, M., Dyson, M., Garland, A., & Brookman-Frazee, L. (2017). Psychiatric comorbidity in autism spectrum disorder: Correspondence between mental health clinician report and structured parent interview. *Autism, 21*(7), 841-851.

Stringer, E. T. (2014). *Action research* (4th ed.). Thousand Oaks, CA: Sage Publications.

Stephan, R. & Aprahamian, M. (2016). Gender and sexuality: Treading complex cultural challenges. In M. M. Amer & G. H. Awad (Eds.), *Handbook of Arab American psychology* (pp. 117-129). New York, NY: Routledge Publisher.

Suleiman, L. M. (2001, January). *Image making of Arab Americans: Implications for teachers in diverse settings*. Paper presented at the annual meeting of the California Association for Bilingual Education, Los Angeles.

Sun, S., Hoyt, W. T., Brockberg, D., Lam, J., & Tiwari, D. (2016). Acculturation and enculturation as predictors of psychological help-seeking attitudes (HSAs) among racial and ethnic minorities: A meta-analytic investigation. *Journal of Counseling Psychology, 63*(6), 617-632.

Swagler, M. A., & Jome, L. M. (2005). The effects of personality and acculturation on the adjustment of North American sojourners in Taiwan. *Journal of Counseling Psychology, 52*(4), 527–536.

The National Center for Education Statistics. (2011). *Achievement gaps: How Hispanic and White students in public schools perform in mathematics and reading on the national assessment of educational progress.* Retrieved from http://nces.ed.gov/nationsreportcard/pdf/studies/2011459.pdf

The U.S. Department of Education. (n.d.). *Sec. 300.39 special education*. Retrieved from http://idea.ed.gov/explore/view/p/,root,regs,300,A,300.39,.html

Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation*, *27*(2), 237-246.

Tincani, M., Travers, J., & Boutot, A. (2009). Race, culture, and autism spectrum disorder: Understanding the role of diversity in successful educational interventions. *Research and Practice for Persons with Severe Disabilities*, *34*(3-4), 81-90.

Tran, A. G. (2014). Family contexts: Parental experiences of discrimination and child mental health. *American Journal of Community Psychology*, *53*(1-2), 37-46.

Tumey, K., & Kao, G. (2009). Barriers to school involvement: Are immigrant parents disadvantaged? *Journal of Educational Research, 102*(4)*, 257-271.

Turmusani, M. (2003). *Disabled people and economic needs in the developing world: A political perspective from Jordan.* Aldershot, UK: Ashgate Publishing.

U.S. Census Bureau. (2000). *The Arab population: 2000: Census 2000 brief.* Retrieved from www.census.gov/prod/2003pubs/c2kbr-23.pdf

U.S. Census Bureau. (2010). *The white population: 2010: Census 2010 brief.* Retrieved from http://www.census.gov/prod/cen2010/briefs/c2010br-05.pdf

U.S. Census Bureau. (2015). *Forum on Ethnic Groups from the Middle East and North Africa.* Retrieved from http://www.census.gov/library/working-papers/2015/demo/2015-MENA-Experts.html

U.S. Department of Education Office for Civil Rights (2014). *Civil rights data collection data snapshot: School discipline.* Retrieved from http://ocrdata.ed.gov/Downloads/CRDC-School-Discipline-Snapshot.pdf

U.S. Department of Health and Human Services. (2001). *Mental health: Culture, race, and ethnicity.* Retrieved from http://www.ncbi.nlm.nih.gov/books/NBK44243/

Venza, J. (2002). *A cross-cultural examination of attitudes and intentions toward seeking professional psychological help: The relationship of attachment, acculturation, psychological distress, and social desirability* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses database. (UMI No. 3049638).

Volkmar, F. R., Westphal, A., Gupta, A. R., & Wiesner, L. (2008). Medical issues. In K. Chawarska, A. Klin, & F. R. Volkmar (Eds.), *Autism spectrum disorders in infants and toddlers: Diagnosis, assessment, and treatment* (pp. 274-299). New York, NY: The Guilford Press.

Wagner, M. M., Newman, L. A., & Javitz, H. S. (2014). The influence of family socioeconomic status on the post-high school outcomes of youth with disabilities. *Career Development and Transition for Exceptional Individuals*, *37*(1), 5-17.

Walsham, G. (2006). Doing interpretive research. *European Journal of Information Systems*, *15*(3), 320-330.

Wang, Y., Deng, C., & Yang, X. (2016). Family economic status and parental involvement: Influences of parental expectation and perceived barriers. *School Psychology International*, *37*(5), 536-553.

Wehbi, S., & Lakkis, S. (2010). Women with disabilities in Lebanon: From marginalization to resistance. *Affilia: Journal of Women and Social Work, 25*(1), 56- 67.

Weisner, T. S., Coots, J. J., Bernheimer, L. P., & Arzubiaga, A. (1997). *The Ecocultural family interview manual.* Unpublished manuscript, UCLA Center for Culture and Health, University of California, Los Angeles, California.

Welterlin, A., & LaRue, R. H. (2007). Serving the needs of immigrant families of children with autism. *Disability and Society*, *22*(7), 747-760.

Williams, M. E., Atkins, M., & Soles, T. (2009). Assessment of autism in community settings: Discrepancies in classification. *Journal of Autism and Developmental Disorders, 39*(4), 660-669.

White, S. E. (2014). Special education complaints filed by parents of students with autism spectrum disorders in the Midwestern United States. *Focus on Autism and Other Developmental Disabilities, 29*(2), 80-87.

Wolgemuth, J. R., Erdil-Moody, Z., Opsal, T., Cross, J. E., Kaanta, T., Dickmann, E. M., & Colomer, S. (2015). Participants' experiences of the qualitative interview: Considering the importance of research paradigms. *Qualitative Research, 15*(3), 351-372.

Yeh, M., Hough, R. L., Fakhry, F., McCabe, K., Lau, A., & Garland, A. (2005). Why bother with beliefs? Examining relationships between race/ethnicity, parental beliefs about causes of child problems, and mental health service use. *Journal of Consulting and Clinical Psychology, 73*(5), 800-807.

Yoon, E., Chang, C. T., Kim, S., Clawson, A., Cleary, S. E., Hansen, M., . . . Gomes, A. M.
(2013). A meta-analysis of acculturation/enculturation and mental health. *Journal of
Counseling Psychology, 60*(1)*,* 15-30.

Yoon, E., Langrehr, K., & Ong, L. Z. (2011). Content analysis of acculturation research in
counseling and counseling psychology: A 22-year review. *Journal of Counseling
Psychology, 58*(1), 83-96.

Yu, J., Cheah, C. S., & Calvin, G. (2016). Acculturation, psychological adjustment, and
parenting styles of Chinese immigrant mothers in the United States. *Cultural Diversity
and Ethnic Minority Psychology*, *22*(4), 504-516.

Zhang, C., & Bennett, T. (2003). Facilitating the meaningful participation of culturally and
linguistically diverse families in the IFSP and IEP process. *Focus on Autism and Other
Developmental Disabilities*, *18*(1), 51-59.

Zhang, D., Katsiyannis, A., Ju, S., & Roberts, E. (2014). Minority representation in special
education: 5-year trends. *Journal of Child and Family Studies*, *23*(1), 118-127.

Appendix A

Institutional Review Board Approval for Study

USF
UNIVERSITY OF
SOUTH FLORIDA

RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 ● Tampa, FL 33612-4799
(813) 974-5638 ● FAX (813) 974-7091

July 28, 2017

Haifa Alsayyari
Teaching and Learning
Tampa, FL 33612

RE: **Expedited Approval for Initial Review**

IRB#: Pro00031403

Title: Perceptions of Immigrant Arab American Parents of Children with Autism Spectrum
        Disorder:
        An Exploratory Study

Study Approval Period: 7/27/2017 to 7/27/2018

Dear H. Alsayyari:

On 7/27/2017, the Institutional Review Board (IRB) reviewed and **APPROVED** the above
application and all documents contained within, including those outlined below.

Approved Item(s):
Protocol Document(s):
Protocol, Version #1.docx

Consent/Assent Document(s)*:
Arabic-USF-consent-form.doc.pdf
English-USF-consent-form.docx.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the
"Attachments" tab. Please note, these consent/assent documents are valid until the consent
document is amended and approved.

It was the determination of the IRB that your study qualified for expedited review which
includes activities that (1) present no more than minimal risk to human subjects, and (2) involve
only procedures listed in one or more of the categories outlined below. The IRB may review

171

research through the expedited review procedure authorized by 45CFR46.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

Kristen Salomon, Ph.D., Vice Chairperson
USF Institutional Review Board

Recruitment Flyer

ARAB AMERICAN Participants Needed For Research

Does Your Child Have A Diagnosis Of Autism Spectrum Disorder?

If you are an Arab American parent of a child who has a diagnosis of Autism

I invite you to participate in this study to share your experience in relation to your child's Autism

The research seeks to understand your experiences of having a child with Autism, and to determine your concerns and needs regarding your child

To participate in this study, you should be:

✓ A parent, primary caregiver, and identified as Arab American
✓ Have at least one child who had been diagnosed with ASD
✓ Not a recent immigrant, and have been in US for more than one year
✓ Have received special services related to your child's disability within the last year
✓ At least one of the parents should be immigrant (not born in the US)

Your voluntary participation would involve up to 3 interviews lasting 45-60 minutes each
Interviews will be at a place and time convenient to you
Transportation will be provided if needed
Your personal information will be treated in complete confidence
In appreciation for your time, you will receive a $10 gift card at the end of each interview

For more information, or to volunteer for this study, please contact:
Haifa Alsayyari
Ph.D. Candidate at USF
813-992-2920
haifa@mail.usf.edu

| Haifa Alsayyari 813-992-2920 haifa@mail.usf.edu | Haifa Alsayyari 813-992-2920 haifa@mail.usf.edu | Haifa Alsayyari 813-992-2920 haifa@mail.usf.edu | Haifa Alsayyari 813-992-2920 haifa@mail.usf.edu | Haifa Alsayyari 813-992-2920 haifa@mail.usf.edu | Haifa Alsayyari 813-992-2920 haifa@mail.usf.edu |

This study has been reviewed and received ethics clearance by
The University of South Florida Institutional Review Board (IRB)
IRB #31403

Appendix C

First English Interview Protocol

1) What did you notice about your child that concerned you before the diagnosis was given?

2) How old was your child when you started to concern about his/her development?

3) What label or description did you give to your concerns before your child diagnosed with autism?

4) Who are the people that you initially spoke to about your concern(s)?

5) Were you encouraged by anyone to seek help? Who? And how they encouraged you?

6) How old was your child when he/she was diagnosed with autism?

7) Who diagnosed your child?

8) What precisely were you told about the diagnosis of autism?

9) Was the diagnosis of autism different from what you had thought? Explain.

10) What information about autism do you have before your child diagnosed with autism?

11) What do you believe is the cause of your child's autism?

12) Is your understanding of autism when it was initially diagnosed differ than how is it now? Explain.

13) What sources do you have to get information about autism? Other sources?

14) What do you know about the local support options that available for your child and your family?

15) What are the informal social support systems that assist you in raising your child with autism? (Extended family, friends, religious leaders, others).

Second English Interview Protocol

1) Looking back on your experiences with your child's identification, what feelings were generated by the diagnosis of autism?

2) What has been the most frustrating or challenging for you surrounding your child's diagnosis with autism?

3) What concerns you about your child diagnosis of autism?

4) When your child was first diagnosed, what was helpful about the way the health care or service providers provided you your child's diagnosis?

5) What helpful techniques have you used to assist you in coping with your child's diagnosis with autism?

6) What helpful techniques did you use to assist your family understand the diagnosis of autism?

7) Tell me please about your child's daily schedule, (from the time he/she wake up to the bed time).

8) What services your child currently receiving?

9) Tell me please about your experience with health care, or special education, or service providers. (What did you like and dislike, what were helpful and what were not).

10) Were you satisfied with the information you received about your child diagnosis from the service providers? Please explain.

11) Are there any areas do you feel you need additional information in? Which areas?

12) Do you believe there are areas in your child's health care or other services that need improvement? Which areas? And how do you think they can be improved?

13) What kinds of services, or treatment, or interventions do you believe your child needs and should receive?

Third English Interview Protocol

1) What are the most significant challenges that caused by autism for your child?

2) What are the most significant challenges that caused by autism for your family?

3) Are there any unexpected positive effects that your child's autism has provided for your family? Explain.

4) What did you learn about yourself as a parent of child with autism?

5) If you were asked to draw a conclusion about your experiences as an Arab American parent of child with autism, what would you say?

6) Would you like to share/add anything else that was not covered in the interview?

Appendix D

Arabic Interview Protocol

بروتوكول المقابلة الأولى

1) ما الذي لاحظته على طفلك وأثار قلقك قبل تشخيصه بالتوحد؟
2) كم كان عمر طفلك عندما بدأت تقلق/ تقلقين بخصوص نموه؟
3) ما هي التسمية أو الوصف الذي أعطيته/اعطيتيه لمخاوفك بشأن طفلك قبل تشخيصه بالتوحد؟
4) من هم الأشخاص الذين تحدثت/ي إليهم أولاً عن مخاوفك؟
5) هل شجعك أي شخص على طلب المساعدة؟ من هو؟ وكيف شجعك على ذلك؟
6) كم كان عمر طفلك عندما تم تشخيص حالته بالتوحد؟
7) من قام بتشخيص حالة طفلك؟
8) ماذا قيل لك بالتحديد عن التشخيص بالتوحد؟
9) هل التشخيص بالتوحد كان مختلفًا عما اعتقدته/اعتقدتيه؟ الرجاء الشرح
10) ما هي المعلومات التي كانت لديك عن التوحد قبل تشخيص حالة طفلك؟
11) ما هو برأيكِ سبب إصابة طفلك بهذا الاضطراب؟
12) هل فهمك لاضطراب التوحد عند بداية تشخيص حالة طفلك اختلف عن فهمك له الآن؟ الرجاء الشرح.
13) ما هي مصادر معلوماتك حول اضطراب التوحد؟ هل هناك مصادر أخرى؟
14) ماذا تعرف عن خيارات الدعم المحلي المتاحة لطفلك ولأسرتك؟
15) ما هي نُظم الدعم الاجتماعي غير الرسمية التي من شأنها أن تساعدك في تربية طفلك ذوالتوحد؟ (الأسرة الممتدة، الأصدقاء، رجال الدين، آخرون).

بروتوكول المقابلة الثانية

1) بالنظر إلى تجاربك حول تشخيص طفلك، ما هي المشاعر التي تولدت لديك إثر تشخيص طفلك بإضطراب التوحد؟
2) ما هي النقطة الأكثر إحباطًا أو تحديًا لك بشأن تشخيص طفلك بالتوحد؟
3) ما هو الذي يقلقك بشأن تشخيص طفلك بالتوحد؟
4) عند تشخيص حالة طفلك في بداية الأمر، ما ذا ساعدك بالطريقة التي قدم بها مقدمي الرعاية والخدمات الطبية تشخيص طفلك بالتوحد؟
5) ما هي الأساليب المفيدة التي استخدمتيها لتساعدك على التعامل مع حالة طفلك بعد التشخيص بالتوحد؟
6) ما هي الأساليب المفيدة التي استخدمتيها لتساعد أسرتك على فهم إضطراب التوحد؟
7) اخبرني/اخبريني من فضلك عن الجدول اليومي لطفلك (من وقت استيقاظه وحتى وقت عودته للفراش).
8) ما هي الخدمات التي يتلقاها طفلك حاليًا؟
9) اخبرني/اخبريني من فضلك عن تجربتك مع الرعاية الطبية، أو التربية الخاصة، أو مقدمي الخدمات. (ما الذي

أعجبك وما الذي لم يعجبك، ما الذي كان مفيدًا وما الذي لم يكن مفيداً).

10) هل أنت راضٍ/راضية عن المعلومات التي حصلت عليها حول تشخيص حالة طفلك من مقدمي الخدمات؟ الرجاء الشرح.

11) هل هناك أي مجالات تود/تودين أن تحصل/تحصلين على معلومات إضافية بشأنها؟ ما هي؟

12) هل تعتقد/تعتقدين أن هناك جوانب في الرعاية الطبية أو الخدمات الأخرى المقدمة لطفلك بحاجة إلى أن تحسين وتطوير؟ ما هي؟ وكيف يمكن تحسينها وتطويرها من وجهة نظرك؟

13) ما هي أنواع الخدمات، أو العلاج، أو التدخلات، التي تعتقد/تعتقدين أن طفلك بحاجة اليها و يجب أن يتلقاها؟

بروتوكول المقابلة الثالثة

1) ما هي أهم التحديات التي يواجهها طفلك بسبب إضطراب التوحد؟

2) ما هي أهم التحديات التي تواجهها أسرتك بسبب إضطراب التوحد؟

3) هل توجد هناك أية آثار إيجابية غير متوقعة شهدتها أسرتك جراء إصابة طفلك بالتوحد؟ الرجاء الشرح.

4) ماذا تعلمت عن نفسك بصفتك والد/ة لطفل من ذوي التوحد؟

5) إذا طُلب منك سرد استنتاج او ملخص لتجاربك كوالد/ة أمريكي/ة من أصول عربية لطفل من ذوي التوحد، فما ستقول/ستقولين؟

6) هل تود/تودين مشاركة/إضافة أي شئ آخر لم تشمله هذه المقابلة؟

178

Appendix E

Demographic Questions

1) Where did you born?

2) Where did your husband born?

3) How long have you been in US?

4) How long have your husband been in US?

5) How old are you?

6) What educational degree do you hold? Where did you earn it? in US? Or Arab world?

7) What educational degree does your husband hold? Where did he earn it? in US? Or Arab world?

8) Do you work? What type of work?

9) Does your husband work? What type of work?

10) How many children do you have?

11) Is there other child with disability in the family?

12) How many members of your family live with you in the same house?

Appendix F

English Informed Consent Form

USF
UNIVERSITY OF
SOUTH FLORIDA

Informed Consent to Participate in Research Involving Minimal Risk
Pro # 31403

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:

Perceptions of Immigrant Arab American Parents of Children with Autism Spectrum Disorder

The person who is in charge of this research study is Haifa Alsayyari. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. She is being guided in this research by Dr. Cranston-Gingras, USF Professor and Associated Dean.

The research will be conducted at USF.

Purpose of the study

Unfortunately, the literature on children with Autism from Arab background is limited. A gap certainly exists in literature examining the needs and concerns of Arab American parents regarding their children with Autism. Therefore, the purpose of this study is to explore Arab American parents' experiences of having a child with Autism, and to determine their needs and concerns, in order to offer sufficient information for special education and related service providers to develop cultural awareness and necessary skills for working with these families and their children.

Why are you being asked to take part?

We are asking you to take part in this research study because you are a parent of a child with Autism who is from an Arab background, you are best suited to speak to about your experiences of having a child with Autism, and your needs and concerns regarding your child.

180

Study Procedures:

- The researcher will interview you up to 3 times for approximately 45-60 minutes in length each time.
- Interviews will take place in a mutually agreed upon location, and transportation will be provided if needed.
- You may decline to answer any of the interview questions if you so wish.
- With your permission, the interview will be audio recorded to facilitate collection of information, and later transcribed for analysis.
- Shortly after the interview has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.
- Researcher will store all documents containing identifying information in a secured file cabinet in the researcher's office with access restricted to the researcher only.
- Research records will be retained for 5 years after the completion of the research, after that will be destroyed.

Total Number of Participants

About ten individuals will take part in this study.

Alternatives / Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

Benefits

There are no direct benefits to you from this study. However, your participation in this study will help us better understand the individual experiences of Arab American parents of children with autism in the United States.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation

You will be compensated a $10 gift card after completing each interview, in total of $30 for completing all the three scheduled interviews.

Costs

It will not cost you anything to take part in the study.

Privacy and Confidentiality

We will keep your study records private and confidential. Certain people may need to see your study records. Anyone who looks at your records must keep them confidential. These individuals include:

- The research team, including the Principal Investigator, study coordinator, and all other research staff.
- Certain government and university people who need to know more about the study, and individuals who provide oversight to ensure that we are doing the study in the right way.
- The USF Institutional Review Board (IRB) and related staff who have oversight responsibilities for this study, including staff in USF Research Integrity and Compliance.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an unanticipated problem, call Haifa Alsayyari at (813) 992-2920.

If you have questions about your rights as a participant in this study, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638 or contact by email at RSCH-IRB@usf.edu.

Consent to Take Part in this Research Study

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

_____   _____
Signature of Person Taking Part in Study   Date

_____
Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in their primary language. This research subject has provided legally effective informed consent.

_____   _____
Signature of Person obtaining Informed Consent   Date

_____
Printed Name of Person Obtaining Informed Consent

Appendix G

Arabic Informed Consent Form

USF
UNIVERSITY OF
SOUTH FLORIDA

إقرار بالموافقة على المشاركة في دراسة بحثية

مقترح #٣١٤٠٣

هذه دعوة للمشاركة في بحث تربوي. هذه **الدراسة البحثية تتضمن فقط آولئك الذين يوافقون على المشاركة، و هذه الوثيقة تسمى "نموذج اقرار بالموافقة على المشاركة بالبحث". الرجاء قراءة المعلومات المذكورة أدناه بحرص وأخذ الوقت الكافي لإتخاذ قرارك. يمكنك طلب مناقشة هذا الاقرار مع الباحث أو فريق البحث لشرح الكلمات أو المعلومات الغير مفهومة أو غير واضحة. كذلك يمكنك أن تتحدث مع أسرتك وأصدقائك بشأن هذا البحث قبل أن تتخذ القرار بالمشاركة. المعلومات الخاصة بطبيعة الدراسة والمعلومات الأخرى حول الدراسة موجودة في الأسفل. في هذا الإقرار نحن نطلب منك المشاركة في بحث تربوي عنوانه مايلي:**

تصورات الآباء العرب الأمريكيون المهاجرين ذوي الأطفال المصابين باضطراب طيف التوحد

الشخص المسؤول عن هذه الدراسة البحثية هو الأستاذة/ هيفاء السياري. وتسمى بالباحث الرئيسي. كذلك قد يكون هناك بعض الباحثين الآخرين ممن يمكنهم أن يتصرفوا نيابة عن الشخص المسؤول. كما أنها تقوم بهذا البحث تحت إشراف د/ كرانستون-غينغراس، أستاذ دكتور في جامعة جنوب فلوريدا.

الغرض من الدراسة

من المؤسف أن عدد الدراسات التي تتناول الأطفال ذوي التوحد من أصول عربية محدود. ثمة فجوة في الدراسات التي تبحث في احتياجات ومخاوف الآباء الأمريكيين من ذوي الأصول العربية فيما يتعلق بأطفالهم ذوي بالتوحد. لذلك، هذه الدراسة تسعى لاستكشاف تجارب الآباء الأمريكيين ذوي الأصول العربية فيما يتعلق بأطفالهم ذوي التوحد، للوقوف على احتياجاتهم ومخاوفهم، ولتوفير معلومات كافية للقائمين على التربية الخاصة ومقدمي الخدمات ذات الصلة، لرفع الوعي الثقافي وتنمية المهارات اللازمة للعمل مع هذه الأسر وأطفالهم.

لماذا نطلب من المشاركة ؟

نود منك المشاركة في هذه الدراسة البحثية لإنك والداً لطفل من ذوي التوحد ومن أصول عربية، وهو ما يجعلك ملائم للحديث عن تجاربك بخصوص طفلك من ذوي التوحد وكذلك التعبير عن احتياجاتك ومخاوفك في هذا الصدد.

إجراءات الدراسة

في حال الموافقة على المشاركة:

- سوف تجري الباحثة معك مقابلتين او ثلاثة لمدة تتراوح بين ٤٥ـ ٦٠ دقيقة تقريباً لكل مقابلة.
- سننفق سوياً على مكان عقد المقابلات، وسوف اوفر لك المواصلات إذا لزم الأمر.
- تستطيع رفض الإجابة على أي سؤال إن رغبت في ذلك.
- بإذن منك، سيتم تسجيل المقابلة صوتياً لتيسير جمع المعلومات ثم تدوينها لاحقا للتحليل.
- بعد إنتهاء المقابلة بوقت قصير، سأرسل لك نسخة من نص المقابلة كي اتيح لك الفرصة للتأكيد على دقة محادثتنا ، ولإضافة او توضيح اي نقاط ترغب بها.
- ستحتفظ الباحثة بجميع البيانات والتسجيلات التي تم جمعها خلال هذه الدراسة في خزينة مغلقة داخل مكتبها، بحيث ان الباحثة هي الوحيدة التي يمكنها الوصول اليها.
- سيتم الإحتفاظ بسجلات البحث لمدة خمس سنوات بعد انتهاء البحث، بعدها سيتم اتلافها.

USF
UNIVERSITY OF
SOUTH FLORIDA

العدد الكلي للمشاركين

سيشارك تقريباً عشرة أشخاص في هذه الدراسة.

البدائل/ المشاركة الطوعية/ الإنسحاب

المشاركة في هذا البحث تطوعية بالكامل. لاينبغي أن تشعر بأن هناك أي ضغط عليك للمشاركة في الدراسة. لديك الحرية للمشاركة في هذا البحث أو الانسحاب من الدراسة في أي وقت وإخبار الباحث. لن يكون هناك أي عواقب سلبية أو فقدان لفوائد مستحقة لك في حال توقفك عن المشاركة في هذه الدراسة.

الفوائد

ليس هناك اي فوائد مباشرة تعود عليك من هذه الدراسة. ولكن، مشاركتك في هذه الدراسة ستساعدنا على فهم أفضل للتجارب الفردية للآباء الامريكيون العرب ذوي الأطفال ذوي التوحد في الولايات المتحدة الأمريكية.

المخاطر أو عدم الشعور بالراحة

هذا البحث لا يحمل أية مخاطر. وهذا يعني أن المخاطر المرتبطة بهذه الدراسة هي نفسها التي تواجهها كل يوم. لا توجد مخاطر إضافية معروفة أو متوقعة يواجهها من يشارك في هذه الدراسة.

التعويضات

ستحصل على"بطاقة هدية" بقيمة ١٠ دولارات بعد الانتهاء من كل مقابلة، اي ما مجموعة ٣٠ دولار عند اتمامك لجميع المقابلات الثلاثة.

التكاليف

لن يكلفك أي شئ للمشاركة في هذه الدراسة.

السرية والخصوصية

كل البيانات والتسجيلات ستحفظ بشكل سري وآمن. الإطلاع على السجلات سيكون أمر محدود ومقتصر على أفراد معينين وسيتم ذلك بشكل آمن. الأفراد الذين يحق لهم الإطلاع هم:

- فريق البحث، بما في ذلك الباحث الرئيسي، منسق الدراسة، وطاقم البحث.
- أفراد من الحكومة وأعضاء الجامعة الذين يحتاجون معرفة المزيد عن الدراسة، والأفراد الذين يقومون بالرقابة لضمان أن الدراسة تُجرى بالطريقة الصحيحة.
- لجنة المراجعة المؤسسية في جامعة جنوب فلوريدا (BRI) والموظفين ذوي الصلة الذين لديهم مسؤوليات الإشراف على هذه الدراسة، بما في ذلك الموظفين في قسم تكامل البحوث والإمتثال بجامعة جنوب فلوريدا.

ربما نقوم بنشر ما نتعلمه من هذه الدراسة. إذا قمنا بذلك، فلن يظهر اسمك في أي أطروحة أو تقرير مرتبط بهذه الدراسة. ولن ننشر اي شئ من شأنه ان يدل الناس على هويتك.

يمكنك الحصول على إجابات لأسئلتك، مخاوفك، أو الشكاوي

إذا كان لديك أي أسئلة بخصوص الدراسة، أو شكاوي حول هذه الدراسة، أو واجهت أي مشكلة غير متوقعة، فضلا إتصال بالأستاذة/ هيفاء السياري على هاتف نقال:(٢٩٢٠- ٩٩٢- ٨١٣)

إذا كان لديك أسئلة حول حقوقك كمشارك في هذه الدراسة، أو لديك شكوى، أو مخاوف أو اهتمامات ترغب في مناقشتها مع شخص خارج إطار البحث، إتصل على لجنة المراجعة المؤسسية في جامعة جنوب فلوريدا (BRI) على الهاتف: (٥٦٣٨- ٩٧٤- ٨١٣)

184

<div dir="rtl">

إقرار الموافقة على المشاركة في هذه الدراسة

أقر أنا الموقع أدناه بموافقتي على المشاركة في هذه الدراسة و بمطلق حريتي. كما أنني أعلم بأنه بعد التوقيع على هذا الإقرار سأكون وافقت على المشاركة في البحث. كذلك لقد تلقيت نسخة من هذا النوذج لأخذها معي.

توقيع الشخص المشارك في الدراسة ----- التاريخ

الإسم المطبوع للشخص المشارك في الدراسة

بيان الشخص الحاصل على إقرار الموافقة

لقد شرحت بعناية للشخص المشارك في هذه الدراسة كافة إجراءات البحث و ماهو متوقع من مشاركتهم. كما إنني أؤكد على أن شرح الإقرار وكذلك إجراءات البحث قد تم باللغة الأساسية التي يتحدث بها المشارك في هذا البحث. كما أن المشارك الموقع أعلاه قام بتقديم موافقة فعلية على المشاركة في البحث وبشكل قانوني.

توقيع الشخص الذي حصل على إقرار الموافقة ---- -- التاريخ

الإسم المطبوع للشخص الحاصل على إقرار الموافقة

--------   ---------------

</div>